Exploring and improving access to direct payments by people with dementia living in rural communities

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Abstract

Direct payments are payments made to individuals eligible for social care services that allow them to manage and pay for their own care rather than receiving it directly from their Local Authority. Research suggests that people with dementia and those living in rural communities may particularly benefit from the additional flexibility afforded by direct payments. However uptake is currently low, particularly amongst older people. There is a lack of research to date in this area addressing the factors of dementia, ageing and rurality in unison. Therefore, the first aim of this study was to explore the experiences of people with dementia living in rural communities in relation to their access to direct payments, and specifically to develop a theory to explain direct payment uptake by this group. The second aim was to use findings to build and pilot an intervention aimed at ensuring that access to direct payments by people with dementia living in rural communities is maximised.

Grounded theory methodology was utilised, and research methods were predominantly qualitative due to the exploratory nature of the research. Focus groups were carried out with two community social work teams, and 26 semi-structured interviews were conducted with people with dementia in receipt of social care services in the community, and their carers and social workers. A theory was developed in order to explain access to direct payments by people with dementia living in rural communities. It was identified that while care managed by the Local Authority is set as the default route for service users, direct payments tend to be perceived as a second option. An intervention to address some of the identified barriers to direct payment uptake was developed and piloted in one community social work team for a period of six months. The intervention was evaluated using questionnaires, interviews with participating social work staff and statistical analysis of direct payment uptake data. Findings suggest that the piloted intervention may be effective in enhancing overall access to direct payments.

This study offers new insights into the previously under-researched area of direct payment access by service users with dementia in rural communities, and presents what is believed to be the first example of a theory to explain uptake of direct payments by this group. It is thought that this research provides the first empirical evaluation of an intervention aimed at increasing uptake of direct payments through changing the way this option is offered by social workers.

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Introduction

This study was based in two adult social work teams at Worcestershire County Council, a county with a substantial rural population. The first aim of the research was to explore access to direct payments by people with dementia living in rural communities, and specifically to develop a theory to explain uptake of direct payments by this group. Grounded theory methodology was utilised and a qualitative approach was taken due to the exploratory nature of the research. A comprehensive literature search was carried out in order to examine barriers to direct payment uptake by adult social care service users, with a particular focus on identifying the difficulties experienced by older people, people with dementia and those living in rural communities. Interviews were conducted with people with dementia, their carers and their social workers as key stakeholders, and each social work team participated in a focus group. Examination of literature to date suggests that this study presents the first example of a theory aimed at explaining uptake of direct payments amongst social care service users. Findings also build on previous research into direct payment access by people with dementia and those living in rural communities, providing some new insights in these areas.

The second aim of the research was to build and pilot an intervention to be utilised in rural communities to help ensure that access to direct payments by people with dementia is maximised. The intervention was designed to address some of the barriers to direct payment uptake identified in the first part of the study. It was piloted in one adult social work team for a period of six months, and was evaluated using pre and post intervention questionnaires, interviews with participating social work staff and statistical analysis of direct payment uptake data. Evaluation findings suggest that the intervention may be effective in enhancing overall access to direct payments. Evidence to date would indicate that this study provides the first empirical evaluation of an intervention aimed at increasing uptake of direct payments through changing the way this option is offered by social workers.

The context of the research is outlined in Chapter 1, with a definition of key terminology and a summary of the background to the research issue. This is followed in Chapter 2 with a literature review examining barriers to direct payment uptake, with a particular focus on the specific difficulties experienced by older people, people with dementia, and those living in rural communities. Chapter 3 provides contextual information about the setting for the research in two specific districts of the county of Worcestershire. The methodological approach adopted for Part 1 of the research is outlined and explained in Chapter 4, which gives a detailed account of the methods of data collection utilised to meet the first aim of the study. Chapter 5 presents and discusses a theory aimed at explaining direct payment uptake by service users with dementia living in rural communities. In line with the second aim of the research, Chapter 6 outlines the methods utilised in building, piloting and evaluating an intervention aimed at maximising access to direct payments, with evaluation findings presented in Chapter 7. Finally, in Chapter 8 there is a review of the contribution to knowledge made by this study together with recommendations for practice and future research.

Chapter 1

Research Context

Direct payments are payments made to individuals eligible for social care services that allow them to manage and pay for their own care rather than receiving it directly from their Local Authority. Research suggests that direct payments can afford service users increased control over the support they receive, and result in higher satisfaction with care services. People with dementia and those living in rural communities may particularly benefit from direct payments due to the additional flexibility offered by this option, for example in enabling service users to receive care from local people familiar to them. However, although uptake is increasing, less than a quarter of social care service users are currently in receipt of direct payments. People with dementia may experience particular challenges in accessing this option, for example due to difficulties in managing their own social care budget, or social workers' perceptions that direct payments are unsuitable for this group. Those living in rural communities may encounter problems gaining access to care services or employing personal assistants who are willing to travel to remote areas. Relatively little research has been conducted to date exploring access to direct payments by people with dementia or those living in rural communities, an area that this research seeks to address.

The aim of this chapter is to outline the context of the research and provide a summary of the key issue under study. The chapter includes five sections, starting in section one with a definition of the relevant terminology. Section two provides an outline of the development of direct payments and the wider personalisation agenda, followed respectively in sections three and four with a brief summary of issues relating to dementia and rurality. Finally, section five sets out the research issue in some detail, with discussion of the advantages and challenges that people with dementia and those living in rural communities may experience in gaining access to direct payments.

1.1 Key terminology

The terms ‘direct payment’, ‘personal budget’, ‘individual budget’ and ‘self-directed support’ are often confused; therefore definitions are presented here. Individuals assessed as eligible for social care services are allocated a set amount of funding for their care, known as a personal budget. Personal budgets comprise social care funding only, whereas individual budgets encompass additional sources of funding available to the service user, such as Disabled Facilities Grants or Access to Work. Service users should be given the option by their social worker to choose how the money allocated to them is spent to meet their needs, an idea termed self-directed support. They can choose to receive their budget as a direct payment that allows them to manage and pay for their own social care, to have the budget managed by their Local Authority, which will commission care services on their behalf, or a combination of the two. Direct payment recipients can use their personal budget flexibly to meet the social care needs identified in their support plan. For example, they may choose to spend the money on personal care at home, help with shopping, transport or leisure activities.

It should be noted that although the subsequent literature review focuses on direct payments, it was observed that the key terms defined above were sometimes used interchangeably in the literature. Therefore, when reporting research findings the terminology utilised by the authors has been replicated.

1.2 Development of direct payments and the personalisation agenda

The first key piece of UK legislation enabling payments to be made to people with disabilities in lieu of social care services was the 1996 Community Care (Direct Payments) Act, implemented in 1997. The introduction of this legislation followed longstanding pressure from the Independent Living Movement, which lobbied for increased choice and control for disabled people (Gardner, 2011). In addition, the timely publication of research by Zarb and Nadesh (1994) highlighted that direct payments were more cost-effective and enabled higher quality support than directly provided services. The 1996 Act applied only to social care service users aged 18-65, notably excluding the largest social care user group of older people (Glasby & Littlechild, 2009). It was also limited in that although it allowed local authorities to make direct payments to service users, it did not make the establishment of direct payment schemes mandatory. Consequently, implementation was slow, with less than half of local authorities initially offering such a scheme to service users (Zarb, Hasler, Campbell & Arthur, 1997).

Subsequent amendments in 2000 extended the 1996 Act to include older people[1], and carers, parents of disabled children and disabled young people aged 16-17[2]. Importantly, the 2001 Health and Social Care Act, implemented in April 2003, made it mandatory for

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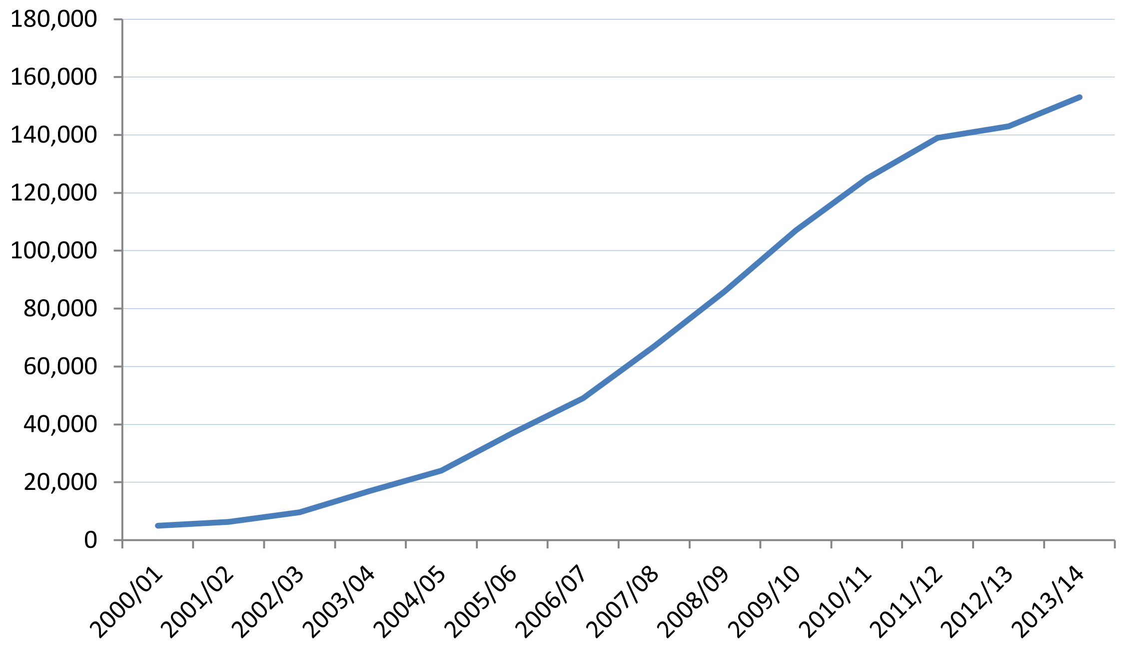
[1] The Community Care (Direct Payments) Amendment Regulations 2000

[2] The 2000 Carers and Disabled Children Act

local authorities to offer direct payments to all those eligible, and uptake of direct payments became a national performance indicator (Department of Health [DH], 2003). More recently in November 2009, new legislation (Health and Social Care Act 2008) was implemented to allow direct payments to be paid to a nominated person to manage the money on behalf of a service user lacking the capacity to consent to receiving it. This change has meant that many more service users who may lack capacity, such as those with dementia, are now eligible for direct payments. Direct payment uptake statistics show a steady increase in the number of service users taking up this option since 2000 (see Figure 1), despite a general decrease in the number of social care service users over this period.

Figure 1: Number of adult social care service users in receipt of direct payments in England, 2000/01 - 2013/14



Source: 2000/01 - 2003/04 data (DH, 2005a), 2004/05 - 2005/06 data (The NHS Information Centre, 2008), 2006/07 - 2011/12 data (Health and Social Care Information Centre [HSCIC], 2013a), 2012/13 - 2013/14 data (HSCIC, 2014a)

Personal budgets were first developed as an idea in 2003 by disability charity In Control (Poll, Duffy, Hatton, Sanderson & Routledge, 2006), which proposed that social care service users should be told how much money had been allocated to them to meet their needs, and given a choice as to how to manage this budget. This approach was adopted in government policy in the 2005 Green Paper *Independence, Well-being and Choice* (DH, 2005b) and the 2006 White Paper *Our health, our care, our say* (DH, 2006), which set out a commitment to pilot individual budgets in 13 local authorities across England. Individual budgets have a wider scope than personal budgets in that they encompass additional sources of funding, such as Disabled Facilities Grants. Subsequently, the government's commitment to the transformation of adult social care was set out in the concordat *Putting People First* (HM Government, 2007), which identified objectives to further increase direct payment uptake and to provide personal budgets to all those eligible for social care services.

Direct payments and personal budgets have remained high on the political agenda, and in 2010 the new Coalition Government affirmed its commitment to the personalisation of care, stating that by April 2013 local authorities should 'provide personal budgets for everyone eligible for ongoing social care, preferably as a direct payment' (DH, 2010, p.19). However, this target was amended in 2012 requiring personal budgets to be provided to 70% rather than all of those eligible. Although the proportion of personal budget holders has increased steadily since 2010, in 2013/14 more than half of Councils were yet to achieve the amended target (DH, 2014), indicating that there is still significant progress to be made. The Care Act 2014, which came into force on 1 April 2015, makes personal budgets a legal entitlement for social care service users for the first time, and also allows for the integration of health and social care personal budgets, ensuring the continued development of personalisation.

1.3 Dementia

Dementia is a term used to describe a collection of symptoms linked to a progressive decline in cognitive function, including memory loss, communication difficulties and problems with thinking and reasoning. These symptoms are a result of damage to the brain caused by diseases such as Alzheimer's disease, the most common form of dementia (Alzheimer's Society, 2013). As the disease progresses, people with dementia therefore have increasing difficulty completing daily activities, often resulting in reliance on social care services and unpaid carers.

Approximately 850,000 people in the UK are estimated to have a dementia in 2015; a number projected to increase to over one million by 2025 (Prince et al., 2014). However, in 2012/13 it was estimated that only 48% of those living with dementia in England had received a diagnosis (DH, 2013), meaning that many people with dementia may have difficulty accessing necessary services and support. The cost of dementia to the UK economy is £26.3 billion per year, over 80% of which is accounted for by social care costs. This includes the cost of long-term institutional care and informal care provided in the community, often by unpaid carers (Prince et al., 2014). It is estimated that almost two thirds of people with dementia live in the community rather than in residential care (Prince et al., 2014).

In recognition of these challenges, the Department of Health launched a national dementia strategy in 2009, aimed at ensuring that all people with dementia and their carers 'live well with dementia' (p.7). One of the key aims of the strategy is to ensure a higher quality of care for people with dementia and their carers, for example through the delivery of flexible, personalised and reliable social care services to people with dementia living in their own home. The role of personalisation and the changes set out in *Putting People First* (HM Government, 2007) are integral to the achievement of this aim. It is proposed that people with dementia should have choice and control over the support they receive, which should be responsive to their needs, flexible in terms of time and setting, and provide opportunities for their participation in a range of personalised activities (DH, 2009b). It is acknowledged within the strategy that the availability of a variety of appropriate local services is necessary in order for this to be delivered.

1.4 Rural issues

Census data show that 18.5% of the population in England and Wales live in a rural area (Office for National Statistics [ONS], 2013b). The population of rural communities is older than average, with those aged 65 and older comprising 21.0% of rural and 15.3% of urban residents in England (Department for Environment, Food & Rural Affairs [Defra], 2012). Although the population of both rural and urban communities is ageing over time, statistics indicate that the proportion of older people in the rural population is increasing over four times as quickly (ONS, 2013b). Furthermore, the proportion of rural residents reporting a health issue or disability limiting their activity increased from 17.5% in 2001 to 18.2% in

2011, while this figure fell from 18.4% to 17.8% amongst urban residents over the same ten-year period (ONS, 2013b). This has clear implications for social care services in rural areas, where demand is likely to increase considerably in the near future.

Access to key amenities tends to be more difficult in rural areas, with rural residents in England considerably less likely than their urban counterparts to live in close proximity to a range of community facilities (Defra, 2013) (see Table 1).

Table 1: Percentage of households in rural and urban areas of England living within the given distance of key amenities by road

	Rural	**Urban**
GP surgery (4 km)	80%	100%
Pharmacy (4 km)	63%	100%
NHS Dentist (4 km)	51%	99%
Hospital (8 km)	55%	97%
Bank/building society (4 km)	41%	97%
Post office (2 km)	71%	96%
Convenience store (4 km)	67%	100%
Supermarket (4 km)	56%	100%
Petrol station (4 km)	67%	100%
Library (4 km)	53%	98%
Pub (2 km)	82%	98%

Source: Defra (2013)

Compounding this issue, there tends to be lower availability of public transport in the most rural communities, with just less than half (49%) of households having nearby access to a regular bus service compared to nearly all (96%) households in urban areas (Defra, 2014a). Correspondingly, only 11% of rural households reported not having access to a car or van compared to 28% of their urban counterparts (Defra, 2014a). This reliance on private transport may become problematic for older, frail residents or those with dementia who are no longer able to drive.

1.5 The research issue

Self-directed support has in general been found to benefit social care service users, particularly in terms of the potential for greater choice and control over the support they receive. In a randomised controlled study of service users with and without individual budgets, Glendinning et al. (2008) found that those in receipt of individual budgets reported significantly higher satisfaction levels with the support they received and greater feelings of control compared to comparison group participants. Furthermore, in two large surveys of personal budget users (Hatton & Waters, 2011, 2013), it was found that those who took their budget as a direct payment generally reported that their care had made more of a positive difference to their lives, specifically including their physical and mental wellbeing, independence, and control over their support and life in general.

Direct payments may afford particular benefits to people with dementia, for example in allowing care to be provided flexibly in order to meet fluctuating needs, or in ensuring continuity of care staff who know the person well. Results of an Alzheimer's Society survey of 1,432 people with dementia and their carers (Lakey & Saunders, 2011) indicate that those in receipt of direct payments were more satisfied in general with the care they received than those who had declined the offer of a direct payment. In addition, they were considerably more likely to report that the person with dementia had the support they needed, that care provided was focused on their needs, and that this support made life easier. Furthermore, Kinnaird (2010) highlighted that direct payments could enable support to be provided by those familiar to the person with dementia, allow choice over the type of support received and the timings of care visits, and assist the person with dementia to remain in their own home for longer. Those living in rural communities may also benefit from the additional flexibility afforded by direct payments. For example, it is suggested that being able to employ relatives or others who live locally to deliver care would be particularly beneficial for those living in isolated areas, and that personalisation may lead to rural service development in response to increased demand for local care services (Manthorpe & Stevens, 2008).

Direct payment uptake has increased considerably in recent years, with almost a quarter of adults in receipt of social care services in the community in England receiving a direct payment at some point during 2013/14 (HSCIC, 2014a). However, although adults aged 65 and older account for over two thirds of social care recipients in the community in England, they are considerably less likely to receive a direct payment than their younger counterparts, with only 14.4% receiving a direct payment in 2013/14 compared to 41.8% of those aged 18-64. Direct payment uptake also declines with age within the older adults group, with almost twice as many people aged 65-74 in receipt of direct payments in England (21.5%) in 2013/14 as those aged 85 and older (12.1%) (HSCIC, 2014a). There are no published statistics on the proportion of social care service users with dementia using direct payments, however it is suggested that uptake amongst this group is considerably lower than average (Kinnaird, 2010). Prior to a change in legislation implemented in November 2009 (Health and Social Care Act 2008), many people with dementia were ineligible for direct payments; therefore little research has been carried out to date to examine access to direct payments by this relatively new client group.

People with dementia may face particular difficulties in accessing direct payments and with care planning in general. For example, organising a schedule of care or creating innovative support packages is likely to be more difficult for someone with a cognitive impairment. People with dementia may lack insight into or be unable to articulate their own needs, and experience fluctuating symptoms so that they do not always require the same level of support to complete tasks, making care planning problematic (Goodchild, 2011). In addition, the vast majority (94.8%) of people with dementia are aged 65 and older (Prince et al., 2014), and are therefore likely to experience the same well-documented issues in accessing self-directed support as other older service users. For example, they may encounter a lack of promotion of direct payments from social workers who believe that they are not suitable for older people (Clark, Gough & Macfarlane, 2004; Newbronner et al., 2011; Vick et al., 2006), or themselves feel that they are unable to take on the extra work and responsibility involved with managing a direct payment in later life (e.g. Dewar, O’May & Donaldson, 2005; Moran et al., 2013; Newbronner et al., 2011). Importantly, older service users tend to receive lower levels of social care funding than other client groups, allowing them to procure little more than basic personal care (Glendinning et al., 2008; Henwood & Hudson, 2009; Jones, 2008) and thus minimising the potential benefits of self-directed support for this group. For example, statistics relating to direct payment expenditure in England show that on average younger adults are allocated a substantially greater budget of £225 per person per week, compared to £188 for those aged 65 and over (HSCIC, 2014c).

Budgetary constraints may be a particular problem for service users with dementia, for example where they need to pay for costly specialist dementia care services, support to help them manage their care budget, or additional care hours should they need extra time to carry out daily tasks with a personal assistant (Goodchild, 2011). Further difficulties experienced by this group include the need to have a carer who is able and willing to take on the management of the direct payment in the absence of appropriate or affordable support services (e.g. Kinnaird, 2010; Routledge & Carr, 2013), a lack of suitable services or appropriately experienced personal assistants to choose from (e.g. Goodchild, 2011; Lakey & Saunders, 2011), and a perception amongst social care professionals that self-directed support is too risky for people with dementia (Lakey & Saunders, 2011; Manthorpe & Samsi, 2012).

Although self-directed support can afford particular benefits to rural service users, there are aspects of rural communities that make direct payment access problematic for this group. For example, the availability of affordable care services may be an issue in areas where service providers encounter lower profitability and a geographically spread client base (Manthorpe & Stevens, 2008, 2010). In line with this, rural residents may have difficulty recruiting personal assistants, due to a smaller pool of potential employees (Commission for Social Care Inspection [CSCI], 2004; Manthorpe & Stevens, 2008, 2010; Ridley et al., 2011) and transport issues whereby some carers are unwilling to travel to clients living in isolated areas, or require service users to pay travel expenses out of their care budget (IFF Research, 2008; Manthorpe & Stevens, 2008). Furthermore, those living in small rural communities who employ local people to deliver their care may have concerns about maintaining confidentiality where they do not wish neighbours to know the nature of their care needs, or indeed that they are receiving care at all (e.g. Clark et al., 2004; Dewar et al., 2005).

Due to their age, condition and location, people with dementia who live in rural communities may be triply disadvantaged in terms of their access to direct payments. Little research has been conducted to examine direct payment access by people with dementia or those living in rural communities, and it is thought that no research to date has specifically focused on how these combined factors impact on access to self-directed support.

1.6 Summary

Although there has been a steady increase in direct payment uptake since implementation in 1997, there is still significant progress to be made in making this option accessible to all. It has been found that direct payments can make a positive difference to service users' lives through enabling greater independence and control. However, many older adults are not accessing the benefits of managing their social care in this way. Older people with dementia living in rural communities may experience particular barriers to direct payment access, an area that merits further exploration. The next chapter presents a comprehensive literature review aimed at examining barriers to direct payment uptake, with a particular focus on the difficulties experienced by this group.

Chapter 2

Literature Review

A comprehensive literature review was conducted in order to examine barriers to direct payment uptake by adult social care service users. A wide range of issues were identified, encompassing initial awareness and promotion of direct payments, concerns and scepticism on the part of service users and social workers, and problems relating to set-up and management processes. Particular challenges experienced by older people, people with dementia and those living in rural communities in accessing direct payments were also identified. However, it was found that very few studies focusing on dementia or rurality in relation to direct payments have been published to date.

The aim of this chapter is to outline the methods utilised in conducting a systematic literature search to examine barriers to direct payment uptake, and to provide a comprehensive review of the relevant research in this area. The chapter comprises three main sections, commencing in section one with a description of the literature review methodology and a summary of the key characteristics of studies selected for inclusion in the review. Section two provides an examination of each of the key barriers to direct payment uptake identified in the literature. The chapter concludes in section three with a review of the specific difficulties in accessing direct payments experienced by older people, people with dementia, and those living in rural communities.

2.1 Literature review methodology

2.1.1 Search strategy

A systematic literature search was conducted in June 2014 and updated in June 2015 in order to identify research studies focusing on access to direct payments by adult social care service users. A number of sources were used to locate articles for the review, primarily the research databases Academic Search Complete, PsycINFO, Sociological Abstracts and Social Care Online. In order to ensure the inclusion of relevant grey literature, several additional databases were searched, namely the Electronic Theses Online Service, the Social Care Research Register, Opengrey and the British Library Catalogue. Searches on Google Scholar and Google Books were undertaken to identify further studies, and finally a hand search of websites of key organisations in the field was undertaken (see Box 1).

Box 1: Key websites searched

Age UK
Alzheimer Scotland
Alzheimer’s Society
In Control
Joseph Rowntree Foundation
Mental Health Foundation
National Audit Office (NAO)
National Development Team for Inclusion (NDTi)
Personal Social Services Research Unit (PSSRU)
Research in Practice for Adults (RIPFA)
School for Social Care Research (SSCR)
Social Care Institute for Excellence (SCIE)
Social Policy Research Unit (SPRU)
Think Local Act Personal (TLAP)

Although the aim of the search was to identify articles pertaining to direct payments specifically, a preliminary scoping search of relevant literature indicated that the terms ‘direct payment’, ‘individual budget’, ‘personal budget’ and ‘self-directed support’ are often used interchangeably. Therefore, these terms were all selected as search terms for the review (including truncation and Boolean logic) where they appeared in the title, abstract or body of the article. This approach was utilised in order to maximise the number of relevant studies for review in this relatively new area of research. The search was limited to research studies published in 1997 or later, as this was the year in which direct payments first became available to social care service users in the UK. A number of additional exclusion criteria were identified, which are outlined in Box 2.

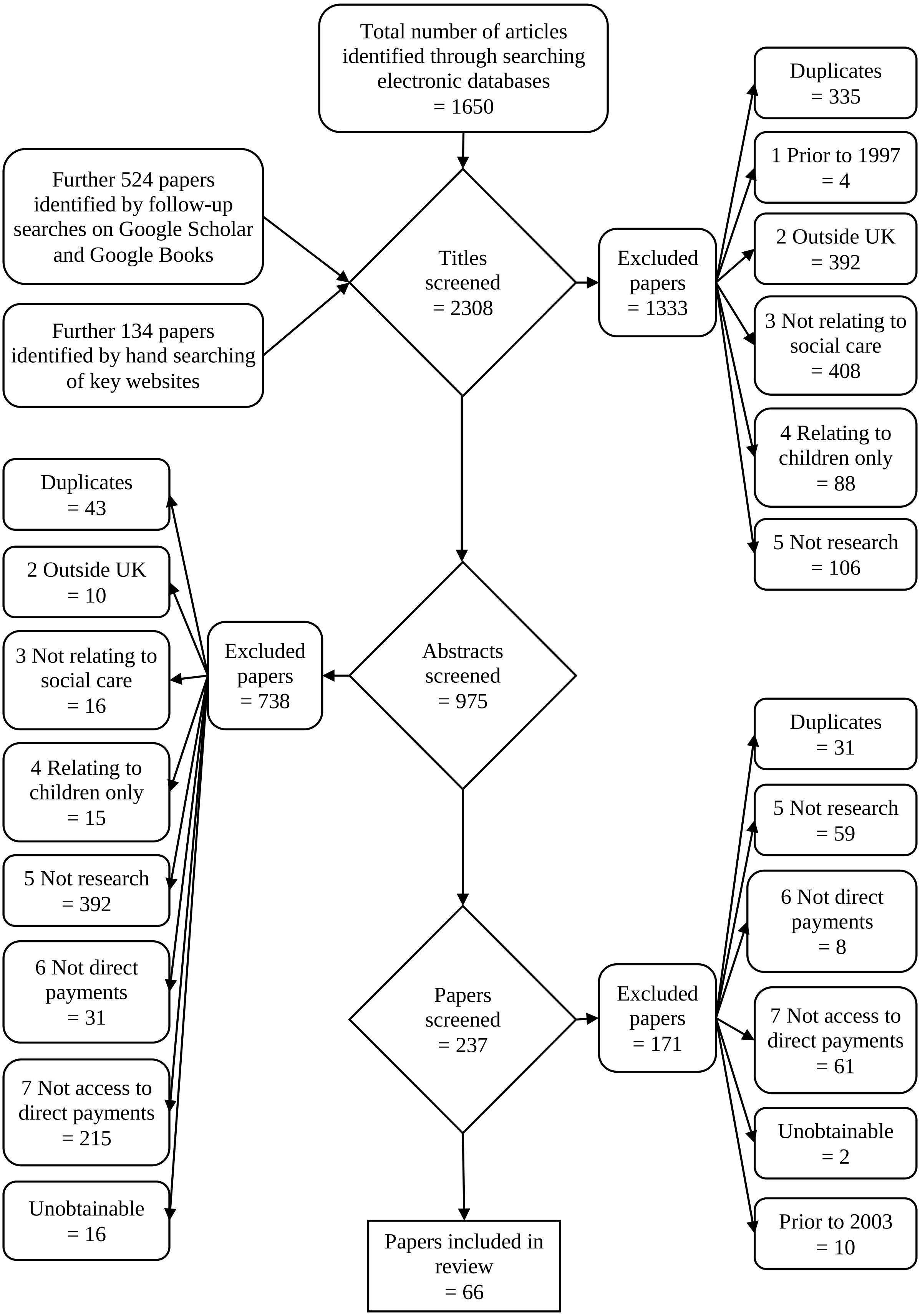
Box 2: Literature search exclusion criteria

1. Studies published prior to 1997
2. Studies conducted outside the UK
3. Studies not relating to the field of social care
4. Studies focusing on children under the age of 18 only, or on the transition from child to adult social care services
5. Articles not reporting primary research: e.g. summaries of existing literature with no new data or analysis, or articles with no stated research aims or methods
6. Studies not relating to direct payments: e.g. those relating only to personal budgets where the service user does not manage their own social care budget
7. Studies not discussing access to direct payments

A total of 2,308 studies were obtained as a result of the initial search (see Figure 2). Following a review of titles and the application of exclusion criteria, this was reduced to 975 studies that were screened by abstract. Finally, 237 studies were read in full, and 76 were selected for inclusion in the review. At each stage, duplicate and unobtainable articles were identified and excluded.

It was originally intended that relevant articles published in 1997 or later would be included in the final review. However, following a more detailed review of included articles, it became apparent that major issues discussed in the older articles were less pertinent to practice today. This was partially because the early direct payment schemes examined in some of these studies tended to be at pilot stage rather than being fully established; therefore many of the issues discussed were general start-up difficulties and awareness of direct payments was very low. In addition, changes in direct payment legislation in 2000 (extending direct payments to older people) and 2003 (making it mandatory for local authorities to offer direct payments to all those eligible) significantly changed the way in which direct payments were offered. Therefore, it was decided that articles published prior to 2003 (N=10) would be excluded from the review, meaning that 66 articles were finally included.

Figure 2: Flow of studies through each review stage[3]



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[3] PRISMA diagram, developed by Moher, Liberati, Tetzlaff and Altman (2009)

It was noted in a number of cases that more than one article reported on the same research study (Baxter & Glendinning, 2011, 2013; Brookes, Callaghan, Netten & Fox, 2013 and Callaghan, Netten, Brookes & Fox, 2012; Davey, Fernandez et al., 2007 and Davey, Snell et al., 2007; Manthorpe & Stevens, 2008, 2010; Priestley et al., 2007, 2010; Spandler & Vick, 2004, 2005, 2006). Of note, six articles reported on findings from the English Individual Budgets Pilot Project (Glendinning et al., 2008, 2009; Jacobs et al., 2011; Manthorpe et al., 2009; Moran et al., 2013; Wilberforce et al., 2012), a Department of Health funded project to pilot individual budgets in 13 local authorities across England, evaluated by the Individual Budgets Evaluation Network. In each case, all articles were included in the review as each reported on a different aspect of research findings or included original content. Therefore, the 66 articles included in the review pertain to 54 distinct research studies.

2.1.2 Characteristics of included studies

Each article included in the review was coded in order that relevant characteristics of the body of selected literature could be examined. Where more than one article reported on the same research study each study was only coded once; therefore 54 studies were coded in total.

In terms of location, selected studies tended to have a national rather than a local focus, with 79% conducted across multiple UK regions. Relatively few studies (6%; N = 3) were conducted specifically in rural areas, suggesting that rurality is a dimension that has not yet been fully explored in relation to direct payment access. Service users (56%) and social care professionals (53%) were almost equally represented in the selected studies; however the experiences of carers were only sought in one third. A range of professionals were sampled, comprising almost equally of frontline practitioners (e.g. social workers, support workers and personal assistants) and managers/policymakers at a national and local level.

Service users from a range of client groups participated in the selected studies, with older people the most frequently sampled group (see Table 2). Only 6% of studies (N = 3) overtly stated that they included participants with dementia, indicating that access to direct payments by this group is currently an under-researched area.

Table 2: Number of selected studies sampling participants from each client group

Client group	Number of studies
Older people	18
Mental health	16
Learning disability	14
Physical disability	13
Sensory impairment	7
Dementia	3
Other	6
Not stated	9

Over half of studies (57%) sampling service users included both direct payment recipients and ‘traditional’ service users (i.e. those whose social care budget was managed by their Local Authority), enabling the issue of direct payment access to be examined from both viewpoints. None included traditional service users only.

Table 3 shows the specific methods used in the selected studies. Although participant interviews were by far the most commonly utilised method of data collection (in almost two thirds of studies), a wide range of approaches were employed, with the majority of studies using multiple methods. The majority (61%) of selected studies were qualitative.

Table 3: Research methods utilised in selected studies

Research method utilised	Number of studies
Interviews	34
Discussion groups	18
Questionnaires	15
Analysis of existing datasets	6
Document/content analysis	5
Consultation events/workshops	5
Other	7

2.2 Barriers to accessing direct payments for adult social care service users

A wide range of barriers to direct payment uptake were identified in the selected literature, which can be broadly grouped into three areas according to the stage of service users in the social care process. Firstly, issues were identified in relation to the initial promotion and awareness of direct payments. For example, service users may be unaware of this option, which was frequently promoted ineffectively or selectively by social workers. Secondly, service users who are aware of and at the stage of considering direct payments may indicate a lack of desire to take up self-directed support. There may be concerns about their ability to manage direct payments, or scepticism of the personalisation agenda on the part of both practitioners and service users themselves. Finally, those who do choose to take up direct payments may experience a range of issues, including set-up and management difficulties, inflexible processes, inadequate support, insufficient services to choose from and budgetary constraints.

2.2.1 Awareness and promotion of direct payments

Awareness of direct payments

Raising awareness of self-directed support has been identified by local authorities as one of the key challenges to the progression of the personalisation agenda in their locality (Association of Directors of Adult Social Services & Local Government Association [ADASS & LGA], 2009). Awareness of direct payments and personal budgets amongst social care service users, carers and the general public is generally reported as low (e.g. Hitchen, 2012; Newbigging & Lowe, 2005; Pearson, 2004). For example, in a survey of 263 social care service users, Bartlett (2009) found that 82% knew nothing (62%) or very little (20%) about personal budgets. Furthermore, results of a similar study conducted one year later (Wood, 2010) indicate that awareness had not increased. Even service users in receipt of personal budgets themselves may not realise that they are receiving one, or are unaware of the choices that they have in relation to the management of their care (Ipsos MORI, 2011). Research (Baxter & Glendinning, 2011; Holmer & Gilder, 2008) suggests that previous contact with Social Services may facilitate earlier awareness of direct payments amongst those with social care needs. However, it is reported (e.g. McMullen, 2003; Sense, 2008; Woodin, 2006) that a significant proportion of service users do not find out about direct payments from their social worker, but via ad hoc non-statutory routes, such as the Internet, information posters or other service users.

Service users themselves highlight that promotion of direct payments by social workers and local authorities in some areas is poor or non-existent (e.g. Priestley et al., 2010; Ridley et al., 2011). Both service users and professionals have reported a paucity of accessible information relating to this option (e.g. Carlisle People First Research Team, 2011; McMullen, 2003; Mind, 2009), which is highlighted as a key factor in hindering take-up (e.g. Davey, Fernandez et al., 2007; Kinnaird, 2010; Lakey & Saunders, 2011). For example, Hitchen (2012) cites cases of service users and their carers giving up on the process of self-directed support in frustration, due to a lack of clear, accessible information. Those carrying out their own research on the Internet in the absence of written information reported having difficulty identifying relevant and accurate information (Baxter & Glendinning, 2011; Lakey & Saunders, 2011). Therefore, service users and carers have suggested that there is a need to develop information materials on direct payments and to make these widely available (Kinnaird, 2010; Newbronner et al., 2011; Woodin, 2006).

Where service users are aware of direct payments, evidence suggests that many find them complicated or confusing (e.g. Carlisle People First Research Team, 2011; IFF Research, 2008; Mind, 2009), for example not understanding how the money can be spent (Eost-Telling, 2010; Glendinning et al., 2008; Ridley et al., 2011). In particular, there has been confusion over the term ‘direct payments’, with some service users mistaking social care direct payments for the Department of Work and Pensions scheme of the same name, relating to the direct payment of benefits (Cabinet Office [CO] & DH, 2005; Dewar et al., 2005).

Where information relating to direct payments is available, research indicates that it may not be sufficiently comprehensive. Several studies point to the need for more detailed information on specific aspects of direct payments, notably employment law and financial management (Abbott & Marriott, 2012; IFF Research, 2008; Sense, 2008). Conversely, some service users have reported that the amount of information they received was overwhelming and difficult to take in (Clark et al., 2004; Newbronner et al., 2011; Spandler & Vick, 2004). It is recognised that good quality written information needs to be balanced with social worker time spent with the service user to discuss or explain direct payments more fully (Ellis, 2007; Newbronner et al., 2011); however inconsistencies in information received from social workers have also been highlighted (Baxter & Glendinning, 2011; Glendinning et al., 2008).

Social workers' lack of knowledge about direct payments has been raised as an issue by both service users and social workers themselves (e.g. Glendinning et al., 2008; Henwood & Hudson, 2007; Hitchen, 2012; Ridley et al., 2011); indeed in some cases it is reported that family carers have needed to educate social workers about the existence of this option (McMullen, 2003; Williams et al., 2003). In addition, the awareness of other (particularly health) professionals may be key to enabling service users to take up direct payments at the point that they become in need of social care services (CO & DH, 2005; Routledge & Carr, 2013), for example when being discharged from hospital. It is suggested (Hitchen, 2012; Lakey & Saunders, 2011; McMullen, 2003) that a lack of knowledge, familiarity and confidence on the part of social workers may be a barrier to direct payment access, as uninformed practitioners are less likely to offer direct payments as an option. For example, they may be unsure about relevant regulations (Vick et al., 2006), unable to explain direct payments adequately to service users due to a lack of understanding of the processes involved (Clark et al., 2004; Hitchen, 2012; Newbronner et al., 2011), or lack confidence in their ability to answer potential questions (Henwood & Hudson, 2009). It is argued (Priestley et al., 2010) that this uncertainty has led to ambivalence towards direct payments amongst some social work professionals.

Social worker training is identified as a key factor in influencing the progress of self-directed support (CO & DH, 2005; Priestley et al., 2010; Vick et al., 2006). For example, in one Welsh Local Authority, intensive training appeared to facilitate a 50% increase in direct payment uptake (Priestley et al., 2007). However, it is recognised (Spandler & Vick, 2004) that large workloads and other urgent training requirements could mean that direct payment training is not prioritised. A lack of financial support for training sessions (Newbigging & Lowe, 2005), poor strategic integration of training (e.g. Manthorpe et al., 2009), and difficulties with training attendance (Clark et al., 2004) are also problematic. In addition, the content of training is sometimes viewed by social workers as inappropriate, for example where training is not pitched at a basic enough level (Vick et al., 2006), or where practical information on paperwork and processes is not included (Eost-Telling, 2010; Glendinning et al., 2008; Priestley et al., 2010). Research (Glendinning et al., 2008; Wilberforce et al., 2012) identifies that some social workers have found training on the underpinning philosophy of self-directed support patronising and unrealistic (although some viewed this as ‘enlightening’), viewing peer support and informal training such as discussion of practice issues or new paperwork as more useful.

Following on from issues with practitioner training, a general lack of guidance for social workers in the operational aspects of direct payments has been identified (e.g. Glendinning et al., 2008), causing delays in the progress of applications (Eost-Telling, 2010) and low confidence on the part of social workers in providing information to service users (Hitchen, 2012). Where guidance is provided, research indicates that this may be ambiguous (Abbott & Marriott, 2012; CO & DH, 2005; Glendinning et al., 2008; Ridley et al., 2011), for example with vague definitions of key terms, contradictory information, and the absence of clear details on how direct payments can legitimately be spent. This may lead to variations in practice and confusion amongst professionals, which may in turn impact on access to direct payments. For example, it is reported (Priestley et al., 2007) that unclear definitions of terms such as ‘capacity’, ‘consent’ and ‘risk’ in direct payments guidance has resulted in uncertainty amongst frontline staff as to the suitability of direct payments for particular client groups. It is suggested that this has particularly affected uptake for people with mental illness, learning disabilities and dementia. Frequent changes to regulations and differing expectations may also lead to confusion, frustration and a lack of confidence on the part of social workers (Ellis, 2007; Griffiths & Ainsworth, 2013; Vick et al., 2006).

The process of offering direct payments

Whether service users are explicitly offered direct payments by their social worker is clearly a vital factor in determining uptake. However, research (Dewar et al., 2005; McMullen, 2003; Spandler & Vick, 2004; Vick et al., 2006) indicates that direct payments are not offered by all practitioners, or to all eligible service users. In one study (Ipsos MORI, 2011), the majority of personal budget holders interviewed from two local authorities did not report being offered direct payments as a choice. Interestingly, Woodin (2006) found that of 30 direct payment recipients interviewed in her research, only one initially found out about this option through information volunteered by their social worker. This may reflect a lack of knowledge or reluctance to offer direct payments on the part of practitioners. Interviews with care co-ordinators in community mental health teams (Vick et al., 2006) revealed that less than half knew that they should offer direct payments to all eligible service users, and some were unable to judge when it was appropriate to present this option. Furthermore, some practitioners may only offer direct payments as a fallback option in cases where managed social care would be problematic, or following a direct request from service users (Clark et al., 2004; Woodin, 2006).

Some social workers may not feel that all service users should be given the option of self-directed support (Clark et al., 2004; Vick et al., 2006), making protective, risk-averse judgements (e.g. Mind, 2009; Moran et al., 2013) or ad hoc assessments as to clients' suitability (e.g. Glendinning et al., 2008; Priestley et al., 2007). For example, some practitioners may only offer direct payments to service users they feel would benefit from managing their own care (e.g. Newbigging & Lowe, 2005), in cases where similar clients had previously used them successfully, or to service users perceived to be stable, trustworthy, articulate and competent (Spandler & Vick, 2004, 2005). The main concern expressed by social workers appears to be regarding service users' ability to manage direct payments (e.g. Clark et al., 2004; Henwood & Hudson, 2007; Moran et al., 2013), particularly in relation to completing the necessary paperwork, employing suitable personal assistants and managing the budget.

Where direct payments are offered to service users by their social workers, research suggests that the way in which they are presented in some cases may be an important barrier to uptake (e.g. Clark et al., 2004; Kinnaird, 2010). For example, they may not always be explained positively with coverage of potential benefits (Spandler & Vick, 2004; Vick et al., 2006). Indeed it has been found that some practitioners may actively discourage service users from taking up direct payments (Priestley et al., 2010; Ridley et al., 2011) or even block them from doing so (Griffiths & Ainsworth, 2013), over-emphasising possible risks (CSCI, 2004; Office for Public Management [OPM], 2010) or portraying direct payments as being complicated and hard work to manage (e.g. Henwood & Hudson, 2009; Lakey & Saunders, 2011). However, as Ellis (2007) reports, some social workers may feel they need to outline the more difficult aspects of direct payments in order to give service users an informed choice.

The way in which direct payments are offered (if at all) by social workers is likely to be at least in part determined by their attitudes towards self-directed support. It is recognised (Vick et al., 2006) that some practitioners view direct payments as a threat to their role; an attitude viewed by senior social work staff as a significant barrier to direct payment access.

Conflicting views from professionals regarding the impact of personalisation on their role have been identified (Glendinning et al., 2008), with some suggesting that this new way of working enabled them to build relationships with service users as in traditional social work, while others felt that they were now completing more paperwork and did not have the opportunity to use the people skills they had developed. Hitchen (2012) points to a need for culture change amongst professionals and service users, from social workers managing the process and service users accepting their decisions (coined as the ‘giving and doing’ tradition by Henwood & Hudson, 2007), to an equal working partnership. However, research (Spandler & Vick, 2004, 2005) suggests that letting go of decision-making may be problematic for some practitioners, for example where they hold rigid ideas or assumptions about how direct payments should be spent, or feel that they should oversee the recruitment and even supervision of personal assistants employed by service users.

The timing of the offer of direct payments is also highlighted as important, with social workers reporting that due to a number of factors many service users first present to Social Services at a time of crisis (Laybourne et al., 2014). For example, there may be a need for a care package to be set up urgently (Vick et al., 2006), at a time when service users feel particularly unwell (Glendinning et al., 2008), or after a significant event such as a bereavement (Newbronner et al., 2011). This may in part be due to tight eligibility criteria for social care, meaning that service users often need to reach crisis point before being eligible for services (Clark et al., 2004; Spandler & Vick, 2004, 2006; Vick et al., 2006). Social workers report difficulties in offering direct payments at this point, suggesting that service users do not want to take on any additional responsibility (Ellis, 2007; Laybourne et al., 2014) or may find it difficult to make choices at such a time (Glendinning et al., 2008). However, research suggests that in some cases professionals could do more to overcome this issue. Clark et al. (2004) reported that some service users thought their social worker could have presented direct payments to them at the first time of contact rather than waiting until a crisis occurred. They also found that some social workers dismissed the idea of arranging an interim care package due to the increased work this would cause, although this could enable service users to have more time to consider direct payments.

Workload issues

Research widely suggests that some social workers may be resistant to the personalisation agenda due to concerns about increased workload, chiefly additional paperwork and excessively bureaucratic processes (e.g. Eost-Telling, 2010; Henwood & Hudson, 2009; Wilberforce et al., 2012). It is argued that the complexity of the set-up process in addition to social workers' already heavy workload may dissuade practitioners from offering self-directed support to service users (e.g. Ellis, 2007; Priestley et al., 2010; Vick et al., 2006), or limit them in terms of the number of service users they can support to take up this option (Spandler & Vick, 2004, 2005). However, a diary study (Jacobs et al., 2011) of 259 care co-ordinators found that despite a general perception that individual budgets were adding to their workload, there was no significant difference in the hours worked per week or amount of paperwork completed between those with a caseload including individual budget holders and those with no individual budget holders on their caseload. The bureaucracy involved in direct payments may also deter service users, with concerns raised about the long and complicated process they would need to go through in order to receive a direct payment (Hitchen, 2012), and the amount of paperwork and general administration they would be required to complete (Carlisle People First Research Team, 2011; Mind, 2009), sometimes disproportionate to the size of smaller care packages (CO & DH, 2005; Kinnaird, 2010; Ridley et al., 2011).

Social workers have expressed worries about taking on the additional responsibilities associated with administering direct payments, such as monitoring budgets, assessing service users' ability to take on self-directed support and providing support in emergencies (e.g. Hitchen, 2012; Priestley et al., 2010; Wilberforce et al., 2012). In some cases, practitioners may feel the need to take on tasks that should be the responsibility of service users. For example, Eost-Telling (2010) cites a case of a social worker who was involved in managing personal assistants and obtaining and negotiating support costs with care agencies on behalf of direct payment users. This may be reflective of the difficulties experienced by some social workers in letting go of responsibilities and decision-making (Spandler & Vick, 2004, 2005).

Further to concerns about the potential for increased workload and responsibilities, social workers have reported difficulties in promoting direct payments due to high existing caseloads, giving them insufficient time to move to or consider new ways of working, share ideas with colleagues, or discuss alternative support options with service users (e.g. Clark et al., 2004; Eost-Telling, 2010; Newbronner et al., 2011; Spandler & Vick, 2004, 2005). Other new initiatives being implemented in social work may also impact on the time practitioners are able to spend on direct payments (ADASS & LGA, 2009; Newbigging & Lowe, 2005; Wilberforce et al., 2012). Moreover, there may be conflict between personalisation policies and other approaches, such as the joined-up, collective approach to care vs. the individualist ideology of direct payments (Henwood & Hudson, 2007), or adult protection vs. promoting choice and control for service users (Ridley et al., 2011).

Inequity in access to direct payments

It is noted that service users in some client groups may be more likely to gain access to direct payments than others, in part due to selective offering of this option by social workers. For example, there is evidence that direct payments are not always offered or promoted to older people (e.g. Newbronner et al., 2011; OPM, 2010; Vick et al., 2006), service users with mental illness (e.g. CO & DH, 2005; CSCI, 2004; Priestley et al., 2007), or those with higher social care needs (Eost-Telling, 2010). This may be due to risk aversion (Glendinning et al., 2008; Moran et al., 2013), assumptions that direct payments are only suitable for certain client groups (Henwood & Hudson, 2007; Laybourne et al., 2014; Moran et al., 2013), or an emphasis in direct payment policies on particular service user groups (and omission of others) (Newbigging & Lowe, 2005; Tobin & Vick, 2004). It also appears that certain client groups are more likely than others to receive support to assist them in setting up and managing direct payments. Three-quarters of social care service users surveyed by Wood (2010) reported that they would require some help if they were to take on a personal budget. However, it is acknowledged (Newbigging & Lowe, 2005; Routledge & Carr, 2013) that support organisations are more equipped to support younger people with physical or learning disabilities than their older counterparts or those with mental illness.

In determining clients’ suitability for self-directed support, it is suggested that social workers consider a number of factors, including relevant past experience and perceived trustworthiness (Spandler & Vick, 2004). Service users’ levels of confidence, articulacy and assertiveness are also important in determining their success in accessing this option (Clark et al., 2004; Griffiths & Ainsworth, 2013; OPM, 2010). Evidence suggests that direct payments are more likely to be offered to service users considered to have the ability to successfully manage their own care (e.g. Glendinning et al., 2004, 2008; Newbigging & Lowe, 2005), or where family support is available to help them achieve this (Clark et al., 2004; Spandler & Vick, 2004, 2005, 2006). Much research has identified that assistance from family members is vital in enabling take-up of self-directed support (e.g. Kinnaird, 2010; OPM, 2010; Williams et al., 2003), often due to concerns about paperwork, which is seen as overwhelming, complex, and unmanageable (e.g. Hatton & Waters, 2013; Ipsos MORI, 2011; Spandler & Vick, 2004). Family members may also play an important role in finding out about direct payments on behalf of their relative (e.g. via the Internet) and in encouraging service users to take up this option (e.g. Baxter & Glendinning, 2011; Griffiths & Ainsworth, 2013; Ipsos MORI, 2011).

Further to selective offering of direct payments to particular client groups, there is evidence of geographical variation in the way that eligibility for direct payments is determined (Dewar et al., 2005; Priestley et al., 2010; Ridley et al., 2011). For example, Clark et al. (2004) observed that local authorities varied as to whether they would allow carers to manage direct payments on behalf of service users. Spandler and Vick (2004) also noted the implementation of additional criteria in some areas, such as the prohibition of direct payments being utilised to replace Local Authority provided services. Priestley et al. (2007) point out that uptake of direct payments is higher in England than in the UK as a whole. They suggest this may be due to a range of factors, including greater numbers of full-time, dedicated direct payment staff in English local authorities, more established support services, a lower level of resistance from practitioners and politicians, higher funding, and greater publicity around direct payments. Other geographical disparities include differences in direct payment set-up time (Davey, Snell et al., 2007; Priestley et al., 2010), the promotion of direct payments (Dewar et al., 2005), the amount of support available to service users (Dewar et al., 2005; Priestley et al., 2010), and the type of care for which funding is agreed (Newbigging & Lowe, 2005; Spandler & Vick, 2004).

2.2.2 Consideration of direct payments

Worries about becoming an employer

Becoming an employer is a key concern of service users in considering self-directed support. Anxiety about strangers coming into their home, the responsibility of managing and co-ordinating personal assistants, recruiting and dismissing staff and burdensome administration is reported (e.g. Dewar et al., 2005; Ipsos MORI, 2011; Moran et al., 2013; Ridley et al., 2011). In particular, service users have identified concerns about the legal aspects of employment, such as ensuring employees have the right to work in the UK, organising holiday and sick pay, paying national insurance and tax, and the threat of employment tribunals (e.g. Clark et al., 2004; Dewar et al., 2005; McMullen, 2003; Moran et al., 2013). Specific worries are also expressed by service users as to how they would cope in the event of emergencies or unplanned absence of personal assistants (e.g. Newbronner et al., 2011; Spandler & Vick, 2004; Wood, 2010). These concerns are echoed by practitioners, who worried that vulnerable clients could be left without care when personal assistants go on holiday or take sick leave (Manthorpe & Stevens, 2008). Even where service users are confident in managing direct payments, they may often combine employing their own personal assistants with agency care to ensure that their needs are always met (Henwood & Hudson, 2009). In line with this, it is noted that some service users may opt to use a care agency rather than personal assistants unless they have family members on hand to provide support in the event of an emergency (Ipsos MORI, 2011).

Concerns about ability to manage direct payments

Many practitioners have identified the misuse of social care funds by direct payment users as a potential issue, for example where money is spent inappropriately leaving little or none of the budget to meet essential needs (e.g. Glendinning et al., 2008; Hitchen, 2012; Spandler & Vick, 2005). However, some argue that this concern is misplaced, as only a minority of service users use funds inappropriately, and the amounts involved are relatively small (Henwood & Hudson, 2007). Social workers have also reported worries about the risks of service users purchasing unregulated, unmonitored care, which they argue increases the likelihood of abuse and means that formal safeguarding procedures such as criminal records and POVA (protection of vulnerable adults) checks are bypassed (e.g. Glendinning et al., 2008; Henwood & Hudson, 2007, 2009; Routledge & Carr, 2013). Conversely, mental health care co-ordinators interviewed by Spandler and Vick (2004) identified that employing non-professional personal assistants with no care qualifications may be positive for service users who seek a more informal environment.

A frequently mentioned concern of practitioners is that service users may be vulnerable to exploitation or abuse from paid carers and family members (e.g. Glendinning et al., 2008;

Henwood & Hudson, 2007; Manthorpe & Samsi, 2012). However, in a survey of almost 800 service users (IFF Research, 2008), it was found that direct payment recipients employing personal assistants were actually less likely to report having experienced abuse (10%) than service users in receipt of support from their Local Authority (18%). However, the authors note that this may be due to those in the latter group having received services for a longer period of time and being visited by a potentially greater number of carers. It may also be the case that service users who are able to manage their own care via direct payments are less likely to be vulnerable to (or perhaps to report) abuse.

Service user and carer co-researchers in Hitchen's (2012) action research study suggested that concerns expressed by practitioners on service users' behalf may be reflective of the paternalism of the social work profession, indicating a need for a shift in responsibility. At the root of this 'paternalism' may be worries about accountability (Eost-Telling, 2010). For example, social workers have expressed anxiety about letting go of their duty of care, and raised questions as to where responsibility would lie in a crisis (e.g. Glendinning et al., 2008; Spandler & Vick, 2004), such as for arranging cover for vulnerable service users in the case of emergencies (e.g. Manthorpe & Stevens, 2008; Priestley et al., 2010).

However, although social workers' concerns about the ability of service users to manage direct payments have been termed paternalistic (Moran et al., 2013), much evidence suggests that these worries are shared by service users and carers themselves. For example, they may be daunted by the thought of managing their own care without sufficient support, or uncertain of their ability to take on the additional workload, responsibility and perceived stress of direct payments (e.g. Glendinning et al., 2009; Henwood & Hudson, 2009; Ipsos MORI, 2011). Some may feel unable to take on any extra responsibility in light of current challenging circumstances (Kinnaird, 2010): for example, almost a third of service users in one study (Lakey & Saunders, 2011) who had chosen not to take up direct payments said that this was because they found it difficult enough to cope with their existing situation. Anxiety regarding the financial aspects of direct payments is a key issue, with concerns raised about opening a new bank account, managing large sums of money, overspending or inappropriate spending, keeping accounts, and filling in tax returns (e.g. Glendinning et al., 2008; Hitchen, 2012; Newbronner et al., 2011; Spandler & Vick, 2004). Worries about managing the administrative aspects of direct payments are also widely expressed, with views that the paperwork may be overwhelming and stressful to manage, difficult to understand, or physically challenging for service users with visual or fine motor impairment (e.g. Clark et al., 2004; IFF Research, 2008; Moran et al., 2013; Spandler & Vick, 2004). Overall, service users appear to view direct payments as confusing, citing a lack of understanding and fears about the potential complexity of managing their own budget and ensuring complicated rules are adhered to (e.g. Carlisle People First Research Team, 2011; Lakey & Saunders, 2011; Routledge & Carr, 2013). However, some research does indicate that once service users are used to managing the administration of their budget they find this less difficult than they had originally anticipated (Baxter & Glendinning, 2013; Glendinning et al., 2008).

Budgetary concerns

Budgetary constraints are widely reported by practitioners as a barrier to the implementation of direct payments (Brookes et al., 2013; Goodchild, 2011; Hatton & Waters, 2011), with over a third of those surveyed by Davey, Snell et al. (2007) identifying this as a hindering factor. Some report that insufficient money is available for self-directed support (e.g. Kinnaird, 2010; Spandler & Vick, 2006; Williams & Tyson, 2010), arguing that the initiative is unrealistic and unaffordable (Henwood & Hudson, 2009; Hitchen, 2012), and pointing to the lack of available finance to bridge the gap between traditional care and direct payments (Ridley et al., 2011). It is also suggested (e.g. Routledge & Carr, 2013; Vick et al., 2006) that financial constraints may hinder service users' potential for creativity in managing their support.

Some service users argue that self-directed support is under-funded and that the budget allocated for their care is unlikely to be sufficient to meet their needs (Lakey & Saunders, 2011; Sense, 2008); a view echoed by social care professionals (IFF Research, 2008). Furthermore, the issue of the hidden costs of direct payments has been raised by both professionals and service users, with worries expressed regarding a range of expenses that may not be allowed for in the care budget, such as travel, staff training, payroll services, holiday and sick pay, tax and national insurance (e.g. Glendinning et al., 2008; Lakey & Saunders, 2011; Manthorpe & Stevens, 2008). There is also confusion amongst service users as to whether direct payments could affect their existing benefits (e.g. Carlisle People First Research Team, 2011; CSCI, 2004; Dewar et al., 2005). Concerns about possible future budget cuts have been raised, with some service users fearing charges being introduced for brokerage or support services, payments not keeping up with the rising costs of services, or losing direct payments altogether (e.g. Callaghan et al., 2012; Glendinning et al., 2009; Hatton & Waters, 2013; Woodin, 2006).

Service users may be less willing to take on the responsibility of direct payments if they only have a small package of care (Moran et al., 2013; Newbronner et al., 2011; Ridley et al., 2011). For example, Davey, Fernandez et al. (2007) have shown a positive statistical link between the size and wealth of local authorities and take-up of direct payments, indicating that where social care packages are more generous, greater numbers of service users choose to take up self-directed support. Inadequate budgets may make it difficult for service users to attract personal assistants to work for them for a relatively small number of hours (Clark et al., 2004; Priestley et al., 2010). Research also suggests that budgetary constraints may limit the options offered to service users in terms of managing their care (Newbigging & Lowe, 2005; Spandler & Vick, 2004), with examples cited of social workers not mentioning direct payments in cases where cheaper care solutions were available (Kinnaird, 2010). Practitioner concerns that direct payments may result in an increase in costs, for example in comparison to services block funded by the Local Authority at a discounted rate, are identified in a number of studies (Ellis, 2007; Glendinning et al., 2008; Henwood & Hudson, 2007; Priestley et al., 2010).

Lack of demand for direct payments

Some practitioners perceive that service users do not wish to take up direct payments (e.g. Kinnaird, 2010; Moran et al., 2013; Vick et al., 2006), citing clients’ reluctance to take on the responsibility of arranging their own care and importantly, satisfaction with existing services. It is also suggested that ‘institutionalised conservatism’ (Henwood & Hudson, 2007), whereby service users find it difficult to be creative in thinking about how they could use their budget in new ways, may be a barrier (Glendinning et al., 2008; Hitchen, 2012). However, there is a danger that social workers may make assumptions or generalisations about service users’ lack of desire for direct payments (Clark et al., 2004), where presumed low demand may simply be due to poor awareness of social care options. In addition, inflexible thinking about direct payments on the part of practitioners may make self-directed support a less attractive option to service users. Spandler and Vick (2004) report that care co-ordinators in their research had rigid ideas as to how direct payments could be utilised and made incorrect assumptions about their clients’ wishes, which meant that service users did not realise how flexible direct payments could be. For example, Ridley et al. (2011) found that service users and carers believed that becoming an employer, which they were reluctant to do, was the only way in which they could take control of their own care.

Nonetheless, some studies do point to an actual lack of demand for direct payments from service users and carers themselves (e.g. Carlisle People First Research Team, 2011; Ipsos MORI, 2011; Kinnaird, 2010). In these cases, explanations were broadly in line with those reported by social workers, as noted above (e.g. Lakey & Saunders, 2011; Williams et al., 2003; Wood, 2010). For example, a Sense (2008) survey found that of service users who decided not to take up direct payments, 58% said that they did not want the additional responsibility and 53% cited satisfaction with their current services or situation. Henwood and Hudson (2009) found that some service users wished to retain traditional day services, citing the value of specialist provision, and structured routine and activities. For some, particularly older service users, there may be no desire for change (e.g. CSCI, 2004; Glendinning et al., 2008; Moran et al., 2013), possibly due to a fear of losing existing services that are considered satisfactory, or anxieties about unknown alternatives (Baxter & Glendinning, 2013; Henwood & Hudson, 2007; Manthorpe & Stevens, 2008; Routledge & Carr, 2013).

Furthermore, research (e.g. Henwood & Hudson, 2007; Ipsos MORI, 2011; Routledge & Carr, 2013) indicates that a significant proportion of service users would not make any changes to their care if they were to take up a direct payment, suggesting that self-directed support would have a limited impact on their lives. For example, half of service users surveyed by Bartlett (2009) who were not in receipt of personal budgets said that they would not change anything if they had control over their social care. Retrospective studies have reported comparable findings; for example Wood (2010) found that 41% of self-directed support recipients surveyed had not made changes to their care since they took control of their social care budget. Similarly, Glendinning et al. (2008) reported that almost a third of those who had moved from managed social care to individual budgets as part of a national pilot programme had not made any changes to their support after six months and did not plan to do so in the future.

Scepticism and resistance

Scepticism about direct payments and the personalisation agenda as a whole on the part of both service users and practitioners has been identified, including suspicion of the underlying motives of personalisation and concerns as to whether direct payments will work in practice and be of benefit to service users. For example, evidence suggests that service users may view the personalisation agenda as a way of the government offloading responsibility for social care in the name of empowerment (e.g. Dewar et al., 2005; Lakey & Saunders, 2011; Manthorpe & Stevens, 2008). Likewise, social workers have reported fears that rather than an initiative to afford service users greater choice and control, personalisation is merely a cost-cutting exercise in response to budget cuts (Brookes et al., 2013; Hitchen, 2012; Ridley et al., 2011), or a method of 'backdoor privatisation' (Pearson, 2010; Priestley et al., 2010). Due to frequent new initiatives in social work, some may view self-directed support as the latest fashionable idea that will soon be replaced (e.g. Eost-Telling, 2010; Henwood & Hudson, 2007; Wilberforce et al., 2012). In turn, service users may be suspicious of practitioners' motives, believing that they are being 'sold' direct payments by their social worker, for example to meet performance targets (Baxter & Glendinning, 2011; Priestley et al., 2010). It is suggested by both service users and practitioners (Priestley et al., 2007; Ridley et al., 2011) that this suspicion may be a result of self-directed support being driven by professionals rather than those receiving care.

A general resistance to the personalisation agenda amongst practitioners has been widely noted (e.g. Brookes et al., 2013; Goodchild, 2011; Hitchen, 2012; Vick et al., 2006). Three-quarters of direct payment support organisation professionals surveyed by Davey, Snell et al. (2007) cited staff resistance as a hindering factor to the implementation of direct payments in England, with almost a third rating this as a critical factor. Resistance may be due to difficulties associated with culture change (e.g. Callaghan et al., 2012; Clark et al., 2004; Manthorpe et al., 2009), increased workload (Glendinning et al., 2008; Henwood & Hudson, 2009), lack of knowledge about direct payments (Priestley et al., 2010), or concerns about changes to the social worker role (Glendinning et al., 2008; Henwood & Hudson, 2007). It has been found (Eost-Telling, 2010) that some social workers have felt patronised by the way in which the personalisation agenda is delivered in their organisation, where training implies that treating service users with respect and as individuals is a novel idea.

Social care professionals have expressed concerns that increased use of self-directed support may impact negatively on existing services (e.g. Ellis, 2007; Pearson, 2010; Priestley et al., 2007, 2010), for example resulting in staffing issues for Local Authority provision if carers choose to leave to work directly for direct payment users (Dewar et al., 2005; Manthorpe & Stevens, 2008). It is argued (Henwood & Hudson, 2007, 2009; Manthorpe & Stevens, 2008; Ridley et al., 2011) that direct payments could actually result in less choice for service users who continue to utilise statutory services, as these may close due to a lack of demand from direct payment recipients. Furthermore, fears are reported that although self-directed support could mean greater involvement in the community for some service users, it may also mean that services such as group activities or day centres are lost (Glendinning et al., 2008; Manthorpe & Stevens, 2008), resulting in increased social isolation for others (e.g. Hitchen, 2012; Newbronner et al., 2011; Vick et al., 2006). In line with this, Spandler and Vick (2004) highlight concerns raised by professionals that direct payments may cause inequity by enabling a minority of service users to have more choice and flexibility regarding their care, while the remaining majority receive lower quality, under-funded services. Likewise, Priestley et al. (2010) suggest that direct payments have the potential to create a two-tier system of care.

Some social workers may not be convinced of the benefits of direct payments for service users, doubting that they could increase independence and autonomy (Vick et al., 2006). This may be due to a lack of exposure to positive examples of service users successfully using direct payments (Spandler & Vick, 2004; Vick et al., 2006). For example, Priestley et al. (2007) found that practitioners who had little experience of direct payments were less positive about their implementation than their more experienced counterparts. Some report concerns that there is no evidence base in support of the benefits of direct payments for recipients (Hitchen, 2012). Service users too have expressed scepticism regarding whether self-directed support could benefit them and change their negative experiences of social care (Newbigging & Lowe, 2005).

Even where practitioners view direct payments as potentially beneficial, there are concerns as to how self-directed support can be achieved in practice (Spandler & Vick, 2004). For example, those working with service users with complex needs point out that direct payments publicity material tends to portray cases of service users with relatively straightforward needs, leaving them unconvinced that self-directed support would work for their own client group (Henwood & Hudson, 2009). Some social workers also report experiencing over-simplistic promotion of direct payments by managers who do not recognise any of the difficulties in implementation (Wilberforce et al., 2012). Henwood and Hudson (2007, 2009) identified a desire on the part of frontline practitioners for more information about the operational aspects of self-directed support and how to tackle problems, rather than simply promotion of the benefits; an approach that added to their general scepticism.

Some social work professionals (Ellis, 2007; Eost-Telling, 2010; Hitchen, 2012) may view direct payments as paying for ‘luxuries’ and meeting service users’ wants rather than their needs, with examples cited such as television subscriptions, cars, holidays, swimming and socialising. Again, it was proposed that unrealistic promotional materials about direct payments contributed to this view, which also resulted in perceptions that direct payments were unachievable in reality (Henwood & Hudson, 2007). However, other practitioners reported that only a minority of service users used direct payments to purchase whatever they wished, with most procuring vital services (Eost-Telling, 2010). Furthermore, it is argued that provided that services purchased meet service users’ defined needs (such as improving social relationships), there should be flexibility in how this is achieved (Henwood & Hudson, 2009; Hitchen, 2012).

2.2.3 Difficulties experienced by direct payment users

Direct payment set-up difficulties

Difficulties around the set-up of direct payments are widely reported, primarily due to a lack of knowledge on the part of practitioners and the amount of work involved for both service users and social workers. Some practitioners identify that they have little knowledge of the processes and paperwork necessary in setting up a direct payment (e.g. Eost-Telling, 2010; Glendinning et al., 2008; Vick et al., 2006). This view is echoed by care recipients, who cite experiences of social workers not understanding how to fill in the relevant forms and making mistakes, elongating the process (Spandler & Vick, 2004). In line with this, some service users have reported long delays in the time taken to set up their direct payment (e.g. Hatton & Waters, 2011; Kinnaird, 2010; Spandler & Vick, 2004), in some cases resulting in demotivation (Eost-Telling, 2010), frustration (Lakey & Saunders, 2011) and a negative effect on mental health (Griffiths & Ainsworth, 2013; Hitchen, 2012).

Service users have identified a number of practical difficulties in setting up direct payments, such as issues with opening a bank account, managing the paperwork and recruiting personal assistants (e.g. Abbott & Marriott, 2012; Glendinning et al., 2009; Hatton & Waters, 2013). Social workers also argue that setting up self-directed support can be considerably more time-intensive than putting a package of mainstream care into place, in terms of additional paperwork and processes (e.g. Spandler & Vick, 2004, 2005, 2006; Williams & Tyson, 2010). For example, care co-ordinators from one Local Authority reported having to fill in eight separate forms for each service user wishing to access direct payments (Newbigging & Lowe, 2005). Others estimated that creating a support plan for direct payment recipients would take at least six times as long as for service users in receipt of traditional care (Glendinning et al., 2008). However, as noted earlier, social workers may over-estimate the additional work created in supporting direct payment users (Jacobs et al., 2011).

Need for support

A clear need for support for service users in setting up and managing direct payments has been acknowledged (e.g. Henwood & Hudson, 2009; Hitchen, 2012; Ridley et al., 2011; Sense, 2008). Practitioners and care recipients point out that good quality support is invaluable in encouraging and enabling service users to take up this option (e.g. Manthorpe & Stevens, 2008; Priestley et al., 2007; Vick et al., 2006), as some may be unlikely to take on the management of their own care without additional assistance (e.g. Homer & Gilder, 2008; Lakey & Saunders, 2011; Spandler & Vick, 2004).

Service users surveyed by Bartlett (2009) who were not currently managing their own care identified that they would need a range of support to take up personal budgets, most commonly guidance on how the funds could be spent (57%), help managing the budget (44%) and information about support costs (47%). These findings were echoed in other studies (e.g. Lakey & Saunders, 2011), which also indicated that administrative assistance (e.g. Dewar et al., 2005; Spandler & Vick, 2004; Wood, 2010), help with support planning (Mind, 2009; Routledge & Carr, 2013), advocacy (Dewar et al., 2005) and peer support (Clark et al., 2004) would be useful. Assistance in procuring services, including support in appointing suitable personal assistants (Dewar et al., 2005; Ipsos MORI, 2011) and in finding out about and choosing between available service options (Manthorpe & Stevens, 2008) was identified as important. Face-to-face contact with a professional who could explain processes clearly was particularly valued in preference to telephone support or written information (Callaghan et al., 2012; Dewar et al., 2005).

Despite this, over half of direct payment recipients interviewed by McMullen (2003) reported receiving insufficient or no support in managing their care. Service users identify a lack of guidance on how to set up and manage their care package (Ellis, 2007), including insufficient information on how to select the right support (Clark & Hornby, 2011; Hatton & Waters, 2013), on legal employment responsibilities (e.g. Clark et al., 2004; CO & DH, 2005; Ipsos MORI, 2011), how to manage excess funds building up in the care account (e.g. Glendinning et al., 2009; Newbronner et al., 2011; Priestley et al., 2010) and chiefly, how the direct payment can be spent (e.g. Glendinning et al., 2008, 2009; Homer & Gilder, 2008; McMullen, 2003). Where provided, it is reported that guidance is sometimes confusing, inconsistent or lacking clarity (e.g. Ipsos MORI, 2011; Newbronner et al., 2011; Sense, 2008).

Research suggests that many of those on direct payments feel unsupported or abandoned by professionals due to low levels of contact once their care arrangements are set up (Ipsos MORI, 2011; Spandler & Vick, 2004). This may lead to uncertainty as to how their budget can be utilised, or to recipients ceasing to use direct payments altogether (Arksey & Baxter, 2012). It is noted that where support services do exist, they may be underdeveloped or overstretched with long waiting lists (e.g. Pearson, 2004; Routledge & Carr, 2013; Vick et al., 2006). In addition, information and publicity about available support services may be inadequate, with many service users unsure of where to turn for support (e.g. Baxter & Glendinning, 2011; Carlisle People First Research Team, 2011; Clark et al., 2004). Arksey and Baxter (2012) suggest that a lack of knowledge about potential support may dissuade some service users from taking on the management of their care, citing an example of one service user who stopped using direct payments because she had not realised support was available, and another who initially decided against taking up direct payments but changed her mind when she found out she could have help with administration tasks.

Where service users do receive support to manage their direct payment, evidence suggests that this may be of variable quality, with incorrect or inconsistent advice given in some cases (CSCI, 2004; Ipsos MORI, 2011). It has been argued that support staff may lack the necessary knowledge and skills, particularly in providing tailored support to particular client groups (Hitchen, 2012; Newbigging & Lowe, 2005; Vick et al., 2006). Spandler and Vick (2004) identify the importance of support being delivered in a non-controlling, personalised way, citing examples of direct payment recipients being given standard recruitment advertisements, job descriptions and interview questions, when some may prefer to customise or develop these themselves.

Market forces

External factors, such as the availability of services to purchase and service users' own procurement skills and knowledge of the market appear to play a significant part in access to self-directed support. A major issue reported by practitioners (e.g. Priestley et al., 2010; Ridley et al., 2011; Vick et al., 2006) is the presence of block contracts, where local authorities have monopoly over a service or have secured provision at a preferential rate due to their size and purchasing power. This may mean that direct payments are not economically viable for those who wish to purchase particular services, or that direct payment recipients are unable to receive the support they would like, resulting in less choice. Fernandez, Kendall, Davey and Knapp (2007) found that when other variables were controlled for, local authorities with relatively little block funded in-house care provision tended to show higher uptake of direct payments by older service users and those with physical disabilities.

Unlike local authorities, individual service users have limited purchasing power and may lack the necessary skills, which could limit their ability to achieve value for money or procure high quality services (e.g. Glendinning et al., 2008; Manthorpe & Stevens, 2008, 2010; Routledge & Carr, 2013). For example, direct payment recipients are in competition for personal assistants with larger organisations that may be able to offer a more attractive package of pay, training and other benefits (CSCI, 2004). Furthermore, where service users decide to utilise care agencies rather than employing carers themselves, they may find the rates charged are too expensive without the discount that may be afforded to larger purchasers (OPM, 2010).

Service users and practitioners alike report a lack of affordable alternative services which may be purchased with a direct payment (e.g. Brookes et al., 2013; Hitchen, 2012; Lakey & Saunders, 2011), with particular gaps around the availability of personal assistants and suitable day activities. Social care professionals suggest that the market has not yet sufficiently developed to keep up with the changing demands of service users (e.g. ADASS & LGA, 2009; NAO, 2011; Newbronner et al., 2011). For example, a lack of provider engagement and service development in response to the personalisation agenda is noted, with little awareness and understanding on the part of providers, who tend not to recognise the new openings self-directed support could afford (Glendinning et al., 2008; Henwood & Hudson, 2007). On the other hand, Henwood and Hudson (2008) identify that providers have little opportunity for dialogue with social care commissioners, which would enable them to keep up to date with local developments and determine the level of demand for particular services.

Newbronner et al. (2011) found that in some instances, personalisation could actually create less choice for personal budget holders. For example, in areas where traditional services in the community are no longer provided, it may become harder for service users to access group activities. However, although this was reportedly the case in some mental health services, the opposite issue was identified for older service users, for whom traditional services may be available with few alternatives. Even where there is a choice of provision, many service users may not be aware of what is available to purchase (Baxter & Glendinning, 2011; Glendinning et al., 2009; Ipsos MORI, 2011), with some identifying a lack of information or support to help them find and choose between appropriate services (e.g. Clark et al., 2004; Clark & Hornby, 2011; OPM, 2010). Likewise, it is recognised by practitioners that assistance in procurement, such as the provision of information, recommendations, or an up to date directory of service providers, would be of benefit to service users (e.g. Eost-Telling, 2010; Hitchen, 2012; Manthorpe & Stevens, 2008). It was acknowledged that researching local services was particularly difficult for those with no Internet access (Ipsos MORI, 2011; Lakey & Saunders, 2011).

Budgetary constraints

Concerns about insufficient care budgets, as previously discussed, are considered to be a major barrier to direct payment uptake. In line with this, financial constraints have also been found to affect existing direct payment recipients, with the limited budget they are allocated impacting on their ability to pay for sufficient support and recruit suitable carers. Many practitioners and service users argue that the budget provided for their social care is not sufficient to meet their needs (e.g. IFF Research, 2008; Lakey & Saunders, 2011; McMullen, 2003), particularly for those using care agencies in preference to becoming an employer (Clark et al., 2004; Clark & Hornby, 2011). Although Fernandez et al. (2007) identify a positive correlation between average direct payment rates and local average care unit costs, Davey (2006) found that nationally, the average direct payment rate per hour of care was lower than the average pay rate of domiciliary carers, and did not always include adequate provision for unsocial hours pay. Furthermore, the hourly direct payment rate allocated may often be lower than the average cost of Local Authority domiciliary care (Davey, Fernandez et al., 2007), suggesting that direct payment users may be provided with less money than traditional service users to pay for the same level of support. This has led in some cases to service users being forced to top up payments with their own money (Clark et al., 2004; Hatton & Waters, 2013), or having to choose between good quality carers and sufficient hours of support (Glendinning et al., 2008; Kinnaird, 2010; Sense, 2008).

Budgetary constraints may result in difficulties in attracting employees, with some service users reporting problems in recruiting or retaining personal assistants due to the low pay or few hours of work they are able to offer (e.g. IFF Research, 2008; McMullen, 2003; Priestley et al., 2010), particularly in affluent areas (Manthorpe & Stevens, 2010). Recruitment may be more challenging when specialist or more experienced carers are required (Kinnaird, 2010; Spandler & Vick, 2004): for example, Sense (2008) cite a case where a direct payment recipient was awarded only £6 per hour to pay for a personal assistant for a deafblind child with epilepsy.

Service users have commonly reported difficulties relating to the ‘hidden’ costs of direct payments, not taken into account when the care budget is agreed. These may include holiday and sick pay, national insurance, staff training expenses, payroll and administrative support, travel expenses, and contingency funds for emergencies (e.g. Clark et al., 2004; Homer & Gilder, 2008; Newbronner et al., 2011; Priestley et al., 2010). These additional expenses may limit the hours of care that service users are able to procure, meaning that they do not receive the support they need.

Inflexibility of direct payments

It is reported by some direct payment recipients that rules and restrictions on how they can use their social care budget have undermined the flexibility of self-directed support (e.g. CSCI, 2004; Glendinning et al., 2009; Spandler & Vick, 2005). There may be inappropriate limitations or tight constraints on how the money can be spent (e.g. Hatton & Waters, 2011; IFF Research, 2008; Spandler & Vick, 2004, 2006), with examples cited such as restrictions on the length of visits by support workers (Kinnaird, 2010), service users not being allowed to utilise self-employed personal assistants (Kinnaird, 2010), spend their budget on anything other than personal care (McMullen, 2003; Tobin & Vick, 2004), or pay for cleaning services or meal preparation (Woodin, 2006). Prohibitions on employing relatives via direct payments are frequently cited (e.g. McMullen, 2003; Priestley et al., 2010; Ridley et al., 2011), which may deter some from taking up this option (Clark et al., 2004; Sense, 2008; Vick et al., 2006). For example, service users have reported feeling more comfortable with their relatives providing care (Homer & Gilder, 2008), experiencing more control and consistency (IFF Research, 2008), and considered that this was a safer option than employing strangers (Vick et al., 2006; Woodin, 2006). The employment of relatives could additionally help overcome recruitment difficulties, for example where service users live in remote areas or require few hours of care (Vick et al., 2006).

There is also evidence to suggest that inflexible rules may be imposed on service users regarding the management of their direct payment account, limiting the amount of control they have in utilising the budget to meet their needs. For example, restrictions may be imposed on the amount of money that can be kept in the care account (Sense, 2008), with no allowance for contingency funds that could be utilised in an emergency (Spandler & Vick, 2004), or the overall budget may be split into separate pots to be utilised for different support needs (Newbronner et al., 2011). Direct payment users report concerns over losing unspent funds in their account (e.g. Carlisle People First Research Team, 2011; Glendinning et al., 2009; Newbronner et al., 2011), which are sometimes taken back by the Local Authority, leading service users to feel penalised for managing their budget economically (Arksey & Baxter, 2012).

Furthermore, both social work professionals and service users have reported that the monitoring and auditing of the care budget can be disproportionate and excessively bureaucratic (e.g. Abbott & Marriott, 2012; CSCI, 2004; Ridley et al., 2011). Conversely, some practitioners have raised concerns that reduced monitoring of service users on self-directed support could result in possible exploitation (Manthorpe & Stevens, 2008). It is acknowledged that a balance between minimising risks to individual service users and ensuring funds are not misspent can be difficult to achieve (Henwood & Hudson, 2007, 2009).

In some cases, the flexibility of direct payments may be constrained by a lack of creativity on the part of both professionals and service users. For example, practitioners may present a limited range of traditional care options to clients (e.g. Henwood & Hudson, 2007; Newbronner et al., 2011), with little consideration given to more imaginative ideas (Hitchen, 2012). Some identified that this was due to workload pressures leaving little time for creative thinking (Clark et al., 2004; Routledge & Carr, 2013), while Glendinning et al. (2008) point to a lack of confidence and experience on the part of care co-ordinators in creating innovative care plans. Routledge and Carr (2011, 2013) argue that a lack of funding has meant that many service users are forced to spend their entire budget on personal care, allowing limited scope for creativity. Furthermore, conservative choices made by service users who may have difficulty in thinking of new ways to obtain support due to previous, long-term reliance on traditional care services, can limit opportunities for innovative procurement (Henwood & Hudson, 2007; Hitchen, 2012; Newbronner et al., 2011).

Difficulties managing direct payments

Service users have widely commented that managing direct payments can be stressful, onerous and overwhelming, with particular difficulties identified relating to becoming an employer and coping with complex paperwork regarding payroll and tax (e.g. Hatton & Waters, 2011, 2013; IFF Research, 2008). A lack of available information and support may make the management process more difficult (Sense, 2008). For example, Clark et al. (2004) cite cases of direct payment recipients who did not realise that they could use self-employed personal assistants or that a support service was available.

Some self-directed support recipients reported that they would not have been able to cope with the management of their care without assistance, for example from accountants, family members, personal assistants and social workers (Clark et al., 2004; Newbronner et al., 2011; Spandler & Vick, 2004). In line with this, a key issue raised in a number of studies is the extra work and pressure created for carers of direct payment recipients, who may find it difficult to take on the management of their relative’s support in addition to their existing caring responsibilities (e.g. Homer & Gilder, 2008; Moran et al., 2013;

Williams et al., 2003). Glendinning et al. (2009) found that carers of direct payment users spent on average more time managing and organising their relative’s care and completing paperwork, which resulted in stress. However, some reported that they felt more valued and empowered due to their relative receiving self-directed support. Consistent with this, further research (e.g. Hatton & Waters, 2011, 2013; Hitchen, 2012; Ipsos MORI, 2011) identifies that the positive impact of managing their relative’s care on carers’ own lives and that of the person they care for is balanced with the extra responsibility of managing the care budget, which may be complex and stressful.

It is argued by service users and practitioners alike that self-directed support systems are overly bureaucratic, for example due to the requirement to open a separate bank account, the amount of paperwork generated by simple purchases to fulfil monitoring requirements, and in some cases service users being forced to pay personal assistants by cheque (e.g. Clark et al., 2004; Glendinning et al., 2009; Hatton & Waters, 2013; Ridley et al., 2011). Poor administration of direct payments by Social Services may cause additional issues for recipients, often due to processing delays or payment issues (e.g. Griffiths & Ainsworth, 2013; Hatton & Waters, 2011; Hitchen, 2012). For example, delays in the completion of care arrangements have led to a number of difficulties for service users, including payments building up in the care account which they are unable to use (Clark et al., 2004; Glendinning et al., 2009), overpayments or undercharging required to be paid back at a later date (e.g. IFF Research, 2008; Lakey & Saunders, 2011), or late payments resulting in problems paying carers on time (Kinnaird, 2010; Priestley et al., 2010).

Difficulties being an employer

A significant issue for direct payment recipients is difficulty in finding personal assistants to provide their care, chiefly due to a lack of available potential employees (e.g. IFF Research, 2008; McMullen, 2003; Newbronner et al., 2011). Over three-quarters of support organisation staff identified low availability of personal assistants as a key hindering factor to the implementation of direct payments (Davey, Snell et al., 2007; Vick et al., 2006). In line with this, Spandler and Vick (2004) report that issues with the recruitment of personal assistants was one of the most common reasons service users in their research decided not to take up self-directed support. However, over half of direct payment recipients sampled by IFF Research (2008) who did not employ someone they knew, said that they found recruiting personal assistants easy or very easy, and in the majority of cases finding a suitable personal assistant took less than one month. Despite this, over a quarter reported only receiving an application from one potential personal assistant. A lack of potential employees may mean that service users have difficulty in finding personal assistants with the necessary skills, experience or understanding of specific conditions (e.g. Clark & Hornby, 2011; Kinnaird, 2010; Manthorpe & Stevens, 2008), particularly for those with complex needs (Henwood & Hudson, 2009; Sense, 2008; Spandler & Vick, 2004). There may be additional issues in recruiting personal assistants who are willing to work unsocial hours, such as early mornings, evenings and weekends (CSCI, 2004; IFF Research, 2008; Spandler & Vick, 2006).

Service users identify that a key barrier to being able to attract personal assistants is the lack of benefits they are able to offer employees, including good rates of pay, training and career development opportunities, job security and sufficient hours of work (e.g. McMullen, 2003; Spandler & Vick, 2004; Woodin, 2006). A lack of training opportunities appears to be a key issue in the recruitment and retention of personal assistants. For example, a survey of 486 personal assistants by IFF Research (2008) found that this was the main reason given by respondents for wanting to leave their post, with 99% reporting that training was useful to their role, and 42% identifying it as essential. Despite this, only 6% of service users employing personal assistants had arranged for formal training to be provided to their current employees. This would require investment that may not be possible due to financial constraints (CSCI, 2004; Homer & Gilder, 2008; Manthorpe & Stevens, 2008).

It is argued (OPM, 2010) that service users' social networks are an important factor in encouraging direct payment uptake, as those who can identify potential employees amongst people they know are likely to be more confident in using self-directed support. However, this may raise issues for those without an established network of contacts. The majority (61%) of service users employing someone via a direct payment surveyed by IFF Research (2008) reported having employed someone they already knew. Moreover, those employing a relative or friend were more likely to report improved consistency in their care following take-up of direct payments than those employing previously unknown personal assistants. Nevertheless, employing friends and relatives may lead to problems (Manthorpe & Stevens, 2008) such as guilt in terminating employment (Arksey & Baxter, 2012; Vick et al., 2006), embarrassment due to low rates of pay offered (Glendinning et al., 2009), or difficulties in defining the boundaries between paid work and activities carried out by the personal assistant as a friend or relative (Woodin, 2006). It is suggested (Arksey & Baxter, 2012; Newbronner et al., 2011) that it would be useful for service users to be provided with guidance on the employment of family members or friends, to ensure that they are informed in advance about potential issues such as these. Social care practitioners have also raised concerns about possible domestic abuse or other pressures on service users to employ family members (Glendinning et al., 2008; Vick et al., 2006), although Manthorpe and Samsi (2012) found that in general professionals tended to be more suspicious of unknown care workers than relatives of service users. Research by Newbronner et al. (2011) highlights that while professionals may be concerned that the employment of relatives as personal assistants could have a detrimental impact on family relationships and on the independence of the service user, this was not the experience reported by service users themselves.

Service users have identified that a register listing suitable, qualified or accredited personal assistants would be a useful tool to assist in recruitment (e.g. Clark et al., 2004; Clark & Hornby, 2012; IFF Research, 2008). Having to employ personal assistants without conducting a criminal records check is highlighted as a worry for some direct payment recipients (CSCI, 2004), and practitioners have reported concerns that the lack of vetting requirements for carers employed via self-directed support may leave vulnerable service users open to abuse (CO & DH, 2005; Glendinning et al., 2008; Henwood & Hudson, 2009). Research suggests that service users may encounter delays and complex procedures when carrying out criminal records checks, or in some cases be unable to carry out checks at all (e.g. Glendinning et al., 2008; IFF Research, 2008; Vick et al., 2006).

The experience of initial recruitment issues may make it difficult for direct payment users to become confident employers, as they may feel the need to act carefully for fear of upsetting personal assistants in case they decide to leave (Clark et al., 2004; McMullen, 2003). National Audit Office (2011) research identifies that almost a third of direct payment recipients employing a personal assistant were finding the experience difficult. A wide range of challenges are reported, including difficulties when personal assistants leave (e.g. Ipsos MORI, 2011; Kinnaird, 2010) or are unreliable (Clark et al., 2004; Manthorpe & Stevens, 2008), managing complex staff rotas (CSCI, 2004), arranging cover (Hatton & Waters, 2013; Lakey & Saunders, 2011), directing employees (Hatton & Waters, 2013;

Spandler & Vick, 2004), dealing with employment law (Ipsos MORI, 2011), completing the necessary paperwork (IFF Research, 2008; Newbronner et al., 2011) and managing the financial aspects such as cash flow and tax (Hatton & Waters, 2013; IFF Research, 2008). Handling disciplinary issues is identified as a key source of difficulty for service users (e.g. Ipsos MORI, 2011; Kinnaird, 2010), who may not be confident in addressing performance issues effectively (e.g. Clark & Hornby, 2011; Spandler & Vick, 2004), or find it awkward to define boundaries or discipline employees who have become their friends (e.g. Arksey & Baxter, 2012; Stainton & Boyce, 2010). One service user interviewed by Woodin (2006) pointed out the difficulty in disciplining employees and then having to ask them to complete personal care tasks.

2.3 Specific barriers experienced by the group under study

Particular difficulties experienced by older people, people with dementia and those living in rural communities have been highlighted in the literature, although the areas of dementia and rurality have been neglected to date. The following section provides an overview of research in these areas, with identification of gaps in the literature that need to be addressed.

2.3.1 Older people

Awareness and promotion of direct payments

Evidence suggests that awareness of direct payments is particularly low amongst older people (Dewar et al., 2005). A survey of over 250 social care service users (Bartlett, 2009) showed that 92% of older respondents knew nothing or very little about personal budgets, compared to 62% of participants overall. It is proposed (Baxter & Glendinning, 2011) that older people whose care needs have gradually increased over time (rather than those with a longstanding disability) may not realise that social care services are available, so do not seek relevant information. Low awareness of direct payments amongst older people may also be reflective of the fact that initial legislation did not allow people aged 65 and over to receive direct payments. An amendment passed in 2000[4] extended access to this group, yet Tobin and Vick (2004) found that many local authorities in England were subsequently slow to amend their direct payment policies. Of 96 policies obtained for analysis in 2004,

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[4] The Community Care (Direct Payments) Amendment Regulations 2000

only one third had been updated to reflect the new eligibility criteria, and under half mentioned older adults as a service user group. Furthermore, older people may find it more difficult to independently gain access to information about direct payments than their younger counterparts, for example as they are less likely to use the Internet (ONS, 2015). A carer of a person with dementia interviewed by Lakey and Saunders (2011) acknowledged that organising self-directed support would be challenging without Internet access, and identified that carers may not have the time to support older relatives in this task. It is suggested (Baxter & Glendinning, 2011) that accessing information via family members is particularly important for older people; therefore those without able and willing relatives may not obtain the information they need in order to make informed choices about their care.

Older direct payment users report that they would have found it useful to have been informed about self-directed support at an early stage rather than at crisis point, and propose that direct payments should be more widely advertised, for example on national or local radio (Clark et al., 2004). It is suggested that social workers mentioning direct payments at an early stage leads to increased uptake (Clark et al., 2004), for example as once traditional care services are in place older people may not wish to make any changes or employ new care staff (Ellis, 2007; Routledge & Carr, 2013). This issue has been overcome by some local authorities through the implementation of an interim package of care that allows older service users additional time to consider the option of self-directed support (Routledge & Carr, 2013), although some social workers may dismiss this as being too much work to put into place (Clark et al., 2004).

Research suggests that social workers do not always present direct payments as an option to all eligible service users, but offer them selectively to those they consider suitable, typically younger adults with disabilities (e.g. Kinnaird, 2010; OPM, 2010; Routledge & Carr, 2013). This may be due to assumptions that older people do not wish to take on the management of their care (e.g. Callaghan et al., 2012; Ellis, 2007; Newbronner et al., 2011) or would find it too difficult (Clark et al., 2004). Laybourne et al. (2014) also highlight concerns on the part of practitioners relating to the ability of older carers (who may have their own health needs) to cope with managing direct payments on behalf of their relative. Social work professionals have acknowledged that self-directed support is not embedded in the culture of older persons’ social work teams, with practitioners tending to set up traditional care packages by default rather than considering direct payments (Clark et al., 2004). In turn, this has meant that social workers are less experienced and have lower confidence in assisting older people to set up a package of self-directed support that meets their needs in a creative way (Glendinning et al., 2008). Some practitioners suggest that self-directed support is only a suitable option for a small number of older service users (Vick et al., 2006). Therefore, direct payments may be offered selectively within this group, for example only to middle class older people (Ellis, 2007), to those with a carer to manage the care package on their behalf (Clark et al., 2004), or those from an ethnic minority background who require tailored care to meet cultural needs (Ellis, 2007).

Concerns and difficulties in managing direct payments

As previously noted, there is a widely-held perception amongst social care professionals that older service users would be unable to manage direct payments (e.g. Callaghan et al., 2012; Laybourne et al., 2014; Moran et al., 2013), meaning that self-directed support may not be promoted to this group (Vick et al., 2006). Glendinning et al. (2008) found that social workers working with older people were particularly risk averse and resistant in relation to the implementation of direct payments. For example, there may be concerns that older people will be unable to understand and manage the financial aspects of their care package (Henwood & Hudson, 2007) or their responsibilities and liability as an employer (Clark et al., 2004), or be vulnerable to abuse or exploitation (Manthorpe & Stevens, 2008, 2010). Individual budget project leads suggest that older people may not wish to take up direct payments as they perceive social care professionals as the experts and do not have the confidence to take on the role of care manager (Moran et al., 2013). Social workers interviewed by Kinnaird (2010) also argue that older people are reluctant to take on the management of their care as they find the extra responsibility too daunting. However, the majority of carers of direct payment users with dementia interviewed in the same study said that they had no difficulty in managing this.

Nevertheless, older people themselves have raised concerns about their own ability to manage direct payments (Wood, 2010), for example reporting that they would not wish or feel able to take on the extra work and responsibilities in their later life (Dewar et al., 2005). Particular concerns relate to the financial management of the budget (Newbronner et al., 2011), such as the risk of inadvertently spending it on the wrong things, or using too much or too little (Moran et al., 2013). Furthermore, those without the necessary IT skills to use spreadsheets, print invoices or search for support providers online may feel that they would not be able to take on direct payments (OPM, 2010).

Older people who have chosen to take up direct payments also report difficulties, chiefly relating to taking on employment responsibilities. For example, recruitment of personal assistants can be problematic (Moran et al., 2013), which may subsequently make it difficult for older service users to assert their authority as an employer, due to worries that employees may leave if they feel the work is too onerous (Clark et al., 2004). However, it is acknowledged (Henwood & Hudson, 2009) that although there is an assumption that older people will find it difficult to recruit personal assistants and become an employer, some utilise their own networks to find suitable people and many may already be employers, with gardeners and cleaners for example. Restrictions on the employment of relatives was a problem for some older people interviewed by Clark et al. (2004); however these constraints have now generally been lifted by local authorities. Dewar et al. (2005) identify that older service users may not feel safe receiving care from a stranger in their own home, reporting that the perceived safety of even unfamiliar Local Authority carers was preferable to unknown carers employed via direct payments.

The paperwork involved with managing a direct payment is seen as over-bureaucratic and overwhelming by many older service users (Clark et al., 2004), with some unsure as to their administrative responsibilities as an employer, for example regarding tax and liability insurance. From a practical perspective, some older people with specific impairments, such as difficulty writing due to visual or fine motor impairment, may find completing forms problematic if their needs are not taken into consideration (Clark et al., 2004).

Perceived lack of desire to take up direct payments

It is argued by some practitioners (Laybourne et al., 2014) that older service users are less likely than their younger counterparts to desire choice and control over their support. In addition, there is a view amongst social care professionals that older people do not want to take on the extra work involved in managing their care (Callaghan et al., 2012; Ellis, 2007; Newbronner et al., 2011), which may impact on the way that direct payments are offered to this group. For example, it is identified by some direct payments support organisation staff (Vick et al., 2006) that social workers often do not mention self-directed support to older service users, due to a misconception that older people do not want to take on the added responsibility, when in reality this may not be the case. Nevertheless, care managers interviewed by Clark et al. (2004) reported that the majority of older service users declined the offer of direct payments, due to an unwillingness to take on employment or paperwork responsibilities. Research indicates that even older people who feel confident in their ability to manage direct payments may not wish to spend time dealing with paperwork and sorting out the financial aspects (Glendinning et al., 2008), in some cases simply because they would prefer to have someone else making arrangements on their behalf (Clark et al., 2004). Where older people do decide to take up direct payments this may not be a positive decision: Clark et al. (2004) found that a major reason given by older direct payment recipients for selecting this route was that it was the only way they could secure the care they needed.

Research suggests that a key reason for lower take-up of direct payments amongst older people is that they do not wish to change their existing care arrangements (Moran et al., 2013; Routledge & Carr, 2013; Wood, 2010). This low desire for change may emanate from higher levels of satisfaction with care services; however it is identified (Callaghan et al., 2012) that older people may tend to tolerate unsatisfactory services and be reluctant to move to another provider, even where they are dissatisfied (NAO, 2011). In a survey of prospective personal budget holders (Bartlett, 2009), around half of older participants reported that they would not make any changes to their care if they were to take up a personal budget. Older respondents were also significantly less likely than those from other client groups to say that they would change everything or a lot about their existing care. Routledge and Carr (2013) suggest that this may be due to fear on the part of older service users that if they change their care arrangements they may lose their existing level of support. Alternatively, the changes that some older people desire may simply not be possible to achieve via direct payments. For example in discussions with older participants, Dewar et al. (2005) found that home and garden maintenance, neither of which can be funded through direct payments, were identified as important.

Brookes et al. (2013) suggest that both older people and those working with this client group are often relatively conservative in their choices, tending to prefer traditional care services (Laybourne et al., 2014; Newbronner et al., 2011; Routledge & Carr, 2013). Henwood and Hudson (2007) identify that social work professionals working with older people may make ageist assumptions that their clients are satisfied with managed social care and appreciate having their care arranged for them. Furthermore, those interviewed by Goodchild (2011) reported that older service users tended to have limited expectations as to what could be achieved in terms of their care. It is suggested (Glendinning et al., 2008; Routledge & Carr, 2013) that creative care planning is more often used with younger people with disabilities, and is therefore an unfamiliar approach in older people's services.

It is proposed by social work professionals that due to a lack of choice of alternative providers and the fact that older service users tend to prefer traditional forms of support, this group are likely to benefit little from direct payments (Ipsos MORI, 2011). In a large randomised controlled trial (Glendinning et al., 2008), whereby service users across 13 local authorities were allocated at random to receive an individual budget or to continue receiving their existing care services, it was found that older people receiving individual budgets reported significantly lower levels of wellbeing than those in the traditional care group. The authors identified a group of older participants who took up individual budgets with no desire to change their care services, and highlighted that this group tended to experience no difference in the care they received but had to take on extra responsibilities in managing their care budget, resulting in an overall negative impact on wellbeing. However, it should be noted that a considerable number of older participants in this study responded via a proxy, who may have attributed disproportionately low or high levels of wellbeing to the older person on their behalf.

Caution with finances

Research suggests that older service users may be particularly cautious with finances, which could act as a barrier to the uptake of self-directed support by this group. For example, older people may be more reluctant than their younger counterparts to spend perceived large amounts of money on support or brokerage services (e.g. Glendinning et al., 2008). Those working with older people interviewed in Manthorpe and Stevens' (2008) research suggested that guidance on fair prices for support services would be useful in enabling older service users to check whether they are receiving value for money. Newbronner et al. (2011) found that older people and their carers tended to be more careful than younger service users in spending their personal budget, and were more anxious about using it for the wrong things. Worries are also expressed relating to contingency planning to cover holidays, potential budget cuts or accidental overspending (Moran et al., 2013). Clark et al. (2004) highlighted problems experienced by older people who accumulated excess funds in their care account through careful saving for unforeseen events. For example, they cite one case of a service user who used her own money rather than her direct payment to meet transport costs, so that she could save money for contingencies; however some of the excess money she had saved was clawed back by the Local Authority at the end of the year. The authors suggest that service users using their budget in this way could also be penalised by having their care hours reduced, if social work staff felt that they were being allocated more funding than was necessary to meet their needs.

Support needed to take up direct payments

Findings from large-scale surveys indicate that older service users are more likely than those from other client groups to report a need for assistance to enable them to take on a direct payment (Bartlett, 2009; Wood, 2010). However, evidence (Hatton & Waters, 2013) suggests that they may be less likely to receive this support than their younger counterparts. For example, older survey respondents using personal budgets were far less likely to report receiving help from an independent support service (5% did so) than people with mental illness (21%), physical disabilities (12%) or learning disabilities (11%). Directors of Adult Social Services surveyed by ADASS and LGA (2009) report that in general, of support organisations offering brokerage or advocacy services to specific client groups, fewer are targeted at older people than at other service user groups. In line with this, Henwood and Hudson (2009) identify that specialist support such as advocacy is more likely to be available for people with learning disabilities than older service users. Many older people may therefore be forced to rely on help from relatives or friends to manage their direct payment (e.g. Ellis, 2007; Moran et al., 2013). This puts additional pressure on carers, who may find it difficult to fit the extra work in with their existing responsibilities (e.g. Clark et al., 2004; Lakey & Saunders, 2011). Ellis (2007) also points out that older people may find it more difficult to identify a suitable relative to support them, as in the case of the oldest old, their partners and children may be older people themselves. Some research has identified specific forms of support that older people may particularly require, including help to consider innovative, non-traditional care options (Routledge & Carr, 2013), information about the likely costs of services, and assistance to use IT (Manthorpe & Stevens, 2008).

Funding for older persons' social care

Social care funding for older people is a particular issue, with research suggesting that older service users are typically provided a lower level of funding to meet their care needs than those from other client groups (Newbronner et al., 2011). For example, following examination of 285 support plans from local authorities (Glendinning et al., 2008; Jones, 2008), it was found that the average annual budget allocated to older service users (£7,680) was considerably lower than that awarded to people with learning (£18,160) or physical disabilities (£11,150). This may make it financially difficult for older people to secure the hours of care they need via direct payments, forcing some to top up their budget with their own money or to receive fewer hours of care than they need per week (Clark et al., 2004). Furthermore, social work professionals have reported that lower cost ceilings may be enforced for older people's care than for other groups (e.g. Henwood & Hudson, 2009), with needs deemed 'essential' for younger service users, such as social activities, only considered 'desirable' for the older age group (Clark et al., 2004). Henwood and Hudson (2009) argue that at the transition from adult to older persons' social care, funding is often reduced along with opportunities for independence and choice, leaving some long-term direct payment users in their early sixties concerned about the funding they will receive in the future.

Lower levels of funding awarded to older service users may mean that they are only able to pay for basic personal care services and have limited scope for innovative care planning (e.g. Clark et al., 2004; Newbronner et al., 2011; Routledge & Carr, 2013). For example, Bartlett (2009) reports that older personal budget holders tend to spend more of their budget on mainstream care and less on education or leisure activities than their younger counterparts. Fernandez et al. (2007) found an inverse correlation in local authorities between the proportion of their older population provided with care and levels of direct payment uptake. They propose that authorities providing care to a relatively large proportion of older residents are likely to provide smaller care packages to each service user, meaning that the possible gains of taking up direct payments are not sufficient to persuade service users to take on the additional responsibility. Likewise, Moran et al. (2013) suggest that the limited choice and flexibility offered by smaller direct payments, which may only allow service users to procure similar support to that offered by their Local Authority, means that some service users do not feel that the potential benefits outweigh the extra work and responsibility involved. This view was echoed by older service users themselves who had opted not to take up direct payments (Ipsos MORI, 2011).

Service availability

The lack of appropriate alternative care services available for older service users to purchase is a further barrier to the uptake of direct payments by this group (Glendinning et al., 2008; Ipsos MORI, 2011). This may be due to a slow market response to the advent of personalisation, suggested by Brookes et al. (2013) to result from low levels of take-up and funding, and insufficient demand for new services from older people, who tend to make relatively conservative care choices similar to their previous provision. However, Bartlett (2009) identified a strong demand amongst older service users for day centres, together with a desire to change their weekday activities, suggesting a need for service development in this area. Clark et al. (2004) argue that inequitable commissioning in the past has resulted in a poorer choice of care services for older people. For example, they identify that some services impose upper age limits felt to be discriminatory by older service users, pointing to the case of a 65-year-old who was told that now she was an older person she would need to start attending a different day centre and going to respite care rather than on group holidays. The authors suggest that examples such as this reflect ageist, service-driven care provision. Conversely, a lack of in-house services may in some cases increase uptake of self-directed support: Fernandez et al. (2007) found that uptake of direct payments by older people was higher in local authorities with a relatively low level of in-house domiciliary care.

2.3.2 People with dementia

A relatively small number of studies (N=3), briefly outlined below, focus specifically on barriers to direct payment access by people with dementia (Goodchild, 2011; Kinnaird, 2010; Lakey & Saunders, 2011). In particular, there is very little research that includes the perspective of the person with dementia themselves, possibly due to low take-up of direct payments or methodological issues concerning research with this group. For example, Goodchild (2011) provides an overview of the barriers to the implementation of personal budgets experienced from an organisational rather than an individual perspective, through interviews with personalisation and dementia service leads. Although people with dementia did take part in the survey and focus groups reported on by Lakey and Saunders

(2011), they represented a minority of participants, comprising 3% of survey respondents and just under a quarter of focus group members. Kinnaird (2010) interviewed social work professionals involved with direct payments and carers of direct payment recipients with dementia. Although no service users with dementia were recruited to the research, the carers in each case had taken on the management of the care budget on behalf of their relative, which gave a useful insight into the barriers they experienced in gaining access to and using direct payments. Overall, research findings in this area tend to rely on individual examples or case studies, with no large body of evidence to draw from, suggesting a need for further research into the personalisation of social care for people with dementia.

Due to the paucity of research in this area, a brief review of the international literature (limited to studies published in the English language) relating to self-directed support for people with dementia was carried out. Five articles were identified (Genet, Boerma, Kroneman, Hutchinson & Saltman, 2012; Glendinning, 2009; Putnam, Pickard, Rodriguez & Shear, 2010; Schneider & Reyes, 2007; Timonen, Convery & Cahill, 2006), although none focused specifically on barriers to accessing self-directed support by this group.

Poor promotion of direct payments to people with dementia

Research suggests that promotion of direct payments to service users with dementia may be inadequate. For example, of the 10 social work professionals interviewed by Kinnaird (2010), only half said they thought all service users would be informed about this option. Levels of awareness amongst service users appear to corroborate this, with only 16% of carers of people with dementia surveyed by Alzheimer Scotland in 2008[5] reporting being told about direct payments by a social worker (although not all those surveyed were carers of current service users). Furthermore, of the 12 people with dementia using direct payments sampled by Kinnaird (2010), seven found out about direct payments via informal means rather than from their social worker. Laybourne et al. (2014) found evidence of misinformation being provided by practitioners to carers of service users with dementia who lacked capacity. It was suggested by one carer in their research that the low uptake of direct payments amongst this group was due to the negative, sometimes hostile attitude of social workers, who tended to dissuade rather than proactively encourage take-up. There was a perception amongst some practitioners that direct payments was not a suitable option

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[5] Cited in Kinnaird (2010) as ‘Alzheimer Scotland self-administered questionnaire sent to its members who had identified themselves as carers, carried out in February 2008’ (p.63).

for service users with dementia, with the view that this group, unlike younger disabled people, had little aspiration for choice and control over their care. Carers of people with dementia surveyed by Lakey and Saunders (2011) also reported encountering a lack of understanding and negative attitudes towards direct payments from social workers, who appeared to be reluctant to actively promote self-directed support to this client group. Goodchild (2011) points to a reluctance amongst professionals to promote direct payments for people with dementia, with some reportedly prematurely suggesting a move to residential care rather than fully exploring options for support in the community. Priestley et al. (2007) identified that a lack of clear guidance on the issues of capacity and risk in relation to direct payments has led to uncertainty amongst practitioners, which in turn has meant that direct payments may not be promoted to particular client groups, such as people with dementia. Age may be a compounding factor, with people with dementia aged 41-64 surveyed by Lakey and Saunders (2011) more likely to report being offered direct payments than their older counterparts aged 80 and over.

Concerns about ability to manage direct payments

The suitability of self-directed support for service users with dementia has been questioned by policymakers, social workers and service users themselves. For example, Timonen et al. (2006) highlight concerns of policymakers that the Finnish voucher system, which allows service users to procure their own care from private service providers, may be unsuitable for people with dementia. For example, choosing from and coordinating services was viewed as too complex for cognitively impaired clients. Similarly, Glendinning (2009) reports on an evaluation of a pilot scheme in Denmark (Socialministeriet, 2006) whereby service users purchased their own care using a cash payment from their municipality, identifying that concerns were raised about the suitability of the new system for care recipients with cognitive impairment.

Research has highlighted a general perception amongst social care professionals that direct payments are associated with high risk for service users with dementia (Lakey & Saunders, 2011; Manthorpe & Samsi, 2012). Adult safeguarding co-ordinators interviewed by Manthorpe and Samsi (2012) expressed concerns that direct payments could increase the risk of financial abuse of this group. Some argued that such cases were relatively common amongst the referrals they received (although data were not collected by client group); however others reported that the use of direct payments did not seem to have resulted in an increase in safeguarding referrals. It was suggested by these participants that direct payments are no more risky than traditional care provision, where appropriate checks are carried out and regulations adhered to. The presence of a carer to manage the direct payment on behalf of the person with dementia may help alleviate concerns about risk, with some social workers reporting that direct payments would be unsuitable for many people with dementia unless they were managed by a carer on the service user's behalf (Clark et al., 2004). Similarly, social work professionals interviewed by Kinnaird (2010) identified that capacity issues may be a barrier to service users with dementia accessing direct payments, as there would need to be a suitable person able and willing to manage the direct payment as the illness progressed. Putnam et al. (2010) also point out that service users with dementia without a family carer are often excluded from self-directed support due to difficulties in organising their own care. In line with this, 85% of direct payment users with dementia surveyed by Lakey and Saunders (2011) were living with a carer. Similarly, in almost all cases of direct payments to service users with dementia cited by personalisation and dementia leads in Goodchild's (2011) research, a carer managed the budget on the service user's behalf.

Service users with dementia may be particularly concerned about managing their social care budget, which could grow substantially as they need increased support (Goodchild, 2011). Of 130 people with dementia and carers surveyed by Lakey and Saunders (2011) who had chosen not to take up direct payments, almost a third said that this was because they found their present situation difficult enough to cope with. 14% reported a lack of confidence in their ability to take on the management of their own care, and 11% said they would find direct payments too complicated to manage. Routledge and Carr (2013) suggest that people with dementia may need additional support to enable them to take up direct payments, but identify that support services are often overstretched or underdeveloped. In discussions with people with dementia and their carers, some of whom were using direct payments, Lakey and Saunders (2011) found that participants were sceptical as to whether sufficient support (together with knowledge of dementia amongst social care professionals) was available. Interviews with Local Authority personalisation and dementia service leads (Goodchild, 2011) highlighted that some local authorities may consider that working with carers in place of the person with dementia themselves in providing support is sufficient. Goodchild (2011) identified that in almost all cases of direct payment recipients mentioned in her research, carers managed the budget on behalf of the person with dementia, which she suggests is indicative of a lack of budget management support for people with dementia in many local authorities.

Budgetary constraints

Evidence suggests that constraints on their personal social care budget may prevent some people with dementia from taking up self-directed support. Of the service users with dementia and carers surveyed by Lakey and Saunders (2011) who had opted not to take up direct payments, 7% said this was because the funding they were allocated was insufficient. Personalisation and dementia leads point out that people with dementia may need additional funding for care, as specialist dementia provision tends to be more expensive than standard support services (Goodchild, 2011). In addition, people with dementia may take longer to carry out daily tasks and therefore need to employ personal assistants for a greater number of hours. They may also be less able to manage recruitment and payroll and so may need to pay for someone else to do so on their behalf (Goodchild, 2011). Despite this, it is reported that service users with dementia tend to be allocated a relatively low budget for their care in comparison to other client groups. This is partially because in many local authorities the cap on the weekly budget is lower for older people than those aged under 65, and also because other service user groups are more likely to receive funding from additional sources, such as Supporting People (Goodchild, 2011). Genet et al. (2012) point to examples from across Europe, such as in Germany and Estonia, where service user groups with cognitive impairment received a lower level of financial support than those with physical disabilities. Research indicates that in some cases, the budget allocated to people with dementia is not sufficient to cover support costs, with service users having to meet the shortfall themselves (Kinnaird, 2010). Budget cuts in social care have also meant that the threshold at which people are eligible for support has increased. This may mean that by the time people with dementia qualify for care, their dementia could be too advanced for them to manage self-directed support themselves, and those who have taken on caring responsibilities for the interim years may not wish to take on further responsibility in managing their relative’s care budget (Kinnaird, 2010).

Inflexibility and restrictions

Contrary to the ethos of personalisation, examples of the inflexibility of direct payments in practice have been highlighted. For example, carers of people with dementia report cases of local authorities not allowing care hours to be used in a single block each day rather than as several separate visits (which may be confusing for those with dementia), or imposing limitations on the activities that may be funded by the direct payment (Kinnaird, 2010). Social care professionals have also identified that the processes and systems in place for direct payments are not always suitable for people with dementia, as they do not take account of fluctuating or increasing support needs (Goodchild, 2011; Lakey & Saunders, 2011). Unresponsive systems may leave service users without sufficient support and prevent them from being able to manage in the community, leading to residential care admission (Kinnaird, 2010). It is suggested (Goodchild, 2011; Lakey & Saunders, 2011) that systems have been tailored to meet the needs of the service user groups initially targeted for self-directed support, such as people with physical disabilities, and that appropriate additional support to enable people with dementia to access direct payments has not been built in. Several social work staff interviewed by Kinnaird (2010) felt that awareness of direct payments amongst staff working with service users from these initial target groups was higher than those working in other teams.

Delays in direct payment setup may be particularly problematic for service users with dementia, who could experience a relatively rapid increase in support needs. Kinnaird (2010) cites a case where direct payments took so long to be arranged that the person’s needs had increased by the time their care was put in place. In another instance, a family carer tried to increase the care her relative received as he needed more support, but processing delays meant that she was unable to pay the support organisation and was forced to consider residential care.

Availability of specialist services

Concerns have been raised by both social care professionals and service users and carers themselves that the social care market is insufficiently developed to offer a choice of support services for people with dementia, acting as a barrier to personalisation (Goodchild, 2011; Kinnaird, 2010; Lakey & Saunders, 2011). This may be the result of a situation where few people with dementia are taking up self-directed support (possibly due to the lack of available services), and consequently new models of support are not being developed by service providers (Goodchild, 2011). In Germany, low historical demand for formal care services due to a traditional preference for family caregiving has meant there is a limited choice of support options. For example, only around 6% of the 12,300 registered community care providers offer support for people with dementia (Röber, 2004, cited in

Schneider & Reyes, 2007). Putnam et al. (2010) found that family carers supporting people with dementia to manage their own support experienced difficulties in procuring affordable, high quality care due to the paucity of services available in their locality. People with dementia and their carers have also reported difficulties in recruiting personal assistants who have a good understanding of dementia and are able to meet fluctuating needs (Henwood & Hudson, 2009; Kinnaird, 2010).

2.3.3 People living in rural communities

Very few studies (N=3) were conducted specifically in rural areas, and only two of these (Dewar et al., 2005 and Manthorpe & Stevens, 2008, 2010) focused on rural issues in relation to direct payments, although this area was briefly discussed in a number of papers (Clark et al., 2004; CSCI, 2004; Kinnaird, 2010; Newbronner et al., 2011; Priestley et al., 2010; Ridley et al., 2011). Dewar et al. (2005) conducted group discussions about direct payments with older people living in rural communities; however as the majority of participants were not social care service users (and only one was a direct payment recipient), many had no prior knowledge of direct payments. As acknowledged by the authors, this may have limited full discussion of the issue under study. The research reported by Manthorpe and Stevens (2008, 2010) offers a comprehensive discussion of rural issues relevant to personalisation through interviews with 33 participants working with rural older people, just under half of whom had experience of individual budgets. Although many issues relevant to the present study were raised, the focus of the research was not specifically on access to direct payments by rural older people but rather the implications of personalisation for rural communities. The authors suggest that the experiences of social care service users and their carers would usefully inform further research in this area.

A brief review of the international literature (published in the English language) was conducted to identify further articles relating to self-directed support in rural areas. Six articles were identified (Bertelsen & Rostgaard, 2013; Genet et al., 2012; Glendinning, 2009; Putnam et al., 2010; San Antonio, Simon-Rusinowitz, Loughlin, Eckert, Mahoney & Depretis Ruben, 2009; Spall, McDonald & Zetlin, 2005), all of which highlighted issues relating to service availability.

Availability of services in rural areas

Availability of care services following the rise in self-directed support is a key concern for those in rural communities. For example, Putnam et al. (2010) report concerns of family carers in relation to the availability of good quality, affordable services in rural areas from which to choose. Spall et al. (2005) noted that social care service users in rural Queensland often experienced little or no choice due to a lack of service provision in their area, meaning some were forced to receive care from agencies delivering substandard care. Bertelsen and Rostgaard (2013) also note that few private providers are willing to offer care services in more isolated areas. Glendinning (2009) identified that, on average, rural municipalities of Denmark had fewer than half as many personal care providers as urban municipalities. In a study of home care across Europe, Genet et al. (2012) identified several barriers to the delivery of care services in remote regions, such as poor road links and migration of the potential workforce to urban centres. They reported a disparity between service availability in rural and urban areas in a number of countries (including Bulgaria, Latvia, Lithuania, Poland and Portugal), identifying a lack of formal and informal services and inadequate infrastructure in rural localities, meaning choice for service users is limited. Furthermore, they reported that in Latvia, Slovenia and Scandinavian countries, where municipalities were responsible for funding home care, rural areas with a relatively high proportion of older people faced funding limitations.

Participants working with rural older people asked to consider the implications of personalisation in rural areas (Manthorpe & Stevens, 2008, 2010) argued that countywide coverage from key service providers is essential. However, it was identified that rural services may be withdrawn or more expensive for service users due to lower profitability and the widely dispersed locations of potential clients. It was suggested that this could be a particular issue if local authorities stopped commissioning services, as without the purchasing power of larger organisations individuals may end up with less cost-effective provision. Spall et al. (2005) reported that the quasi-market model of social care provision introduced in Queensland had not worked in rural localities, as the decrease in guaranteed funding, together with high costs incurred by providers serving remote areas, resulted in cuts to existing services and a lack of new services entering the market. In line with this, concerns have been raised by both practitioners and service users that increased uptake of self-directed support could result in the closure of already limited existing services (Priestley et al., 2010). For example, established community facilities such as day centres may be forced to close due to a reduced number of users (Manthorpe & Stevens, 2008, 2010). It was proposed that financial incentives may be needed for new services to open in isolated areas, to ensure that easily accessible facilities are available for older people locally, enabling them to continue living independently (Manthorpe & Stevens, 2008, 2010). Priestley et al. (2010) suggest that a lack of service availability in rural communities may actually lead to social work staff promoting direct payments to rural service users, for example where there are few in-house services providing appropriate support locally.

Workforce availability and transport issues

Finding staff to work as personal assistants may be difficult in rural communities (CSCI, 2004; Dewar et al., 2005; Kinnaird, 2010; Ridley et al., 2011), particularly where only a few hours of support are required (Newbronner et al., 2011). This may be partially due to poor transport links in isolated areas, or the distance employees would need to travel to more remote locations. Just over a fifth of direct payment employers reporting recruitment difficulties surveyed by IFF Research (2008) said that transport issues were a factor. Care workers may also not wish to travel to isolated areas in the dark or in adverse weather, particularly where roads are poor or where there is no mobile phone signal (Manthorpe & Stevens, 2008). Clark et al. (2004) found a preference for local advertising amongst older direct payment recipients in order to overcome these issues, with one participant reporting that she advertised for personal assistants only within a five-mile radius of her home. The issue of transport costs is also problematic, as paying travel expenses to staff may mean service users have less money to spend on the care they need; however if these expenses are not met, personal assistants may be unable to work in rural locations (Manthorpe & Stevens, 2008). Utilising a care agency rather than employing personal assistants may cause further difficulties where agencies do not employ staff from the locality (Manthorpe & Stevens, 2008). Transport issues may also affect the activities of the service user themselves, for example if they have to pay for taxis out of their care budget due to a lack of available public transport (Manthorpe & Stevens, 2008). A rural direct payment user interviewed by Dewar et al. (2005) pointed out that using personal assistants to help with shopping would be more expensive for service users in rural areas due to the increased travel time to the shops, which the personal assistant would need to be paid for.

Those working with older people in rural areas have expressed concerns about the availability of an appropriately skilled and experienced workforce who are able and willing to work as personal assistants (Manthorpe & Stevens, 2008). In a qualitative study of service users participating in a self-directed support programme in Arkansas, San Antonio et al. (2009) found that some participants had difficulty recruiting and retaining carers due to their remote location. Research (Manthorpe & Stevens, 2008, 2010) has highlighted that in some rural areas with high employment rates and relatively high wages and living costs, there may be few inhabitants looking for lower paid care work. In addition, young people may move out of isolated areas to go to university and not return, leaving an older residual population (Manthorpe & Stevens, 2008). Recruitment difficulties may lead to service users employing friends or family members rather than utilising established care agencies. It is suggested that this could create problems such as a decline in neighbourly arrangements for informal support as some older people start paying for help (Manthorpe & Stevens, 2008).

Confidentiality issues

Concerns about confidentiality may be a key issue for older social care service users in rural communities (Dewar et al., 2005; Manthorpe & Stevens, 2008, 2010; Ridley et al., 2011). The particular stoicism and self-reliance of rural older people is commented on by those working with this group (Manthorpe & Stevens, 2008, 2010), who identify that those who wish to remain independent may be embarrassed about having people caring for them, and not want others in the community to know that they need support. It is suggested that the nature of small communities may make it more difficult for people to keep this private, leading to a reluctance to access care services. In line with this, older people themselves report concerns about keeping anonymity in rural or remote localities, suggesting that becoming an employer could pose particular problems in the case of disagreements, where issues may be the subject of gossip (Dewar et al., 2005). Those working with rural older people acknowledged that disagreements such as these may be especially difficult to cope with in close-knit small communities (Manthorpe & Stevens, 2008, 2010). One older direct payment user interviewed by Clark et al. (2004) reported deliberately recruiting personal assistants who lived some distance away, so as to ensure that those in her locality did not find out about her sensitive care needs.

2.4 Summary

A comprehensive review of the literature revealed a wide range of issues influencing uptake of direct payments by adult social care service users. A systematic search indicated that there is currently relatively little published research focusing specifically on barriers to direct payment access by people with dementia and those living in rural communities. However, the research examined in this chapter suggests that together with older service users, these groups may face particular challenges in accessing direct payments. The next chapter provides an outline of the local rural context of the present study.

Chapter 3

Local Context

Worcestershire is a non-metropolitan English county with a population of 572,200 (ONS, 2014), located within the West Midlands. Worcestershire is classified as 'Urban with Significant Rural' by Defra (2014b), and therefore provides a suitable base for this research. The county of Worcestershire has six districts, two of which (hereafter referred to as Area 1 and Area 2) were selected as the focus of this research on the basis of their rurality.

The aim of this chapter is to provide a context for the research by outlining key demographic information and data relevant to the research aims in relation to Worcestershire, Area 1 and Area 2, with national comparisons where appropriate. The chapter includes four main sections, respectively focusing on general demographic information, dementia, direct payments and rurality. The first section provides demographic information about Worcestershire and the selected districts of Area 1 and Area 2, presenting data on income and benefits, population age, health, and social care provision. This is followed in section two with an overview of the local dementia context, including the prevalence and diagnosis of dementia, use of social care services by this group, dementia services within Worcestershire, and relevant local strategies. The third section provides data on direct payment uptake in Worcestershire, and gives an outline of the local policy context and procedures relating to direct payments. The rurality of Worcestershire, Area 1 and Area 2 is outlined in the final section, which goes on to compare rural and urban demographic data, concluding with information about access to facilities and transport in the county.

3.1 Demographic information

3.1.1 Income and benefits

According to the Index of Multiple Deprivation (Department for Communities and Local Government [DCLG], 2011), Worcestershire is less deprived than the majority of counties in England, ranking 112th out of 149 local authorities (74th percentile). On average, residents of Worcestershire have a mean household income comparable to the national average and are less likely to claim key out-of-work benefits than the population of England as a whole. However, the picture in each of Worcestershire's six districts varies considerably, with a particular contrast between Area 1 and Area 2 (see Table 4). Index of Multiple Deprivation rankings (DCLG, 2011) indicate that Area 2 is substantially more deprived than Area 1, ranking 128th (38th percentile) out of 326 Local Authority districts in England, compared to the Area 1 ranking of 223rd (68th percentile).

Table 4: Comparison of median household income and rate of out-of-work benefit claimants, in Area 1, Area 2, Worcestershire and England

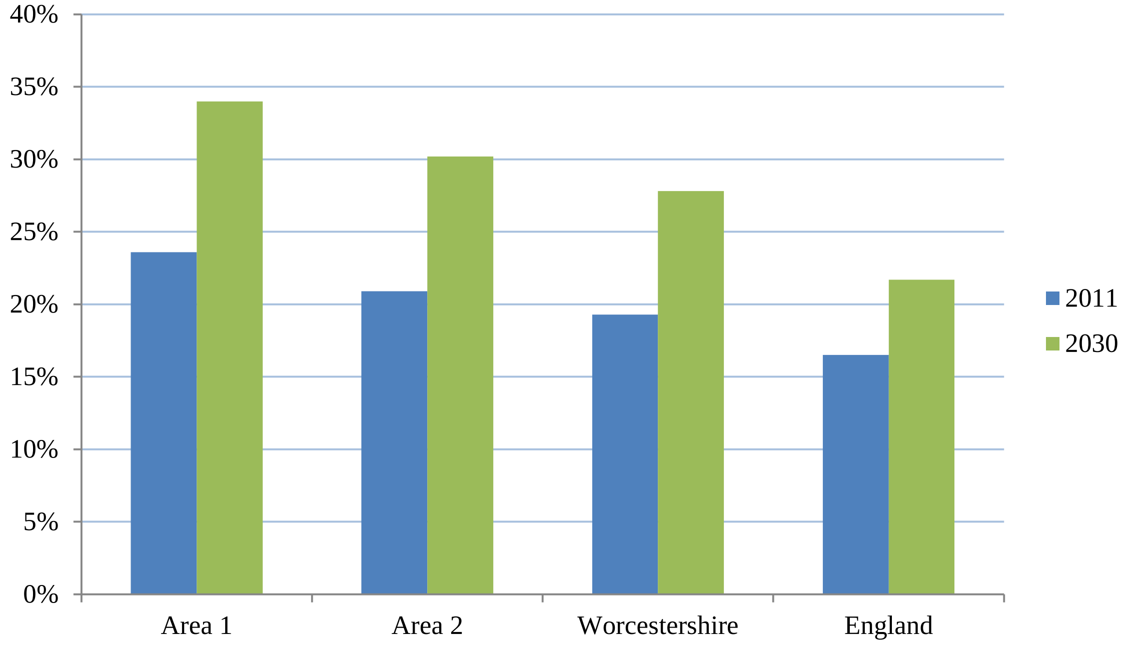
	Area 1	**Area 2**	**Worcestershire**	**England**
Mean household income[a]	£36,694	£33,482	£37,000	£36,367
% of 16-64 year-olds claiming key out-of-work benefits[b]	7.2%	10.3%	8.0%	9.8%

Source: ONS (2014)[b]; PayCheck CACI, cited in Worcestershire County Council [WCC] (2013)[a]

3.1.2 Population age

Worcestershire has a greater proportion of residents aged 65 and over (19.3%) than the English average (16.5%), putting it in the 75th centile nationally (ONS, 2011b). Within Worcestershire, the proportion of older people living in Area 2 (20.9%) and particularly Area 1 (23.6%) is higher than the national average (see Figure 3). Area 1 is among the 25 districts in the UK with the highest proportion of residents aged 65 and over (ONS, 2011b). The proportion of the Worcestershire population aged 65 and over is predicted to increase by 8.5 percentage points to 27.8% between 2011 and 2030; higher than the predicted increase of 5.2 percentage points for England as a whole (ONS, 2010). Again, this increase is projected to be higher than the national average in Area 1 (10.4 percentage points) and Area 2 (9.3 percentage points) (ONS, 2010) (see Figure 3).

Figure 3: Estimated percentage of the population aged 65 and over in 2011 and 2030 in Area 1, Area 2, Worcestershire and England



Source: ONS (2010; 2011b)

3.1.3 Health

Life expectancy of males and females living in Worcestershire and Area 1 is above the England average, while residents of Area 2 have a life expectancy comparable to the national average (Public Health Observatories [PHO], 2014) (see Table 5).

Table 5: Life expectancy (years) for males and females in Area 1, Area 2, Worcestershire and England

	Area 1	**Area 2**	**Worcestershire**	**England**
Males	80.4	79.2	79.8	79.2
Females	83.5	83.0	83.5	83.0

Source: PHO (2014)

The level of general health in Worcestershire is comparable to that in England as a whole, with 81.4% of the Worcestershire population reporting to be in ‘good’ or ‘very good’ general health, compared to 81.2% nationally. However, self-reported rates of ‘good’ or ‘very good’ health in both Area 1 (80.7%, 38th percentile) and Area 2 (78.8%, 21st percentile) are below the national average (ONS, 2013a), possibly reflective of the older population in these areas.

3.1.4 Social care provision

A total of 5,233 adults living in Worcestershire were in receipt of community-based social care services in 2011 (WCC, unpublished). The majority of community-based social care recipients both in Worcestershire (60.7%) and nationally (65.0%) are aged 65 and over (The NHS Information Centre, 2011; WCC, unpublished).

Census data indicate that in 2011 there were 63,685 people providing unpaid care in Worcestershire, comprising 11.3% of the population; a higher proportion than in England as a whole (10.2%) (ONS, 2013a). The percentage of the population with caring responsibilities is also higher than the national average in Area 1 (12.6%) and Area 2 (11.4%), possibly reflecting the higher proportion of older people residing in these areas. The majority of carers in Worcestershire (66.8%) provide 1-19 hours of unpaid care per week, with 11.7% providing 20-49 hours, and a significant minority (21.5%) providing 50 hours or more (ONS, 2013a).

3.2 Dementia

3.2.1 Prevalence and diagnosis

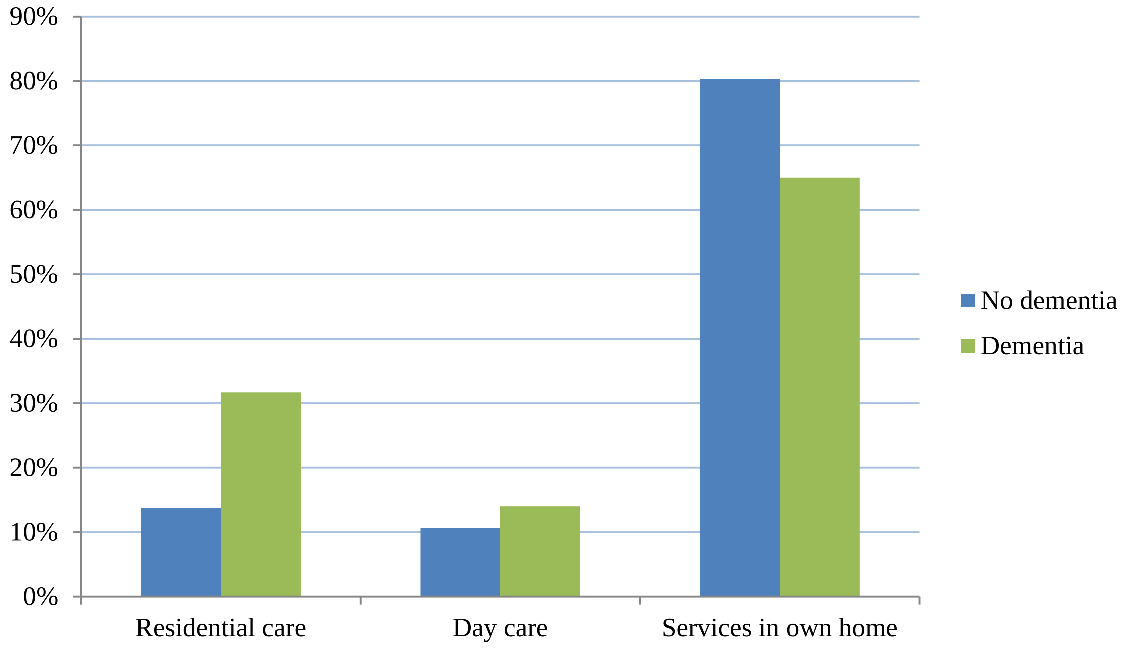
It is estimated (NHS Worcestershire Public Health Information Team, cited in WCC & NHS Worcestershire, 2011) that there were 8,019 people living with dementia in Worcestershire in 2012, projected to rise by 3% per annum to 10,262 in 2020. Prevalence of dementia in Worcestershire is higher than the national average. It is estimated using mid-2010 population data (ONS, 2011a) that 1.4% of the population of Worcestershire had a dementia in 2010, compared to 1.2% nationally (Tesco, Alzheimer’s Society & Alzheimer Scotland, 2012). The estimated proportion of people with dementia in Area 2 is in line with the Worcestershire average at 1.4%; however it is considerably higher (1.8%)

in Area 1 (NHS Worcestershire Public Health Information Team, cited in WCC & NHS Worcestershire, 2011). Research by Tesco et al. (2012) identified that there were 2,945 people with a diagnosis of dementia in Worcestershire in 2011, comprising only 37% of the total estimated number of people with dementia in the county. This is considerably lower than the national diagnosis rate of 43%, and puts Worcestershire in the bottom fifth of counties in the UK for its rate of dementia diagnosis (Tesco et al., 2012).

3.2.2 Use of social care services by people with dementia

It is estimated (WCC, 2011a) that 816 people known to have a dementia were in receipt of social care services in Worcestershire in 2009-10. The majority of these (65%) received social care in their own home and around a third in residential care. Nevertheless, when compared to other service user groups, people with dementia were more likely to be in residential or day care, and less likely to receive services in their own home (WCC, 2011a) (see Figure 4). Within Worcestershire, social care service users with dementia are almost twice as likely to have a named family carer (48.8%) than those without dementia (26.3%) (WCC, 2011a).

Figure 4: Percentage of social care service users in Worcestershire with and without dementia using residential and community social care services in 2009-10[6]



Source: WCC (2011a)

3.2.3 Local strategies for dementia care and support

Following the launch of the national dementia strategy in 2009 (DH, 2009b), a five-year dementia strategy for Worcestershire was released (WCC & NHS Worcestershire, 2011) in order to address local challenges and to set out how the aims of the national strategy would be achieved in the county. In line with the key areas of planned improvement in the national strategy, the aims of the Worcestershire dementia strategy (WCC & NHS Worcestershire, 2011, p. 14) are to:

- Raise public awareness and understanding of dementia
- Maximise the number of people with access to early diagnosis
- Develop key dementia support services with adequate resources
- Develop the understanding and skills of the workforce supporting people living with dementia

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[6] Percentages may add up to more than 100% where service users used more than one service during 2009-10.

- Ensure that the principles of Dignity in Care are recognised and promoted in all contacts with people receiving services

A carer strategy for Worcestershire (WCC & NHS Worcestershire, 2010) launched in 2010 complements the local dementia strategy by setting out the expansion of specific support services for carers of people with dementia, aimed at enabling them to provide good quality care.

3.2.4 Dementia services

The Worcestershire dementia strategy (WCC & NHS Worcestershire, 2011) was informed by mapping exercises of dementia services across the county in 2008 and 2009, identifying existing support services and highlighting gaps in provision. As a result, the following dementia support services were identified as being available in Worcestershire:

- Dementia Advisors, whose role is to provide people with dementia and their carers with information and support regarding care planning
- Specialist services for older people with mental illness (including dementia), such as day services and inpatient provision
- Domiciliary care specifically aimed at supporting people with dementia (the 'side by side' service)
- A young onset dementia support service
- Peer support groups across the county for people with dementia and their carers, such as dementia cafés
- Support groups and training for carers of people with dementia

(WCC & NHS Worcestershire, 2011)

At the time of the mapping exercise, there were 100 registered nursing and care homes in Worcestershire providing residential care for people with dementia, and over half (55%) of care home beds in the county were allocated to this service user group (WCC & NHS Worcestershire, 2011).

An inequity of service provision across Worcestershire was identified, with fewer dementia services available in rural areas (particularly in South Worcestershire) than in the more urban districts to the north of the county. In addition, an overall lack of capacity was highlighted (WCC & NHS Worcestershire, 2011) across a number of services, including peer support, day care, assisted technology, rehabilitation, rapid response, and support services for people with young onset dementia.

3.3 Direct payments

3.3.1 Direct payment uptake

Of all adults in Worcestershire in receipt of community-based social care services in 2013-2014, 28.7% were in receipt of a direct payment, compared to 19.1% of those in England and 17.7% of those in comparator local authorities[7] (HSCIC, 2014b). This indicates a considerable improvement in access to direct payments since 2008-09, when direct payment uptake was lower in Worcestershire (4.5%) than in comparator local authorities (6.5%) and in England as a whole (5.6%), placing Worcestershire in the 30th percentile (The NHS Information Centre, 2010).

Worcestershire data highlights a marked decline in direct payment uptake with age (WCC, unpublished). This is consistent with national figures, which show that adults aged 18-64 in receipt of community-based services are more than twice as likely (27.2%) than those aged 65 and over (11.1%) to have taken up direct payments (HSCIC, 2014a). Direct payment use in Worcestershire also varies considerably by client group, with uptake substantially higher amongst those with a learning (19%) or a physical disability (14%) than amongst mental health service users (8%) in 2011 (WCC, unpublished). Again there is a similar pattern nationally, with those with a learning or physical disability over four times as likely (13.1% and 13.8% respectively) to have taken up direct payments than those with mental illness (3.2%) (The NHS Information Centre, 2010) (see Figure 5).

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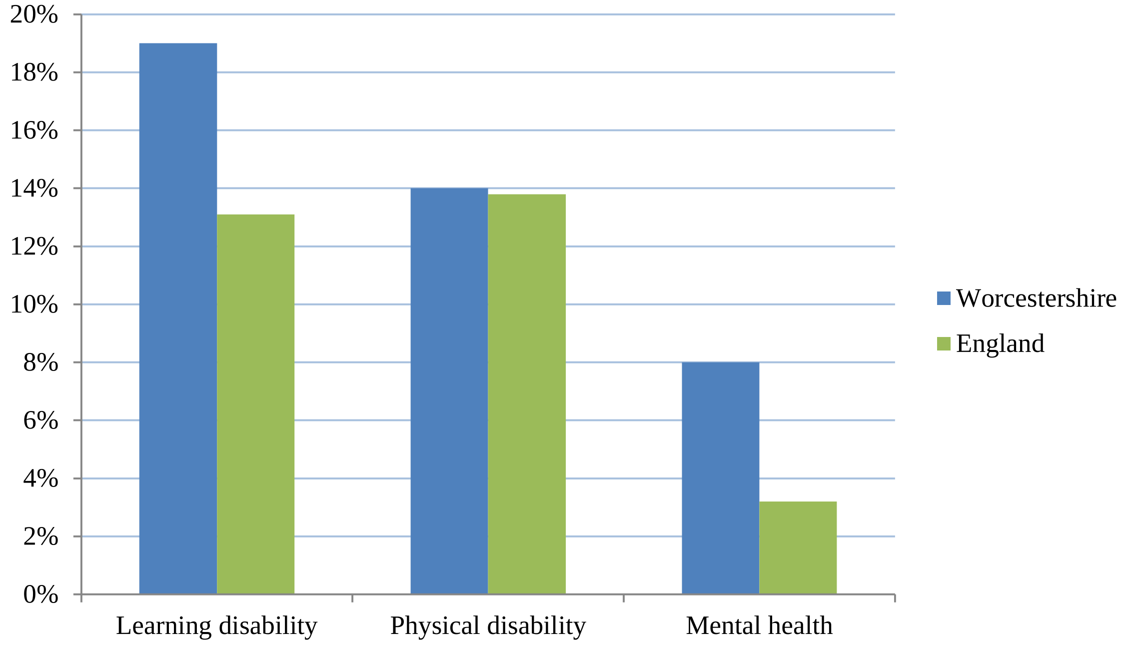
[7] The fifteen local authorities identified by The Chartered Institute of Public Finance and Accountancy (2009) as being most similar to Worcestershire in terms of socio-economic characteristics.

Figure 5: Percentage of adults receiving community-based social services via a direct payment by client group in England and Worcestershire[8]



Source: The NHS Information Centre (2010); WCC (unpublished)

In Worcestershire in 2011, service users with no named informal carer were over twice as likely (22%) than those with a carer (9%) to take up direct payments. Direct payment uptake appears to increase with rurality, with 14% of service users living in large urban areas receiving direct payments, compared to 15% of residents in town and fringe areas, and 19% of those living in villages, hamlets and isolated dwellings (WCC, unpublished)[9].

3.3.2 Direct payment uptake by people with dementia

In 2011, less than one in ten (8.9%) people known to have a dementia receiving community-based social care services in Worcestershire were in receipt of a direct payment; considerably lower than the rate of uptake across all service user groups (14.4%) (WCC, unpublished)[10]. There is a marked decline with age in the proportion of service

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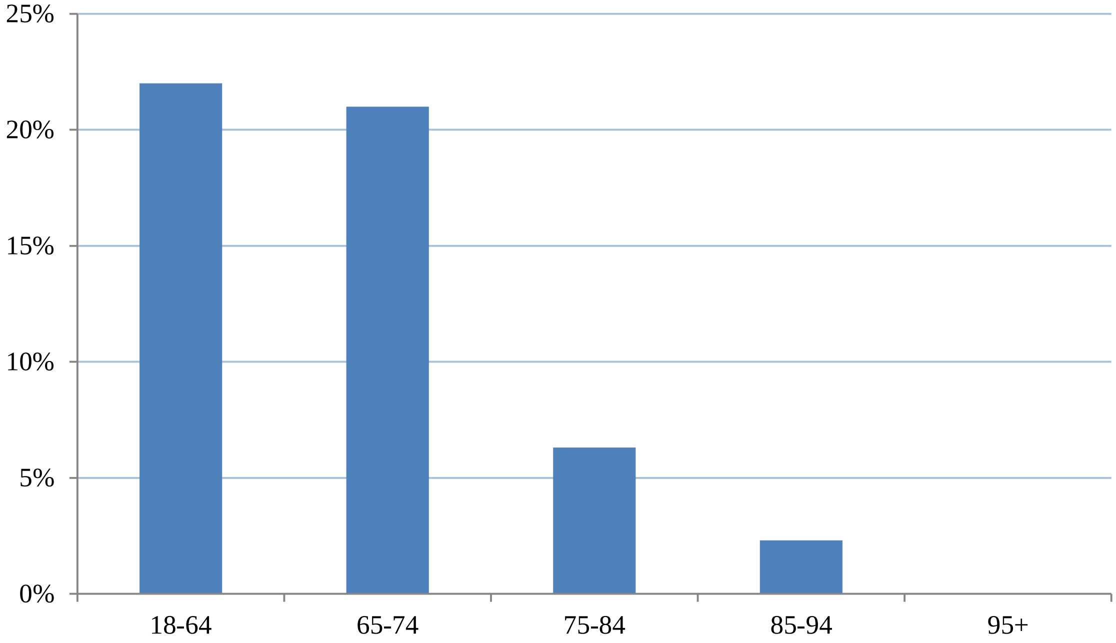
[8] Data are not directly comparable as they are indicative of direct payment uptake in Worcestershire for 2011 and in England for 2008-09. In addition, the data for Worcestershire include adults of all ages, whereas the national data include only those aged 18-64.

[9] No national data are available on direct payment uptake by location and by the presence of a carer.

[10] No national data are available on direct payment uptake by people with dementia.

users with dementia taking up direct payments, with a particularly striking difference between those aged under and over 75 (see Figure 6).

Figure 6: Percentage of adult community-based social care service users known to have a dementia in Worcestershire taking up direct payments by age group



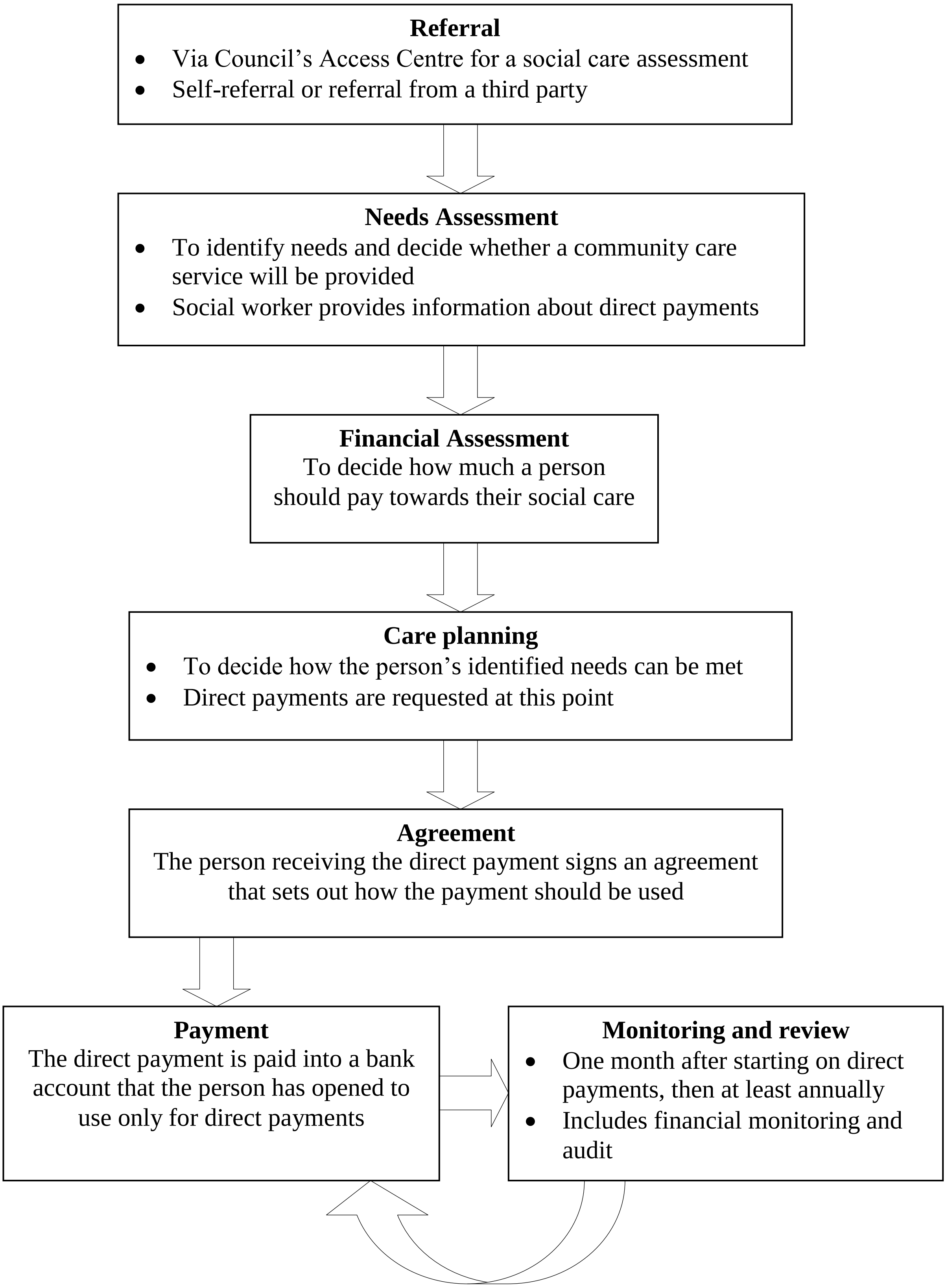
Source: WCC (unpublished)

Whereas when all client groups are considered, those with no named carer are over twice as likely to receive a direct payment than those with a carer, the opposite is true for people with dementia in Worcestershire: 11.5% of those with a named carer take up direct payments, compared with 4.9% of those with no carer (WCC, unpublished).

3.3.3 Local policy context

Following the publication of Department of Health guidance on direct payments (DH, 2009a), a policy and procedure for direct payments in Worcestershire was established (WCC, 2011b). This sets out the process of setting up a direct payment, and includes guidelines on eligibility, how direct payments can be used, and when they should be offered. In accordance with national guidelines (DH, 2009a), the Worcestershire policy states that there is ‘a “Duty” to offer a Direct Payment at every assessment and review’ of those eligible for social care services (WCC, 2011b, p.3). The policy refers to the change in legislation (Health and Social Care Act 2008) allowing access to direct payments by those lacking capacity where a nominated person could manage the budget on their behalf. However, although a number of client groups are specifically mentioned as being eligible for direct payments (including disabled young people and those with learning disabilities, sensory impairment, HIV and AIDS), there is no direct mention of older people or those with dementia. The process of setting up a direct payment in Worcestershire is summarised in the following flowchart (see Figure 7).

Figure 7: Process of setting up a direct payment in Worcestershire



Referral
- Via Council's Access Centre for a social care assessment
- Self-referral or referral from a third party

Needs Assessment
- To identify needs and decide whether a community care service will be provided
- Social worker provides information about direct payments

Financial Assessment

To decide how much a person should pay towards their social care

Care planning
- To decide how the person's identified needs can be met
- Direct payments are requested at this point

Agreement

The person receiving the direct payment signs an agreement that sets out how the payment should be used

Payment

The direct payment is paid into a bank account that the person has opened to use only for direct payments

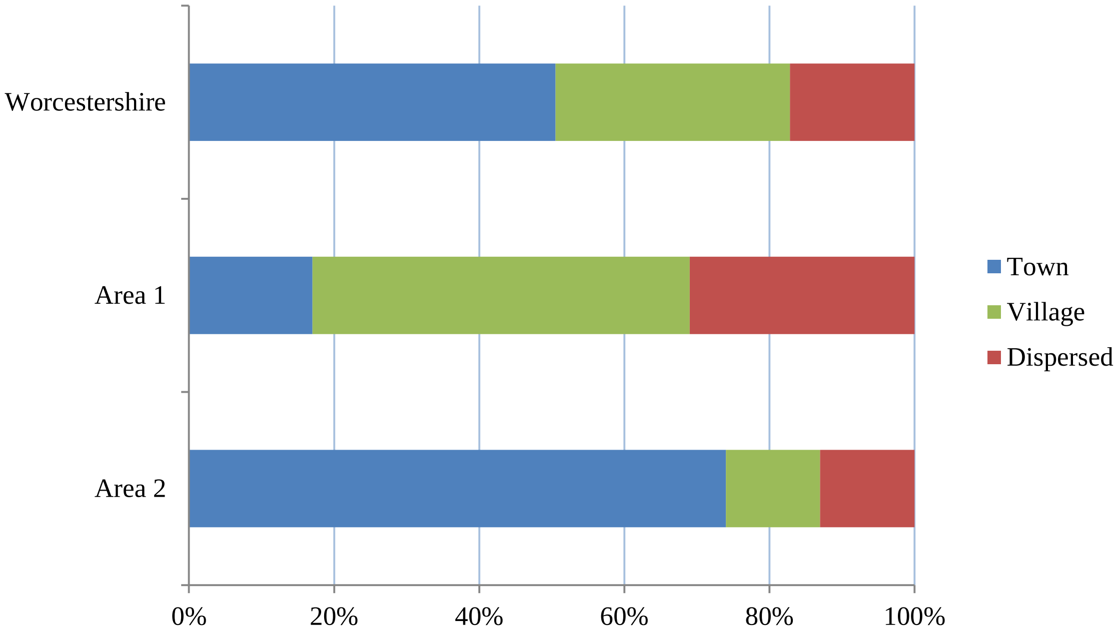
Monitoring and review
- One month after starting on direct payments, then at least annually
- Includes financial monitoring and audit

3.4 Rurality

3.4.1 Rurality of Worcestershire

Worcestershire is more sparsely populated than England as a whole, with an average of 3.3 people per hectare, compared to the national average of 4.1 (ONS, 2013a). Area 1 is the most sparsely populated district of Worcestershire, with a population density of 1.3 people per hectare (ONS, 2013a). In contrast, Area 2 is more densely populated on average than England or Worcestershire as a whole, with 5.0 people per hectare (ONS, 2013a). Worcestershire is classified as ‘Urban with Significant Rural’ according to the 2011 Rural-Urban Classification (Defra, 2014b), with 38.4% of its population residing in rural communities. This is a substantially higher proportion than in England as a whole (23.6%) (Defra, 2014b). Area 1 is classified as ‘Largely Rural’, with over half (52.4%) its population living in rural communities, while Area 2 is classified as ‘Urban with Significant Rural’, with 42.1% of its population residing rurally (Defra, 2014b). Half of the rural population of Worcestershire and around three quarters of the rural population of Area 2 live in towns, whereas in Area 1 the vast majority of the rural population (82.9%) live in villages or dispersed dwellings (ONS, 2009) (see Figure 8).

Figure 8: Percentage of the rural population living in towns, villages and dispersed dwellings in Area 1, Area 2 and Worcestershire as a whole



Source: ONS (2009)

Around a quarter (25.4%) of those living in rural areas of Worcestershire are pensioners, a higher proportion than in the county as a whole (21.2%) (Oxford Consultants for Social Inclusion [OCSI], 2009).

3.4.2 Rural demographics

In comparison with the total population of the county, those living in rural Worcestershire are on average less likely to receive a range of benefits or to be unemployed (see Table 6).

Table 6: Percentage of Worcestershire population in receipt of benefits

	Rural Worcestershire	**Whole of Worcestershire**
Income Support	2.0%	3.8%
Housing and Council Tax Benefit	12.6%	17.3%
Incapacity Benefit	3.7%	5.1%
Jobseeker’s Allowance	2.6%	4.1%
Pension Credit (% of older population)	15.4%	19.8%

Source: OCSI (2009)

The population of rural Worcestershire is also on average less likely than that of Worcestershire as a whole to have health problems or to claim health or disability related benefits (see Table 7).

Table 7: Percentage of Worcestershire population with health problems or claiming health or disability related benefits

	Rural Worcestershire	**Whole of Worcestershire**
Limiting long-term illness	27.4%	33.4%
Permanently sick or disabled[11]	3.4%	4.0%
Attendance Allowance	14.2%	15.6%
Disability Living Allowance	3.5%	4.4%

Source: OCSI (2009)

3.4.3 Access to facilities and transport

Residents of rural Worcestershire are considerably less likely than those in urban areas of the county to live in close proximity to a range of amenities. For example, 94% of residents in urban areas of Area 1 live within two kilometres by road of a post office, compared to only 53% of their rural counterparts (Commission for Rural Communities [CRC], 2011). On average, the population of rural Area 1 have to travel further to reach a range of facilities than those living in rural England as a whole. In contrast, residents of rural Area 2 tend to live closer to amenities (including banks and building societies, supermarkets and GP surgeries) than is the case nationally (see Table 8).

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[11] % of working age adults

Table 8: Percentage of households in rural areas of Area 1, Area 2 and England within the given distance of key amenities by road

	Area 1	**Area 2**	**England**
GP surgery (4 km)	53%	86%	80%
Pharmacy (4 km)	37%	79%	66%
Dentist (4 km)	38%	75%	57%
Bank/building society (4 km)	38%	72%	50%
Post office (2 km)	53%	82%	75%
Convenience store (4 km)	56%	94%	71%
Supermarket (4 km)	43%	69%	61%
Cashpoint (4 km)	70%	89%	84%
Petrol station (4 km)	63%	85%	73%
Pub (2 km)	83%	94%	88%

Source: CRC (2011)

While urban areas of Worcestershire have good bus and rail links, public transport provision is variable across the county, with some villages inaccessible by public transport. Possibly in reflection of this, only 10.7% of households in rural Worcestershire do not have a car or van, compared to 17.6% in Worcestershire as a whole (OCSI, 2009). Almost half (45%) of households in rural Worcestershire with no car are one hour or more away from the nearest hospital by public transport, compared to 21.7% of no car households in urban areas of the county (OCSI, 2009).

3.5 Summary

Residents of Worcestershire are on average more affluent than the population of England as a whole. This may mean that a greater than average proportion of the county’s population are not entitled to social care funded by the Local Authority, and are thus ineligible for direct payments. In terms of the present study, it may therefore be useful to consider the perspective of social care service users who are required to fund and manage their own care, in addition to that of those receiving direct payments. The proportion of Worcestershire residents aged 65 and over is higher than the national average, and is predicted to increase substantially over the next 20 years. Consequently, demand for older people's services in the county is likely to increase in the near future. The estimated prevalence of dementia in Worcestershire is also higher than national estimates; however the rate of diagnosis is considerably lower than in England as a whole. Only around a tenth of the estimated population with dementia in Worcestershire are in receipt of social care services from the Local Authority. Thus it is important to acknowledge that many people with dementia in Worcestershire may not be known to Social Services.

The most recent available data prior to the commencement of this study in 2012 indicated that direct payment uptake was lower in Worcestershire than in comparator local authorities and England as a whole, therefore it was important to examine why this might have been the case. Within Worcestershire and nationally there is a marked decline in direct payment uptake with age. Uptake also varies considerably according to client group, with those with a mental illness substantially less likely to be in receipt of a direct payment than those with a physical or learning disability. In Worcestershire, less than one in ten people known to have a dementia who are eligible to receive a direct payment do so, considerably lower than the average rate of uptake. This suggests that in order to be effective, an intervention aimed at increasing access to direct payments will need to address the issues experienced by groups with traditionally low uptake, who have previously been neglected in both policy and practice. Service users with no named carer are twice as likely as those with a carer to take up direct payments in Worcestershire, while the opposite is true for people with dementia, indicating the relative importance of the presence of a carer in direct payment uptake by this group.

Worcestershire is more sparsely populated than England as a whole, with almost a third of its population residing in a rural area. Its rural residents are considerably less likely than those in urban areas of the county to be adequately served by public transport, or to live in close proximity to a range of amenities. Perhaps due to their relative isolation, residents of rural Worcestershire are more likely than their urban counterparts to own a car or a van. People with dementia living in rural areas could experience particular difficulties in regards to transport, as they may have relied on driving their own vehicle in order to access facilities, an ability they are likely to lose as their illness progresses. Rural communities in Worcestershire are on average populated by a higher proportion of pensioners; therefore dementia prevalence is likely to be greater in these areas. Despite this, a lack of dementia support service provision in rural Worcestershire has been identified. This could affect direct payment uptake as there may be few available alternative services for direct payment recipients to choose from, or conversely rural residents may need to use direct payments in order to access appropriate care. Possibly in reflection of this, Worcestershire residents living in rural communities are on average more likely to receive a direct payment than their urban counterparts.

An outline of the methodological approach and specific data collection methods utilised in order to address the first aim of this study are presented in the next chapter.

Chapter 4

Part 1 – Research Study

Research Methods and Methodology

Grounded theory methodology was utilised in order to develop a theory that could explain access to direct payments by people with dementia living in rural communities. Due to the exploratory nature of the research, a qualitative approach was taken. The study was based in two adult social work teams at Worcestershire County Council. Social work staff, people with dementia and their carers were selected for inclusion in the research as they were identified as key stakeholders with the greatest influence over access to direct payments by people with dementia. The main methods of data collection were interviews and focus groups.

The aim of this chapter is to outline and explain decisions taken regarding the methodological approach adopted in addressing the first aim of this research, and to provide a detailed account of the methods of sampling, recruitment, data collection and analysis. The chapter includes nine main sections, starting with an outline of the research aims in section one. Section two focuses on the selection of grounded theory methodology and provides a justification for this choice of approach. This is followed in the third section by a rationale for the choices made regarding participant selection and sampling. Sections four and five comprise discussion of the main methods of data collection, respectively interviews and focus groups, providing justification for the selection of these methods, an account of participant selection and recruitment, and a description of data collection procedures. A report of the recording method used in both interviews and focus groups is provided in section six. Section seven gives an account of data analysis procedures and an evaluation of the application of grounded theory. This is followed in section eight by an outline of the ethical review processes, and the chapter concludes in section nine with an account of data storage and anonymisation methods.

4.1 Research aim

The first aim of the research was to explore access to direct payments by people with dementia living in rural communities, and specifically to develop a theory to explain access to direct payments by this group.

4.2 Study design

4.2.1 Selection of grounded theory methodology

Grounded theory methodology (Glaser & Strauss, 1967) was selected primarily because it would enable the development of a theory from the research data, in accordance with the first aim of the research. Birks and Mills (2011) suggest that grounded theory is appropriate in studies where ‘the generation of theory with explanatory power is a desired outcome’ (p.16). In addition, grounded theory methodology is particularly appropriate to address under-researched areas such as the topic of this study, as it emphasises the generation of new theory rather than reliance on current thought and existing literature (Charmaz, 2006). As such, the grounded theory researcher does not need to develop a hypothesis to verify but can instead approach the research with an open mind from the outset. Furthermore, grounded theory allows for the employment of diverse research methods. This was a factor that was felt to be important in the current study, as it would enable the study of the research topic from a range of perspectives, encompassing individual and wider contextual factors. Charmaz (2006) contends that unlike many qualitative methodologies, grounded theory provides the researcher with explicit guidelines on data collection and analysis. The clear guidance and rigorous, systematic handling of qualitative analysis characteristic of this approach made it appear an appropriate option for this relatively new area of study.

4.2.2 Outline of grounded theory methodology

Grounded theory methodology was developed by Glaser and Strauss in the 1960s and outlined in their seminal text *The Discovery of Grounded Theory* (1967). It is now acknowledged as being the methodology most widely used by qualitative researchers in the social sciences (Bryant & Charmaz, 2007). At a time when the general approach to research was deductive, focusing on replication and verification, grounded theory provided an alternative, inductive methodology based on the generation of theory from research data. It offered systematic guidelines for qualitative research, which at the time was widely viewed as being subjective and unmethodical, and thus inferior to quantitative methods. Charmaz (2006) argues that grounded theory ‘legitimized qualitative research as a credible methodological approach in its own right’ (p.6).

Table 9 provides an outline of the key methods of grounded theory research.

Table 9: Key elements of grounded theory research

Element	**Outline**
Theoretical sampling	An iterative sampling process, whereby the researcher purposively samples relevant data to further develop the emerging theory.
Coding data	The process of deriving concepts to label raw data. These initial concepts are then linked to create higher-order categories.
Memo writing	An aid to analysis and theoretical integration. Memos are notes written by the researcher to record, develop and refine their ideas, codes and categories.
Theoretical saturation	The point at which all categories are fully defined and developed, and additional data collection and analysis no longer adds anything new to the developing theory.
Identifying a core category	The selection of one category that represents what the research is about, and encapsulates and links all other categories to create an integrated theory.

Since the initial establishment of grounded theory by Glaser and Strauss in 1967, Strauss, later with Corbin, has taken grounded theory in a new direction while Glaser has remained true to the original approach, now known as classic grounded theory. Strauss and Corbin (Strauss, 1987; Strauss & Corbin, 1990, 1998) set out a more detailed, systematic approach to data analysis (known as Straussian grounded theory) that guides the researcher in finding the meaning in the data, with a new emphasis on verification. Glaser (1992) argues that this new approach is not true grounded theory due to its prescriptive nature and the emphasis on verification rather than induction, suggesting that it would result in data being forced into established categories rather than allowing meaning to emerge. More recently, the development of constructivist grounded theory, most notably by Charmaz (2000), has moved grounded theory away from its initial objectivist approach. Charmaz (2000) rejects the assumption that there is a single, external reality within the data that can be discovered by an objective researcher, instead arguing that theories are co-created by the researcher and research participants, who each bring their own perspectives to the research.

4.2.3 Selection of approach to grounded theory

Following the selection of grounded theory methodology, it was necessary to choose between the three main approaches to grounded theory: classic, Straussian and constructivist. Heath and Cowley (2004) advise that a synthesis of approaches should not be attempted, as the researcher may 'violate the philosophical underpinnings' of each (p.147); therefore the decision was taken to adopt a single approach. In determining which approach to follow three key criteria were considered:

- Compatibility with the ontological perspective of the researcher
- Fit with this particular research project
- Usefulness of the guidelines

Compatibility with my own ontological perspective

The ontological perspective of the researcher was first considered, in accordance with Mills, Bonner and Francis' (2006) proposal that 'researchers must choose a research paradigm that is congruent with their beliefs about the nature of reality' (p.2). They argue that approaches to grounded theory can be placed on a 'methodological spiral', with the classic, objectivist approach at the beginning, followed by Straussian grounded theory, and finally the constructivist approach.

A belief in an objective reality that may be discovered from data by an unbiased researcher initially directed me to classic grounded theory, as its underlying assumptions appeared to be in line with my own. I agree with Glaser's (2002) assertion that including the researcher's interpretation, as proposed by Charmaz (2000), constitutes an 'unwarranted intrusion' (p.3), which I consider may detract from the main focus of the research. In addition, as argued by Glaser (2002), I believe that grounded theory should focus on using patterns identified in the data to explain behaviour rather than on narratives about individual participants. In comparing the two approaches, Breckenridge, Jones, Elliott and Nicol (2012) assert that whereas constructivist grounded theory focuses on ‘interpretative understandings of participants’ meanings’, classic grounded theory ‘aims for conceptual understanding of social behaviour’ (para. 8). I believe that a wider understanding of patterns of behaviour rather than an interpretative focus on meanings and stories can provide a more objective approach with greater explanatory power. Nevertheless, like Strauss and Corbin (Corbin & Strauss, 2008; Strauss & Corbin, 1998) I recognise the importance of considering the wider context in which situations or problems occur, an area neglected in classic grounded theory. As the Straussian approach to grounded theory explicitly considers context but is not too far removed from Glaser’s objectivist approach, this appeared to be the method most compatible with my own ontological perspective.

It is argued (Mills et al., 2006) that Strauss and Corbin ‘possess a discernible thread of constructivism in their approach to inquiry’ (p.1). This is acknowledged by Corbin in the most recent incarnation of Straussian grounded theory (Corbin & Strauss, 2008), where she explicitly expresses agreement with constructivism. However, closer examination of the literature indicated that the apparent constructivism inherent in Straussian grounded theory is a contested notion. For example, Charmaz (2000) argues that the methodological approach of Strauss and Corbin points towards objectivist assumptions. Mills et al. (2006) state that Straussian grounded theory contains a combination of postpositivist and constructivist ideas; an approach that MacDonald and Schreiber (2001) suggest indicates that ‘people can find support in it for any ontology that they wish’ (p.44).

Fit with this particular research project

The compatibility of classic, Straussian and constructivist grounded theory with this particular research project was subsequently considered, both in terms of the practicality and suitability of each approach. The Straussian and constructivist approaches appeared to provide a methodology which was more realistic than that of classic grounded theory, taking practical considerations into account. This can be illustrated by the difference in the way theoretical sampling is handled by the three approaches. Whereas Glaser and Strauss (1967) assert that theoretical sampling should comprise ideas driving further data collection, Corbin and Strauss (2008) acknowledge that time constraints can make this problematic in practice. They suggest that theoretical sampling can involve sampling for new concepts in existing data rather than necessarily recruiting new participants to the research. Similarly, Charmaz (2000) argues that theoretical sampling is achieved through the refinement of ideas rather than an increase in sample size. The more flexible definitions of theoretical sampling proposed by Corbin and Strauss (2008) and Charmaz (2000) were judged to be more suited to the current research due to anticipated difficulties recruiting participants from a fairly specific and thus limited sampling frame.

The emergent approach of classic grounded theory (Glaser & Strauss, 1967) was considered by the researcher as problematic in some regards, specifically the assertion that the research problem should ‘emerge’ from the data, and that the research should not begin with defined research questions. Charmaz (2006) on the other hand acknowledges that researchers embarking on a grounded theory study often have pre-existing interests and assumptions relating to their discipline, which sensitise them to develop relevant questions to explore. Straussian grounded theory (e.g. Strauss & Corbin, 1998) appeared to provide the most helpful and realistic advice on the selection and definition of a research problem, for example taking into account the need to study the literature in order to identify under-researched areas, and allowing for the study of pre-assigned or suggested research questions.

The approaches considered also differ in their handling of the existing literature, a key concern in this project with its requirements to develop a well-researched proposal and comprehensive literature review. Glaser (1978) advocates an open approach in this regard, proposing that reviews of the literature should be undertaken only following data analysis in order to enable the researcher to develop their theory free of preconceived ideas. Similarly, Charmaz (2006) advocates deferring the literature review until after analysis has begun, in order that it does not impede creativity in theory-building. However, she acknowledges that an initial literature review may be a prerequisite of research proposals, suggesting that once this is complete researchers should ‘let this material lie fallow’ (p. 166) until the theory has been developed. Conversely, Corbin and Strauss (2008) argue that the literature can play a useful role in promoting theoretical sensitivity, suggesting ideas for interview questions and theoretical sampling, and providing material for comparison. They also, like Charmaz (2006), value the prior experience and knowledge of the researcher, proposing that it enhances sensitivity to the data. This approach appeared more helpful than the ‘blank slate’ stance advocated by Glaser (1978), as it usefully suggested a way of generating initial questions and sampling ideas.

The Straussian and constructivist approaches to grounded theory appeared to provide a better fit with this particular project in terms of their added emphasis on contextual factors. Denscombe (2007) argues that in applying grounded theory there is a danger that external factors may be ignored, and thus that the situation under study may be divorced from its context. Whereas the broader context in which experiences are located is neglected by Glaser (1978), Corbin and Strauss (2008) acknowledge the importance of considering political, social and cultural factors in order to fully understand experiences, while Charmaz (2006) advocates positioning gathered data ‘in their relevant situational and social contexts’ (p.11). The consideration of these factors was felt to be particularly important for the current area of study as the personalisation of social care is highly political, and uptake of direct payments may be affected by a variety of factors external to the individual.

Usefulness of the guidelines

Finally, the utility of the guidelines provided by classic, Straussian and constructivist grounded theory were compared. Although Charmaz (2006) provides a detailed guide to constructing grounded theory, she does not outline a step-by-step breakdown of how theory may be co-constructed by researchers and participants in practice. Hunter, Murphy, Grealish, Casey and Keady (2011) argue that the practicalities of this approach may be so individual and varied that it is exceptionally difficult to apply, thus making it a challenge for a researcher new to grounded theory. Glaser (1978) proposes an open approach to data analysis, in line with his assumption that meaning will emerge from the data provided that analysis is objective. In contrast, the Straussian approach (Corbin & Strauss, 2008; Strauss, 1987; Strauss & Corbin, 1990, 1998) provides clearer guidelines, analytical techniques and a more structured, systematic approach to coding, consistent with the belief that the researcher must actively seek meaning in the data. Glaser’s approach is criticised (e.g. Hunter et al., 2011) for providing ‘conceptual explanation and compelling justification’ (p.8) for grounded theory methodology as opposed to demonstrating how it could be applied in practice, while McCallin (2003) suggests that the more detailed Straussian approach is helpful to novice grounded theory researchers. However, Glaser (1992) argues that Strauss and Corbin’s approach does not constitute grounded theory, contending that the analytical guidelines result in ‘forced, full conceptual description’ (p.5) rather than the emergence of theory from data. Melia (1996) concurs that the procedures of the Straussian approach may hinder the process of inductive theory development, proposing that ‘the technical tail is beginning to wag the theoretical dog’ (p. 376).

For a researcher new to grounded theory, the detailed, structured approach provided by Straussian grounded theory held appeal, despite concerns that the prescriptive guidelines may impede theory development as argued by Glaser (1992) and Melia (1996). Nevertheless, Strauss (1987) does emphasise that the suggested procedures ‘are by no means to be regarded as hard and fixed rules’ (p.7), but rather guidelines to aid researchers in analysing data. This was reassuring and provided the option of using the techniques of the Straussian approach flexibly, insofar as they are helpful to analysis. Furthermore, Heath and Cowley (2004) suggest that the different approaches to grounded theory may suit different styles of researcher, proposing that ‘researchers vary in the extent to which a tendency to interpret spontaneously must be developed or contained, so different approaches will suit… the researcher themselves’ (p.148). As a researcher in the first ‘development’ category, the more detailed guidance provided by Strauss and Corbin appeared to be best suited to my own style of analysis.

Selection of Straussian grounded theory

Following the assessment of classic, Straussian and constructivist grounded theory against the stated criteria, the Straussian approach was selected. This approach was considered to provide the best fit with the ontological perspective of the researcher, as it would enable the adoption of an objectivist stance while allowing for the consideration of wider contextual factors important to the topic under study. In addition, it appeared to provide a realistic, pragmatic approach to research, and offered structured guidelines useful to the novice grounded theory researcher.

4.2.4 Selection of methodological approach

Due to the exploratory nature of the research, a qualitative approach was taken. The utilisation of methods such as semi-structured interviews and focus groups enabled the exploration of direct payment access by people with dementia living in rural communities, in accordance with the first aim of the research. Access to direct payments by people with dementia is a relatively new area of study, therefore quantitative methods with predetermined options (e.g. questionnaires or structured interviews) were judged to be unsuitable. In addition, as few people with dementia are currently in receipt of direct payments, a quantitative approach may have been unviable due to an insufficient population size.

4.3 Selection of participants and sampling procedures

4.3.1 Focus on social work teams

The decision was taken to focus the research on two adult community social work teams in Worcestershire (hereafter known as Team 1 and Team 2), each covering a substantial rural area and taking referrals of people with dementia. As key gatekeepers to direct payments placing social work staff at the centre of the research enabled close examination of the factors affecting access to direct payments in general, and by people with dementia living in rural communities in particular. This approach also provided access to other key stakeholders, namely people with dementia and their carers who had taken the decision as to whether or not to take up direct payments. Accessing these participants via their social worker had the potential to introduce bias to the research, as social workers may have been selective in referring service users to the researcher. For example, they may have decided not to approach particular service users who they considered would be unwilling or unable to participate in the research, or to exclude those who had had a negative experience with Social Services. However, due to the specific nature of the research, social work teams provided the most effective point of access to the identified participant group.

Focusing on two separate social work teams allowed for the inclusion of people with dementia and their carers from distinct locations, thus enabling the researcher to explore whether access to and experiences of direct payments were affected by locality. The social work teams selected covered areas that provided a contrast in terms of access to facilities and transport, both factors that may influence direct payment uptake. In addition, the inclusion of two social work teams enabled the exploration of possible differences in the attitude and approach of each team towards direct payments, and the impact of this on the experiences of service users.

The two social work teams involved in the research were identified in collaboration with the Operational Services Manager of Social Services at Worcestershire County Council.

Team 1 was selected as it covered the most sparsely populated district of the five community social work teams in Worcestershire, thus enabling a focus on rural issues. The team covering the second most sparsely populated district could not be included due to re-organisation within the team at the time of the research, making participation impractical. Thus Team 2, which covered the next most sparsely populated district in Worcestershire, was included in its place.

Following the identification of the social work teams, the researcher met the Team Manager of Team 1 and the Acting Practice Educator of Team 2, in order to explain the research and to gain feedback regarding the viability of the proposed procedures. The researcher provided information leaflets about the research to be circulated throughout both teams, and offered to attend a meeting with each team to explain the research in more detail and answer any questions; this was requested by Team 2.

4.3.2 Research participants

Social work staff, people with dementia living in rural communities, and family carers were selected for inclusion in the research, as they were identified as key stakeholders with the greatest influence over access to direct payments by people with dementia. It was therefore considered that exploring their experiences would enable examination of the reasons why people with dementia and their families do or do not gain access to direct payments.

As gatekeepers to direct payments, social workers have much control over how (and whether) direct payments are offered and presented to service users. Their experiences of offering direct payments and of supporting service users to utilise this option provided an insight into the way in which individual service users react to the social care options with which they are presented. Social work staff were able to offer a broader overview of the research issue, identifying general differences between service users who opt to take up direct payments and those who do not. In addition, the inclusion of social work staff in the research enabled exploration of the processes involved in offering and setting up direct payments, including any difficulties experienced such as organisational constraints.

As direct recipients of social care, it was thought that service users with dementia may be able to provide an insight into their experiences of receiving care purchased via a direct payment or organised by their Local Authority. They may have the final decision as to whether or not to take up direct payments, thus it was important to explore the choices they had made. Carers of people with dementia are often responsible for making decisions relating to the care of their relative or friend, and tend to take on much of the organisation of the care provided. The inclusion of family carers in this research therefore enabled exploration of the choices they had made relating to direct payments and their experiences of organising care, whether fully supported or via a direct payment.

Three main cohorts of participants were included in the research, each comprising people with dementia living in rural communities, and their carers and social workers. Firstly, in order to explore the reasons why direct payments are not taken up in some cases, those in receipt of social care who had opted not to take up direct payments were recruited to the study. Secondly, service users who were in receipt of direct payments were included, in order to enable the exploration of their decision to take up direct payments and their experiences of managing their own care, including any difficulties encountered. The third cohort comprised those who were entirely funding their own social care. This group was not originally included, but added to the research during the fifth month of data collection following the recommendation of an external reviewer. The decision to include this group was taken as it was anticipated that many of the issues experienced by self-financers (e.g. in regard to recruiting and employing their own carers) would be similar to those faced by people in receipt of direct payments. Self-financers may also provide a different perspective due to their greater financial capital and often lesser involvement with Social Services, meaning that they may not receive as much support in procuring care as their funded counterparts.

4.3.3 Inclusion of participants with dementia

Until recently, the active participation of people with dementia in research has been limited and their potential contribution overlooked (Hellström, Nolan, Nordenfelt & Lundh, 2007; Hubbard, Downs & Tester, 2001), often due to perceived ethical issues. However, it is argued (Hellström et al., 2007) that the exclusion of people with dementia from research based on ethical grounds ‘cannot be justified’ (p.612), and that their voices should be heard. Sherratt, Soteriou and Evans (2007) assert that those with reduced capacity should be afforded the right to help others, and that ‘this includes the right to contribute to research and the right to participate on grounds of altruism’ (p.476).

Previously, people with dementia were often excluded from research on the justification that they may become distressed if they participate (Hellström et al., 2007). However on the contrary, evidence suggests that they may actually experience benefits as a result of taking part. For example, an invitation to contribute to research may give a person with dementia a sense of self-worth and meaning (Kapp, 1998; Moody, 1985), validation, and increased self-esteem (Barnett, 2000) as they feel valued as an individual. Dewing (2002) suggests that participating in research can be a therapeutic experience for people with dementia if it is conducted in a person-centred way. It is therefore argued (Hellström et al., 2007) that the benefits to people with dementia of participating in research tend to ‘far outweigh the risks’ (p.608). Furthermore, the exclusion of people with dementia from research raises concerns of validity, for example where proxy accounts (e.g. by family carers) of living with dementia are relied upon. In their study of community care outcomes for people with dementia, Bamford and Bruce (2000) found clear disparities in the responses of service users and carers, reflecting a difference in priorities. Therefore, it is important to recognise that the views and experiences expressed by proxies may not necessarily be representative or reflective of those of the person with dementia.

On the basis of the above evidence, the decision was taken to include people with dementia where possible in this study. The first aim of the research was to examine the reasons why people with dementia do or do not gain access to direct payments; therefore it was essential that the experiences of people with dementia themselves, as key stakeholders, were explored. As research findings were used to inform the building of an intervention aimed at improving access to direct payments by people with dementia, the study also had the potential to benefit this group in the future. In order to ensure as far as possible that contributing to the research was a positive experience for participants with dementia, the advice of James McKillop (McKillop & Wilkinson, 2004), a person living with dementia with substantial experience of participating in research, was considered and implemented. For example, permission was sought directly from the person with dementia before the interview commenced, even where a consultee had already consented on their behalf. Participants were asked where they wanted the interview to take place to ensure it was in a setting they felt comfortable with, and a choice of morning and afternoon interview times was provided to maximise their ability to contribute.

4.3.4 Sample and sampling

Strata were identified to ensure that the sampling frame was systematically related to the research issue and key stakeholders (see Table 10), and in order to enable the exploration of the experiences of a range of participants with different characteristics and viewpoints. Within these strata, sampling was voluntary for the social worker groups and opportunistic for the service user and carer groups (from which participants were identified by their social workers), due to the limited sampling frame and anticipated recruitment difficulties.

Table 10: Sampling strata and participant codes

	Cohort 1[12]	**Cohort 2**[13]	**Cohort 3**[14]
People with dementia	PWD1	PWD2	PWD3
Carers	C1	C2	C3
Social workers	SW1	SW2	SW3

Using a voluntary sample had the potential to introduce bias to the research, as social work staff who volunteered to take part in interviews may have been those who were more experienced in working with, or had a more positive view of direct payments. Examination of details obtained from the 14 social work staff who participated in the focus groups enabled a comparison to be made between those who subsequently volunteered to take part in an interview and those who did not. The group who chose to participate in an interview had been in their role for longer on average, tended to be in a more senior position (for example, all were registered social workers), and were more likely to have experience both of presenting direct payments to service users and of supporting service users to utilise this option. Therefore, less experienced social work staff may have been under-represented in the interview sample. Despite this, the sample was representative of a diverse range of

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[12] Cases where the person with dementia was in receipt of social care provided by the Local Authority but had opted not to take up direct payments.

[13] Cases where the person with dementia was in receipt of direct payments for their social care.

[14] Cases where the person with dementia was entirely funding their own social care, as they were ineligible for care provided by the Local Authority or direct payments due to their personal funds.

positions relative to the topic under study, with varying characteristics in terms of experience (in the case of the social workers), and age, location, care history and household set-up amongst participants with dementia and their carers. In addition, the characteristics of participants with dementia were very similar to those of the wider sampling frame from which they were drawn (i.e. all people with a recognised dementia living in Worcestershire who were in receipt of social care services in the community). For example, the average age of the interview sample was 82.9 (range 65-91 years), while the average age of the sampling frame was 82 (range 62-96 years). In regards to location, 61% of the sample group and 58% of the wider group lived in a village, hamlet or isolated dwelling.

Issues relating to both social workers and carers acting as gatekeepers may have produced sampling bias. First, it was necessary to rely on social workers to recruit people with dementia and their carers to the research. This may have resulted in the over-representation of those who had a good relationship with their social worker and/or a positive experience of Social Services. Second, of the 13 people with dementia whose care was discussed in the research, only two took part in interviews themselves. In all other cases, the decision as to whether the person with dementia would participate was taken by their carer. In some instances, the carer of the person with dementia prevented the researcher from having any contact with their relative, as they believed they would be unable to take part in an interview or would become distressed by the interview topic. This belief may have been correct, and in some cases was corroborated by the person’s social worker. However, it may have been that carers were being over-protective, thus excluding people with dementia from the research who may have been able and willing to take part. Nevertheless, in the four cases in this study where the person with dementia was present during the interview with their carer, the researcher observed that, as advised by their carer, they would have been unable to take part in the interview themselves. For example, they were non-verbal, unable to engage in reciprocal communication, or were not aware that they were in receipt of support, which would have precluded discussion about the decisions made about their social care.

The ability of people with dementia to participate was a general issue in this research, as those receiving social care solely because they had a dementia tended to be by definition at a relatively advanced stage of the disease in order to be eligible for care. In reflection of this, both service users with dementia who were able to participate in an interview were receiving social care primarily due to their physical needs. This is in line with previous interview studies involving participants with dementia, which have only tended to recruit those at the mild to moderate stage of the disease (e.g. Olsson, Lampic, Skovdahl & Engström, 2013; Samsi & Manthorpe, 2013). The under-representation of people with dementia in this research meant that their experiences in relation to decision-making about their care could not be fully explored. However, it was observed that in practice, the person with dementia had no or limited involvement in the decision to take up or decline direct payments, with the carer in each case being the key decision-maker in regard to their care. Nevertheless, eliciting the views and experiences of service users with dementia would have provided a valuable perspective on the decision-making process. Although more inclusive methods such as observation have been successfully used with this group in studies relating to quality of life for example (e.g. Kuhn, Kasavka & Lechner, 2002; Wetzels, Zuidema, de Jonghe, Verhey & Koopmans, 2010), it was considered that this approach would not have provided effective insight into the issue of decision-making around direct payments.

As the research was match-funded by Worcestershire Public Health and had the support of social work team managers, this may have meant that participants felt some pressure to take part, although it was emphasised that participation was voluntary. In addition, these factors may have resulted in some participants believing that the research was not truly independent, which may have affected their responses. In order to mitigate this it was explained in participant information booklets and at the start of each interview and focus group that discussions would be kept confidential.

As the research progressed, it became apparent that the sampling frame could have been widened to include other stakeholders, notably personal assistants employed by agencies or via direct payments, and frontline staff members of the agency providing support to people using direct payments in Worcestershire. The inclusion of personal assistants would have enabled the exploration of any differences in the experiences of those employed through agencies and those employed via a direct payment. Frontline staff at the support agency could have provided additional insight into the concerns raised and issues experienced by people with dementia and their carers who were considering taking up, or were in receipt of direct payments. Due to time constraints and as the research sample had been specified in advance to the ethics committee, it was not practical to include these groups in the interview part of the research.

Sample size

The decision to recruit 12 triads to the interview part of the study (where each triad comprised a person with dementia and their carer and social worker) with a maximum of 36 interviews was taken with reference to existing published research and recommendations made in the literature, in addition to consideration of practical issues such as anticipated recruitment difficulties. Although specifying sample size in advance is not recommended (e.g. Glaser & Strauss, 1967) for studies utilising grounded theory, due to the requirement of theoretical sampling until saturation point, Corbin and Strauss (2008) suggest that theoretical sampling can involve sampling for new concepts in existing data rather than necessarily recruiting new participants to the research. It is proposed (e.g. Onwuegbuzie & Leech, 2007) that qualitative samples should be small enough to allow for detailed, rich analysis but large enough to enable saturation of data (Flick, 2006). In line with similar studies (e.g. Manthorpe & Stevens, 2010; Ridley & Jones, 2003), it was decided that conducting between 20 and 30 interviews would meet these requirements, providing a balance between generating sufficient interview data to ensure saturation, while being achievable in terms of anticipated recruitment issues and time to analyse each interview in depth.

4.4 Focus groups

4.4.1 Selection of focus groups as a data collection method

A focus group was conducted with each participating social work team in order to enable the inclusion of a greater number of participants and therefore a wider range of experiences and perspectives, making findings more generalisable. Less experienced social work staff (including student social workers and social work assistants) who were under-represented in the interview sample took part in the focus groups, possibly because a group discussion was perceived as less intimidating than a one-to-one interview (Kamberelis & Dimitriadis, 2013). A semi-structured approach was utilised, which helped to maintain the focus of the discussion while allowing new ideas to emerge. This also made it easier for comparisons to be drawn between the two groups.

While one-to-one interviews are criticised for being overly individualistic, focus groups can enable the exploration of the research issue through the lens of social interaction (Kvale, 2007). King and Horrocks (2010) suggest that this can give the researcher the opportunity ‘to obtain opinions or attitudes at another level… [revealing] the social and cultural context of people’s understandings and beliefs’ (p.61). Group interaction and discussion can enable greater generation and development of ideas than may be possible in a one-to-one interview, as participants can question, contradict, elaborate, amend or qualify each other’s contributions (King & Horrocks, 2010). This provides valuable insight into the reasoning behind the views they express (Denscombe, 2007) and can reveal group norms. In this research it was observed that focus group participants prompted one another to talk about relevant experiences, raised additional viewpoints and refined ideas; hence the interactive nature of this method was helpful in enabling a range of issues to be explored. It is argued (Kvale, 2007) that focus groups are a helpful tool in exploratory research such as this, as the nature of group interactions can result in more spontaneous expression of views and experiences. Birks and Mills (2011) suggest that focus groups are particularly suited to grounded theory studies, as the broad range of perspectives provided by multiple participants is helpful in developing categories of the emerging theory.

A key limitation of focus groups is that there can be the tendency for certain individuals to dominate the discussion, meaning that those who are more reserved may not contribute their own experiences and viewpoints, which could be valuable to the research (Birks & Mills, 2011). This was the case to a certain extent in the current research: participants in both teams who were less experienced or in a more junior role to others in the group tended to contribute less to the discussions. However, their reticence may have been because they did not have relevant experiences that they could contribute (e.g. experience of supporting people with dementia to use direct payments), rather than because they felt uneasy about taking part.

4.4.2 Selection and recruitment of focus group participants

All social work staff and both team managers from Team 1 and Team 2 were invited via email to take part in the focus groups; therefore within these teams participation was voluntary. The invitation was sent directly to team managers, who passed it on to all team members. Information booklets specifically regarding the focus groups were given to each team manager to circulate to their team several weeks before the focus group took place (see Appendix 1). These booklets included information about the purpose of the research as a whole, a description of what would happen in the focus group, an outline of the benefits and disadvantages of participating in the research, an explanation of how research data would be kept confidential, and researcher contact details. It was clearly stated in the booklet that participation was entirely voluntary and that participants could withdraw from the research at any time without penalty.

4.4.3 Participant characteristics

Five members of social work staff from Team 1 and nine from Team 2 took part in the focus groups; therefore there were 14 participants in total. Eleven of the participants were registered social workers, two were social work assistants, and one was a student social worker. Participants had between three months and 11 years of experience at the time of the focus group (*M* 3.9 years, *SD* 3.7). The majority (10 out of 14) had experience of presenting direct payments to service users with dementia; however only six had experience of supporting service users with dementia to use direct payments. Participants in the two focus groups were well-matched in terms of role and experience.

4.4.4 Focus group procedures

A separate focus group was conducted with each social work team; therefore two focus groups were carried out in total. Each focus group took place in a private meeting room at the Worcestershire County Council premises where each team was based, in order to maximise participation. Both focus groups were conducted in January 2012 and were held one week apart, with Team 2 participating first. The focus groups were facilitated by a Senior Researcher using a guide prepared by the researcher, which allowed the researcher to focus on the discussion and take notes to aid transcription. Both focus groups were audio recorded for the purpose of transcription using two digital voice recorders, one placed at either end of the room.

On entering the meeting room, participants were asked to complete an attendance slip with their name, contact details, role, number of years of experience, and details of their experience regarding direct payments. All participants were asked to fill in and wear a name sticker. Each participant was also asked to sign two copies of a consent form (see

Appendix 2), one of which they retained, and one that they returned to the researcher. Prior to the beginning of each discussion, the facilitator welcomed participants to the focus group and introduced himself and the researcher. Participants were reminded of the aim of the focus group, and were asked not to disclose any of the subsequent discussion to anyone outside the group. The purpose of the audio recording was explained, and participants were reminded that only researchers involved in the study would listen to the recording and that they would not be identified in any report of the research findings. They were then given the opportunity to raise any questions or concerns about the focus group.

A discussion time of around 45 minutes was aimed for in each focus group. The discussion with Team 1 was 41 minutes in duration, and the discussion with Team 2 was 49 minutes in duration. This difference may be attributed to the fact that there were fewer participants in the discussion with Team 1. Both focus groups were conducted in a semi-structured format with a standard set of four main questions to guide the discussion, each with four or five follow-up questions or prompts (see Appendix 3). Prior to the start of the main part of the discussion, all participants were asked to introduce themselves and briefly outline their experiences of direct payments. The first two main questions focused on participants' experiences of offering direct payments to service users (particularly those with dementia or those living in rural areas) and supporting service users who were using direct payments. The latter two questions required participants to reflect on their experiences to discuss how direct payments had worked as an option for people with dementia and their carers, and to identify factors that would make it easier for them to work with direct payments. Following the first focus group with Team 2, the four main questions were kept the same for the subsequent focus group with Team 1. However, the follow-up questions were changed to reflect topics raised by participants in the first focus group that the researcher wished to explore in more depth. At the end of each discussion, the facilitator asked if there was anything else participants would like to say and thanked them for their time. Participants were again reminded that only researchers involved in the study would listen to the recording of the discussion and that they would not be identified in any report of the research findings. They were then given the opportunity to ask any questions.

4.5 Interviews

4.5.1 Selection of interviews as a data collection method

Interviews were selected as a method of data collection as they allowed for the in-depth exploration of the experiences of key stakeholders in relation to the research issue. Interviewing the selected participants enabled the examination of the whole social care process, encompassing the lead up to the initial referral, decisions regarding care options, the first experience of social care, and subsequent events. A semi-structured approach was utilised in order to ensure that issues pertinent to the research were fully explored, while also allowing flexibility for participants to raise previously unanticipated points and for the researcher to follow up areas of interest. Gray (2009) suggests that the focused nature of semi-structured interviews helps to increase validity. Furthermore, in addition to allowing for a targeted focus on the research topic, it is argued that interviews afford the researcher flexibility to clarify and explore new ideas and apparent contradictions (Denscombe, 2007). Charmaz (2006, p.29) proposes that the ‘combination of flexibility and control inherent’ in interviews makes this method particularly conducive to grounded theory studies as the researcher can direct data collection, enabling theoretical sampling and subsequent theory development. On a practical note, interviews tend to have a higher response rate than many methods of data collection, as they are normally scheduled in advance at a time and location convenient for the participant (Denscombe, 2007). This was an important consideration in relation to this study as the limited size of the potential sample meant that participation needed to be maximised.

4.5.2 Selection and recruitment of interview participants

There were three cohorts of interview participants, each comprising people with dementia living in a rural area of Worcestershire, and/or their carers and social workers. People with dementia were defined as those who were recorded as having a dementia on the case notes held about them by Social Services. This did not necessarily mean that they had a formal diagnosis of dementia, although this was the case in the majority of instances. Carers were defined as relatives or friends involved in organising the care of the person with dementia. Rurality was defined using the Rural/Urban Definition (England and Wales) (ONS, 2004), which classifies all settlements with a population of less than 10,000 as rural. Therefore, participants with dementia living in a postcode area within a settlement with a population of 10,000 or higher were excluded from the research. Participant recruitment continued until 12 triads had been recruited to the study. Each triad comprised a person with dementia, their carer/s and their social worker.

Social workers

All social work staff from Team 1 and Team 2 whose caseload included people with dementia living in a rural area were invited to take part in the research interviews. Therefore, within each social work team sampling was voluntary. Social work staff were invited to participate via an email from the researcher circulated to each team by the team manager. Information booklets were also provided in electronic and hard copy form (see sample in Appendix 4). These booklets included information about the purpose of the research as a whole, a description of what would happen in the interviews, an outline of the benefits and disadvantages of participating in the research, an explanation of how research data would be kept confidential, and researcher contact details. It was clearly stated in the booklet that participation was entirely voluntary and that participants could withdraw from the research at any time without penalty.

Directly following each focus group, the researcher gave a brief presentation to the social work teams to remind them about the interviews, including how they could participate, what taking part would involve, and what the benefits of participation would be. All focus group participants were asked to complete an attendance slip that included a tick box section to assess whether they would be eligible to take part in the interviews, and where they could indicate whether they would be willing to be contacted by the researcher to discuss their possible participation. The researcher sent personalised emails to social work staff who agreed to be contacted in this way to invite them to participate in the interview part of the study.

People with dementia and carers

Social work staff willing to participate in the interviews were asked to identify potential participants with dementia from their caseload; therefore sampling was opportunistic. After identifying a potential participant, social workers gave a brief verbal explanation of the research to the person with dementia and/or their carer (either during a home visit or by telephone), and asked their permission to pass their contact details onto the researcher. The researcher then telephoned or visited potential participants (depending on the preferences of each participant and the recommendations of their social worker) to explain the research in more detail, give them the opportunity to raise questions or concerns about any aspect of the study, and invite them to take part in the research. All potential participants were given an information booklet (see sample in Appendix 5) and a summary information sheet (see sample in Appendix 6) about the research at least one week prior to deciding whether to take part in the interview. This was either posted or emailed to them by the researcher with a covering letter or email, or handed to them by their social worker or the researcher during a home visit. The information booklet included information about the purpose of the research as a whole, a description of what would happen in the interview, an outline of the benefits and disadvantages of participating, an explanation of how research data would be kept confidential, and researcher contact details. It was clearly stated in the booklet that participation was entirely voluntary and that participants could withdraw from the research at any time without penalty. The summary information sheet included a picture of the researcher and several bullet points which briefly described what taking part in the research would involve, and emphasised that participants would be free to withdraw from the research at any time without giving a reason. The information booklets and summary information sheets were produced in large font (Arial size 14), with the text clearly spaced and sentences as short as possible in order to enhance readability. Key terms were explained, and the language used was as simple as possible. The information booklets had an average Flesch Reading Ease score of 64 (Flesch, 1948), which indicates that their readability was standard (i.e. that they could be read by a 14-year-old of average ability).

Recruitment issues

It was originally planned that data would be collected over a period of six months; however difficulties recruiting participants meant this was extended to nine months. During the first five months of the data collection period, only two families and their social workers participated in interviews. All service users and carers approached by their social workers and invited to take part in the research agreed to do so, with the exception of one who declined due to ill health. Therefore, low initial levels of participation by social workers appears to have been the main reason for the delay in recruitment. This may have been due to a lack of awareness of the research and how they could take part, the complexity of the research methods, or difficulties identifying service users from their caseload who met the study criteria.

The recruitment issues were addressed in a number of ways, firstly by reducing the complexity of the research methods. Initially it had been planned that participating social workers would record meetings where they presented a service user with dementia with their social care options. The researcher would then carry out follow-up interviews with those present at the meeting. However, this process did not fit in with the way in which new referrals were handled and therefore would have been time consuming for social workers and potentially confusing for service users. For example, prior to making the routine visit to discuss a service users' social care options, social workers would have needed to make an additional visit or telephone call to service users in order to explain the research and give them at least a week to decide whether they wished to take part. In addition, only service users who had been newly referred to Social Services would be eligible to take part in this section of the research, thus limiting the number of potential participants. Therefore, this part of the research was amended to comprise a single interview with each key stakeholder. This widened the participant selection criteria and meant that participating in the research was less complex and time consuming for social workers. This change was implemented at the end of the second month of the data collection period, and communicated to social work staff via email and at social work team meetings.

Secondly, in order to ensure social work staff remained aware of the research throughout the data collection period, regular updates and reminders were given to each social work team. The researcher sent emails to the social work teams approximately on a monthly basis. Each email included an update on the research and a reminder to team members of the groups of service users who were eligible to take part. In addition, the researcher attended team meetings with each social work team in order to remind team members about the research, update them regarding the recruitment of participants, and give them the opportunity to ask questions or raise any issues. The researcher attended two meetings with Team 1 and three meetings with Team 2 during the data collection period. The only issue raised about the research during these meetings was that members of both teams were unsure how to identify whether a service user lived in a rural area. The researcher explained the Rural/Urban Definition (ONS, 2004) being utilised for the research, and obtained a list of postcodes covered by both social work teams which classified each postcode area as urban or rural according to this definition. This list was used to create a spreadsheet for each social work team that team members could use to easily identify whether a particular postcode area was urban or rural, which was circulated to each team via the team managers. Social work staff were also informed that they could email a service user’s postcode to the researcher to check whether it was classed as urban or rural.

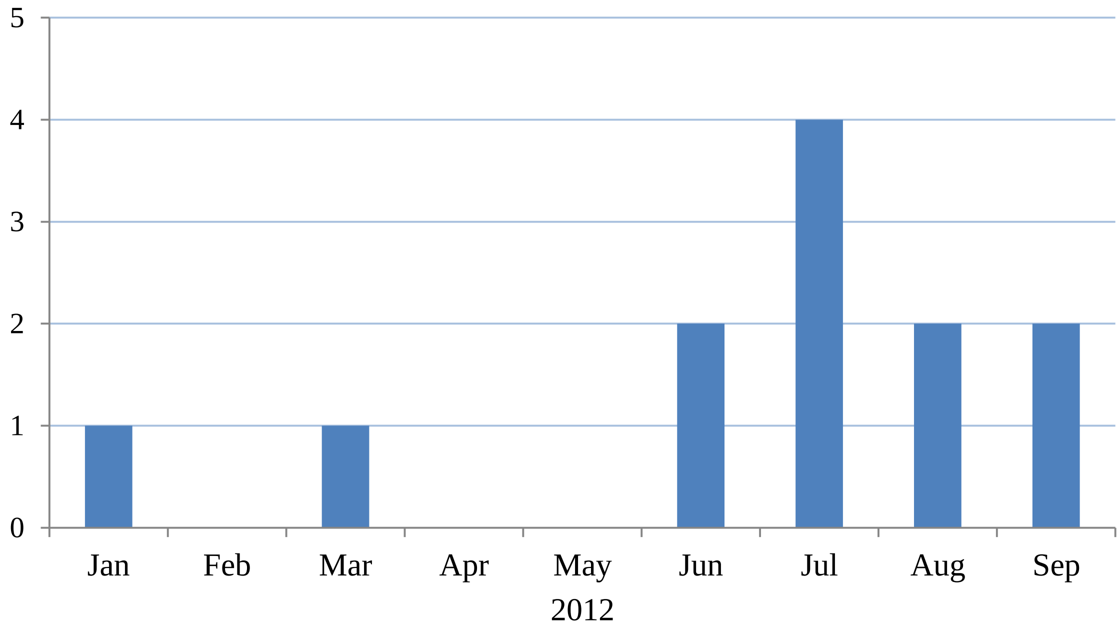
Thirdly, following a recommendation by an external reviewer of the research, a new cohort of participants (Cohort 3 - people with dementia living in rural areas who self-finance their care) was added to the research in the fifth month of data collection. This widened the selection criteria and gave a greater number of social workers the opportunity to take part. This change was communicated to social work staff via email and at social work team meetings.

Finally, in order to maximise the number of service users who would be eligible to take part in the research, the general selection criteria were widened. Initially it had been decided that service users in Cohort 2 (those who were in receipt of direct payments for their social care) would only be recruited to the research if they had been receiving direct payments for at least six months. However, as several potential participants identified by social workers had been receiving direct payments for less than six months, they were included in the research in order to maximise participant numbers. This was advantageous in that the initial take-up of direct payments was fresher in the minds of these participants, enabling them to talk about their experiences in more detail. It also allowed the researcher to explore the concerns of those who were actually in the process of taking up direct payments. However, a limitation of this approach was that some participants had little experience of using direct payments, and may not have encountered particular issues or benefits of this option at such an early stage. Towards the end of the data collection period, it was necessary to include one service user with dementia who did not live in a rural area, in order that the required number of participants could take part in the research.

In addition to widening the selection criteria, an unequal number of triads were recruited to each group in order to maximise overall participation. The highest number of triads were recruited to Cohort 2 (those who were in receipt of direct payments for their social care), possibly because the title of the research and initial recruitment efforts focused on this group. Fewest triads were recruited to Cohort 3, those who self-financed their care. This may have been due to the late addition of this group in the fifth month of data collection, or because social workers tend to have less contact with those funding their own care.

Following the implementation of these measures, the rate of participant recruitment increased from the sixth month of the data collection period onwards (see Figure 9). Interviews were therefore concentrated in the last four months of this period, meaning that there was a delay between interviews being conducted and subsequently transcribed, due to time constraints. This made ongoing analysis and alterations to interview questions problematic. In order to overcome this, where transcription was delayed the researcher listened to interview recordings and made a note of preliminary analyses, so that questions asked in subsequent interviews could be altered to enable the exploration of important points.

Figure 9: Number of triads recruited during each month of the data collection period



4.5.3 Participant characteristics

As originally planned, 12 triads were recruited to the research in total, each comprising a person with dementia (in one case a husband and wife with dementia), their carer/s, and their social worker. Four triads were recruited to Cohort 1, six triads to Cohort 2 and two triads to Cohort 3. A total of 25 participants took part in the interviews across all three groups, comprising 15 carers, two people with dementia and eight social workers. The majority of interviews were conducted on a one-to-one basis; however a joint interview attended by two carers was conducted in two instances. Three of the eight social workers who took part each participated in two separate interviews regarding different service users. Therefore, 26 interviews were conducted altogether. There were nine participants in Cohort 1 (including two social workers who each participated in two interviews), 13 participants in Cohort 2 (including one social worker who participated in two interviews) and three participants in Cohort 3 (see Table 11).

Table 11: Number of interview participants in each group

	Cohort 1	**Cohort 2**	**Cohort 3**	**Total**
People with dementia	2	0	0	2
Carers	5	8	2	15
Social workers	2	5	1	8
Total	9	13	3	**25**

Social workers

Social workers had been in their role for between two and 30 years at the time of participating in the research (*M* 9.2, *SD* 8.9) and had two to five years' experience of supporting service users to use direct payments (*M* 3.8, *SD* 1.2). All had experience of presenting direct payments to people with dementia and six of the eight had experience of supporting a person with dementia to utilise this option. These six social workers had each supported an average of seven people with dementia to use direct payments (range 2-15, *SD* 4.6). Five of the social workers who participated were members of Team 1 and three were members of Team 2, perhaps in reflection of the fact that the area covered by Team 2 is less rural. Half of the social workers who participated in the interviews had previously taken part in the focus group conducted with their team.

Carers

Four male and 11 female carers participated in the interviews, with an age range of 43-93 years (*M* 62.3, *SD* 13.6)[15]. This is broadly consistent with national figures (ONS, 2013c), which indicate that females are more likely to have caring responsibilities, and that those in the 55-64 age group are most likely to be carers. Six of the carers were the children of the person with dementia, four were friends, three were the spouse, and two were other

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[15] One carer declined to supply their date of birth.

relatives. All but one of the carers of people with dementia in receipt of direct payments were responsible for managing the direct payment. The remaining carer was responsible for overseeing personal assistants employed using the direct payment, on behalf of another carer who managed the direct payment. Participating carers of people with dementia who received direct payments were on average younger (range 43-67 years, *M* 57.7, *SD* 9.2) than carers of people with dementia who were in receipt of fully managed care (range 65-93 years, *M* 70.8, *SD* 17.6).

People with dementia

Although only two people with dementia were able to participate in the interviews, data were collected regarding all 13 people with dementia whose care was discussed. Two of the people with dementia were husband and wife, and their care was discussed in the same interview with their carer and social worker. Five of the participants with dementia were male and eight female, and they were aged 65-91 years (*M* 82.9, *SD* 7.2). Nine of the 13 had been offered direct payments by their social worker. Seven were receiving direct payments and had been doing so for between one month and three years (*M* 7 months, *SD* 11.6) at the time they or their carer were interviewed. Of this group, four had been in receipt of care managed by the Local Authority prior to taking up direct payments, for an average of one year and nine months (range 1 week - 5 years, *SD* 4.9). Four of the people with dementia were receiving care managed by the Local Authority at the time of the interview and had been doing so for an average of 2.3 years (range 9 months - 4 years, *SD* 16), with the remaining two participants funding their own care. Participants with dementia who received direct payments were on average younger (range 65-91 years, *M* 79.4, *SD* 8) than those who were in receipt of fully managed care (range 86-90 years, *M* 88.4, *SD* 1.8). This is consistent with local and national data, which indicate a marked decline in direct payment uptake with age (HSCIC, 2014a; WCC, unpublished). In total, seven participants with dementia lived in a village, hamlet or isolated dwelling, five lived in a town or fringe area and one lived in an urban area. Six of the seven people with dementia in receipt of a direct payment lived in a village, hamlet or isolated dwelling, whereas none of those who were receiving fully managed care did so. This is in line with local data, which indicates that direct payment uptake appears to increase with rurality (WCC, unpublished).

4.5.4 Interview procedures

The researcher contacted potential participants with dementia and/or their carers by telephone to ask if they would be willing to participate in an interview, at least one week after they had been given an information booklet and summary information sheet about the research to consider. If they agreed to participate, the researcher arranged an interview date and location convenient for the participant. All participants with dementia and the majority of carers wished to be interviewed in their own home. Four of the 15 carers who took part asked to be interviewed at the home of the person with dementia, with the person with dementia present, and one asked to be interviewed at their own workplace. Therefore, no travel expenses were paid to participants. If there was sufficient time between the interview being arranged and conducted, a letter was sent to participants with the researcher's contact details, confirming the date, time, location and topic of the interview. When an interview date had been arranged with a person with dementia and/or their carer, the researcher contacted the person's social worker by email to arrange an interview date and location convenient for the social worker. All but one of the social workers asked to be interviewed in a private meeting room at their workplace; the remaining social worker asked to be interviewed in a private meeting room at the University of Worcester.

Prior to the start of each interview, participants were asked to complete an attendance slip and to sign two copies of a consent form (see sample in Appendix 7), one of which they retained and one that they returned to the researcher. In the case of participants with dementia, the researcher assessed whether they had the capacity to consent to participating in the research, in accordance with British Psychological Society guidance (Dobson, 2008) and in consultation with their carer and social worker. In one case, the person with dementia was assessed as not having the capacity to consent to their participation. In this instance, a suitable personal consultee was identified in accordance with Section 32 of the Mental Capacity Act 2005 Code of Practice and in consultation with DH (2008) guidance. The personal consultee was provided with an information sheet that explained their role as consultee (see Appendix 8) and the same information booklet about the research that was provided to participants with dementia. They were given the opportunity to raise any questions or concerns with the researcher. The personal consultee was asked to sign two copies of a declaration form (see Appendix 9) to confirm that in their opinion the person with dementia would have no objection to taking part in the research. They retained one copy and returned the other to the researcher. The personal consultee was invited to be present during the interview with the person with dementia, and opted to do this.

After participants had signed the consent form and prior to the start of the interview, the researcher reminded participants of the aim of the research and how findings would be used. The purpose of audio recording the interview was explained, and participants were reminded that only researchers involved in the study would listen to the recording and that they would not be identified in any report of the research findings. The researcher emphasised that they were interested in what participants had to say, and that there were no right or wrong answers. It was explained that participants did not have to answer any questions they did not want to and that they were free to stop the interview or have a break at any time. Participants were then given the opportunity to raise any questions or concerns prior to the start of the interview.

The interviews conducted ranged from six minutes to one hour 39 minutes in duration (*M* 53.2 minutes, *SD* 23.7). On average, interviews with Cohort 2 participants (range 25-74 minutes, *M* 57.5, *SD* 13.7) were longer than those with Cohort 1 (range 6-99 minutes, *M* 50.5, *SD* 32.2) and Cohort 3 (range 24-79 minutes, *M* 43.7, *SD* 30.3) participants. It is thought that this was due to there being most detail to be discussed with participants in Cohort 2 who were receiving direct payments (e.g. regarding how the direct payment was managed), and least with those in Cohort 3 who were entirely funding their own care. Interviews with people with dementia were substantially shorter in duration (range 6-15 minutes, *M* 10.2, *SD* 6.4) than those with carers and social workers. This may be attributed to the participants with dementia generally giving less detailed answers to the interview questions and being unable to answer some of the questions fully. On average, interviews with carers (range 24-99 minutes, *M* 60.9, *SD* 21.9) were longer than those with social workers (range 25-74 minutes, *M* 51.9, *SD* 19.4). This may be because there tended to be fewer interruptions in the interviews with social workers, and because the social workers who participated tended to be more subject to time constraints as they took part during working hours. All interviews were audio recorded for the purpose of transcription using a digital voice recorder, which was placed on a flat surface between the researcher and the participant/s.

Interviews were conducted in a semi-structured format with a standard set of main questions to guide the discussion, each with a number of follow-up questions or prompts. A set of standard interview guides were used (see Appendix 10); however interview questions were tailored to take the situation of each participant into account. For example, in some instances irrelevant questions were removed and some questions added or altered for individual participants. In addition, the interview guides were developed throughout the data collection period to reflect topics raised by participants, and so that the researcher could explore some issues in greater depth (Strauss & Corbin, 1998). There were between seven and 12 main questions in each interview. Interviews started with a relatively open question to give participants the opportunity to explain their situation in their own words, and the remainder of questions focused on specific aspects of their experiences. At the end of each interview, the researcher asked if there was anything else participants would like to say and thanked them for their time. Participants were again reminded that only researchers involved in the study would listen to the recording of the discussion, and that they would not be identified in any report of the research findings. They were then given the opportunity to ask any questions.

4.5.5 Strengths, limitations and issues experienced

Gray (2009) suggests that due to the necessarily limited sample size of interview research, it may be difficult to make generalisations from findings. Arksey and Knight (1999) propose that two key principles should be followed in order to maximise generalisability: first ‘to select a sample that allows for a subject to be viewed from all relevant perspectives’, and second, to ‘keep increasing the sample size… until no new viewpoints are emerging from the data’ (p.376). These principles were adhered to as far as possible in the current study, in that the sample selected was representative of a range of viewpoints, and data were analysed until saturation point in accordance with grounded theory methodology.

A further limitation of interviews is the potential for bias, in part due to reliance on the accuracy of participants’ accounts of their experiences. However, the inclusion of a range of stakeholders in this study meant that data could be triangulated, thus increasing reliability. While some accounts may have been inaccurate due to difficulties in recall, details could be corroborated by other participants, and participating social workers were able to check the details of each case in their notes before commencing the interview. In order to limit the effect of interviewer bias, the researcher endeavoured to maintain a neutral, non-judgmental stance in the delivery of questions and responses, avoiding leading questions. However, it was anticipated that social desirability bias, whereby research participants tend to give a positive account of their own attitude to the researcher, may have posed a particular problem in this study. As all participants were aware that the second part of the research would comprise the development of an intervention aimed at improving access to direct payments, it is highly possible that they perceived the interviewer to have a positive stance on direct payments.

Due to the limited number of suitable referrals to Social Services during the data collection period, it was not possible to interview only people with dementia and carers who had recently taken the decision as to whether or not to take up direct payments. On average, participants in receipt of direct payments had been receiving direct payments for seven months, and those who had opted not to take up direct payments had been receiving social care for 2.3 years. It was anticipated that difficulties in recall could affect the richness of the data, as participants would not be able to give a detailed explanation of the initial decisions they made relating to their social care. However, although this was problematic in some instances, the majority of participants were able to provide a thorough account when prompted. Furthermore, this approach was advantageous in that participants were generally experienced users of direct payments or fully managed social care, and were therefore able to discuss a range of issues that they had encountered, which those newly referred may not have experienced. In addition, the majority of participants reported that they had been at crisis point when they were referred to Social Services. The delay in interviewing meant that this crisis was likely to be less raw for participants, so there was reduced potential for them becoming distressed when discussing their referral with the researcher.

Utilising a semi-structured interview format proved very useful in keeping the interview on track, and all but one of the interviews conducted remained on-topic for the majority of the time. Beginning each interview with a relatively open question allowed participants to tell their story, which gave a valuable insight into issues that may not otherwise have been explored. Participants reported that they found the interview process interesting and thought provoking, as in some cases they were prompted to think about issues they had not previously considered. In accordance with this, Corbin and Strauss (2008) suggest that interviews can provide participants with ‘an opportunity to talk in depth about issues that they hadn’t talked much about before, giving them additional insights into their own behavior’ (p.28).

The interviews with people with dementia were substantially shorter in duration than those with carers (*M* 60.9 minutes) and social workers (*M* 51.9 minutes), at an average of only 10.2 minutes. Participants in all other interviews talked considerably more than the interviewer, whereas in the case of participants with dementia, the interviewer and participant contributed in equal amounts. This tended to be because participants with dementia gave much shorter answers and needed more specific prompts. They found it difficult to discuss hypothetical situations, and memory difficulties meant that they could not recall the decisions that had been made about their care. In one case, the carer was also present at the interview and was able to provide prompts, which were helpful in enabling the person with dementia to talk about events they had previously forgotten. However, the person with dementia tended to rely on their carer to provide answers for them, and had talked in more depth with the researcher prior to the interview when their carer was not in the room. In one instance it became apparent that a participant with dementia did not like discussing their care and was uneasy about the interview process, as they did not want any changes to be made to their existing arrangement. Therefore, the interview was ended after only six minutes, when the person with dementia appeared to close off the discussion:

> ‘I’m well looked after, I’m pleased. I can’t grumble at anything, so um… If that answers all your questions…’

This has clear implications for the richness and reliability of the data, as the experiences of people with dementia themselves were not explored in as much depth as those of other participants. Despite these difficulties, it was felt that the inclusion of people with dementia in the research provided a valuable insight into their experiences, as the viewpoint of the person with dementia was very different to that expressed by their carer and social worker.

As previously acknowledged, the sampling frame could usefully have been widened to include personal assistants employed by agencies or via direct payments, and frontline staff members of the agency providing support to direct payment recipients in Worcestershire. This would have provided additional insight into the research issue; however due to time constraints it was not practical to include these groups in the present study.

4.6 Recording method

All interviews and both focus groups were recorded using a digital voice recorder, in order to provide a complete, accurate and objective record of each discussion. This approach enabled the interviewer to concentrate fully on the interview and thus to maintain the conversational flow, follow up on important points, and prompt and probe responses when needed. Having an audio record of each discussion allowed for the re-examination of interview data, thus providing an opportunity for theoretical sampling, as the researcher could follow up new ideas by sampling data from previously analysed interviews to develop the emerging theory. Audio recording enabled the transcription of all interviews verbatim, facilitating thorough analysis. Although transcribing was an extremely time consuming process it was found that the actual act of transcription aided analysis, as it enabled the researcher to become very familiar with the data, tentatively identify emerging themes, and make comparisons between the experiences of different participants. Re-listening to the interviews also provided the researcher with the opportunity to reflect on their interviewing style and the effectiveness of the interview questions, so that this could be developed and refined for subsequent interviews.

One limitation of audio recording is that non-verbal communication is not recorded and can therefore be missing from the transcription and analysis. Although the researcher took notes where possible to record participants' body language, this was sometimes difficult to carry out without disrupting the flow of the interview. Video recording of interviews was considered but rejected, as it would have been problematic to carry out in participants' homes (where the majority said they would like to be interviewed) and could be intrusive and thus affect responses. Although all participants said that they were happy to be audio recorded and did not appear self-conscious or inhibited, it is possible that any discomfort may not have been discernible during the interview. King and Horrocks (2010) argue that 'sometimes the inhibiting effect of recording only becomes apparent when you switch the machine off and the interviewee immediately opens up with some highly relevant material' (p.45). This was the case in this research, particularly in one instance where the interviewee had seemed confident during the interview, giving detailed and insightful responses, but as soon as the voice recorder was switched off provided an additional, valuable viewpoint. A number of steps were taken by the interviewer to try to ensure participants felt at ease with being recorded. For example, confidentiality was emphasised and explained, the voice recorder was switched on prior to the commencement of the interview in order to give participants time to get used to it, and the interviewer did not draw attention to the voice recorder during the interview.

4.7 Data analysis

Verbatim transcripts of all interviews and focus groups were analysed in line with the coding procedures proposed by Strauss and Corbin (1998). The qualitative data analysis software package NVivo was used to assist with the organisation and reordering of data, as this allowed for a large number of codes to be generated and easily grouped into categories (see Appendix 11).

At the initial stage of open coding, transcripts were examined line-by-line in order to yield a large number of concepts and thus ensure openness to exploring all possibilities. This initial coding was directly grounded in the data in order to avoid the imposition of preconceived ideas on the analysis. Subsequently, axial coding was undertaken, whereby the concepts identified during open coding were grouped together into categories. Properties of each category and their dimensions, conditions and consequences were defined in terms of how they could explain direct payment uptake by social care service users with dementia living in rural communities. Memos were written throughout the process of analysis in order to help develop and define codes and categories, generate hypotheses and questions and guide theoretical sampling. Finally, the process of selective coding enabled the integration and refinement of an explanatory theory. Diagramming was used throughout analysis as a tool to refine and integrate ideas, and a visual model was developed that explained the final theory in a systematic way. One central category was identified that encompassed all other categories, and represented the core process that appeared to explain the issue under study. Superfluous concepts were excluded, and gaps in the properties and dimensions of each category were identified and filled. This was achieved through re-examination of existing data, and the addition or alteration of questions in upcoming interviews to explore relevant issues in more depth. Analysis was completed once no new information that could contribute to the theory was emerging from the data, and when all categories were sufficiently developed in order to account for variability. Therefore, it was considered that theoretical saturation was achieved as far as is possible. The theory was validated through checking to ensure it could explain the case of each service user participating, and account for variation between and within individuals.

4.8 Ethical review

4.8.1 Ethical approval

The research was granted ethical approval (with conditions) from the Social Care Research Ethics Committee approximately three weeks after the initial application was submitted, following the attendance of the researcher at an Ethics Committee meeting. The committee asked the researcher to clarify the consent procedure and the process of identifying consultees where participants lacked capacity to consent to take part in the research. All conditions were met and final ethical approval granted two months after the initial application.

4.8.2 Research governance approval

The research was granted research governance approval from Worcestershire County Council around three weeks after application. This followed the researcher's attendance at a meeting with Council staff to discuss the research procedures and how any additional workload for social work staff resulting from the research could be minimised.

4.9 Storage of data and confidentiality

All electronic data collected during the study were stored on a University computer in the researcher's office, protected by a password known only to the researcher. Paper copies of signed consent forms and attendance slips were stored securely in the researcher's office in a locked filing cabinet. All interview and focus group data were anonymised at the point of transcription. Signed consent forms and pseudonyms allocated to participants were stored separately to participant data. Individual participants will not be identified in any reports of the research unless they give written permission, and data will be held for no longer than five years from the commencement of the study.

4.10 Summary

Following assessment of the three major approaches to grounded theory against identified criteria, Straussian grounded theory was selected as it appeared to provide the best fit with this study. Centring the research on two social work teams provided an effective point of access to key stakeholders, and enabled close examination of the factors affecting uptake of direct payments. Interviews were utilised as a method of data collection as they allowed for the in-depth exploration of participants' experiences in relation to the research issue. Focus groups were also conducted to enable the inclusion of a greater number of participants and thus a wider range of experiences and perspectives, making findings more generalisable. Verbatim transcripts of the interviews and focus groups were coded and categorised, in order to develop a theory to explain uptake of direct payments by people with dementia living in rural communities. The next chapter presents the theory developed as a result of this research, and identifies key influences on the decisions made by people with dementia and their families in relation to the management of their care.

Chapter 5

Part 1 – Research Study

Results and Discussion

Four key influences on the social care decision-making process of people with dementia and their carers were identified, namely the offering of direct payments, services users’ and carers’ acceptance of their situation, the weighing up of the perceived benefits and drawbacks of direct payments, and the judgement of service users and carers as to their ability to manage this option. It was identified that care managed by the Local Authority is set as the default route for service users, while direct payments tend to be perceived as a second option. Research findings were used to develop a theory to explain direct payment uptake by service users with dementia in rural communities.

Each of the four key influences are presented and discussed with reference to existing literature in sections one to four. The theory developed from the identified influences is outlined in section five, illustrated by two participant case studies in section six.

Quotes from interview and focus group participants included throughout this chapter are labelled with an alphanumeric code so that the participant group and individual contributions can be identified (see Table 12). Pseudonyms are used in all cases where names have been mentioned. Within each cohort, triads (comprising a person with dementia, their carer and their social worker) have been labelled alphabetically. For example, a quote from a person with dementia in the first triad of Group 1 would be labelled PWD1A, while a quote from their carer would be labelled C1A. Focus group participants have been individually labelled alphabetically.

Table 12: Key

	Person with dementia	**Carer**	**Social worker**
Cohort 1: Where the person with dementia was in receipt of Local Authority social care but had opted not to take up direct payments	PWD1	C1	SW1
Cohort 2: Where the person with dementia was in receipt of direct payments for their social care	PWD2	C2	SW2
Cohort 3: Where the person with dementia was entirely funding their own social care as they were ineligible for care from the Local Authority due to their personal funds	PWD3	C3	SW3
Focus group 1: Social work staff from Team 1 who took part in a focus group			FG1
Focus group 2: Social work staff from Team 2 who took part in a focus group			FG2

5.1 Offering of direct payments

The way in which (and indeed whether) direct payments were offered to service users and their carers had considerable influence over take-up of this option. Four key factors outlined in this section affected uptake; namely the selective offering of direct payments by social workers, the timing of the offer, the precedence assigned to direct payments as an option, and the extent to which social workers promoted direct payments.

5.1.1 Selective offering

Whether service users and their families were offered direct payments was a clear influence on uptake. In all cases in this research, direct payment recipients had been offered this option by their social worker, with no examples of service users who had entered the social care system already aware of this route. Examination of younger service user groups may have yielded cases such as these, for example where younger carers or service users themselves had become aware of direct payments via their current profession or networks, or had conducted their own research on the Internet. It is suggested (Baxter &

Glendinning, 2011) that the latter is an activity carried out less often by older people when seeking information about their support options. Previous research (Dewar et al., 2005) indicates that awareness of direct payments is considerably lower amongst older service users than their younger counterparts. For the service user group sampled in this research, direct payments not being presented to them by their social worker tended to preclude them from taking up this option. In three of four cases where service users had not taken up direct payments, they or their carers initially reported not having been offered this option by their social worker, and were not aware that managing their own care was a possibility. Even where carers themselves had previously worked in the care sector, there was a reliance on social workers for up to date information:

> '... how do you know these things until some social worker says oh she might be entitled to this or that, you know what I mean? ... [16] It's all down to the social workers really' (C2D1[17])

Further exploration indicated that direct payments may be offered selectively by social workers, who made decisions based on perceived suitability of the service user (primarily whether they had a carer willing and able to take on the direct payment on their behalf) and on their own judgement as to whether direct payments would be beneficial for the family in question (sometimes due to real concerns about the availability of appropriate services). This is in line with previous research, which indicates that some social workers only offer direct payments to service users they consider able to cope (e.g. Glendinning et al., 2008; Laybourne et al., 2014; Mind, 2009), or to those they feel would benefit from this option (Newbigging & Lowe, 2005; Spandler & Vick, 2004). In particular, there is a perception amongst social care practitioners that the majority of older service users would be unable to manage direct payments (e.g. Clark et al., 2004; Moran et al., 2013; Vick et al., 2006).

> 'I try and [offer direct payments to] most people where I can. But it just depends on if there is a suitable person involved really, that I feel would be able to take that budget on' (SW2B)

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[16] Ellipses are used to denote where words have been omitted from participant quotes.

[17] Where separate interviews were conducted with more than one carer of the same person with dementia, a number has been added to the end of the label to distinguish between participants.

This indicates a paternalistic attitude on the part of social workers, whereby the decision as to whether to take up a direct payment is taken out of the service user’s control. It was identified in the literature (Dawson, 2000) at a relatively early stage following the implementation of direct payments that social workers acted as gatekeepers, withholding the choice of self-directed support from service users they perceived as incapable. This paternalism appears to be a persisting key issue throughout health and social care. For example, a recent scrutiny report of the implementation of the Mental Capacity Act 2005 (United Kingdom Parliament, 2014) highlighted that ‘prevailing professional cultures of risk aversion and paternalism have inhibited the aspiration of empowerment from being realised’ (p.24).

5.1.2 Timing

The timing of the offer of direct payments was an important influence on the decision-making of service users and their families; however there was some debate as to the optimal time that this should be carried out, with the suggestion that this may differ on a case-by-case basis. In some cases it may be beneficial for direct payments to be offered as soon as possible, in order to allow service users time to start thinking about managing their own care and to raise any questions with their social worker. In support of this, several family carers commented that they would have taken up direct payments on behalf of their relative at an earlier date had they been aware of this option. Social work staff suggested that direct payments may not be offered initially by all practitioners due to their limited experience in this area (e.g. if they perceive the set-up process and necessary paperwork as complicated), and that this practice may change over time as experience increases.

Conversely, other families acknowledged that they may not have taken up direct payments at an earlier stage if offered, as they needed time to get used to receiving care in the first instance. In these cases, taking on direct payments was described as part of a wider process that they had taken ‘one step at a time’ (C2F), the first step being approaching Social Services for care, the second receiving care, and the third taking on the management of the care:

> ‘We may well have [taken up direct payments at an earlier stage if they were offered]… but… I think it was just one step at a time... I think we had to go through a couple of stages before we got to that point’ (C2F)

Furthermore, the first visit to a service user by their social worker may not always be the most appropriate time to present direct payments as an option. For example, carers often approached Social Services when they were at crisis point or at a time when they felt overwhelmed with caring responsibilities:

> ‘Dad’s dementia was that bad, that me and Mum were just like, our brains were like jelly, we were racing round here and there, so I wouldn’t have had the clarity of mind to have gone, “Yeah, we could do [direct payments], and that would be easier”. It was sort of a, “Oh no, leave it as it is, and when it calms down a bit or he’s in respite, then we can have a look at that”. Which is what we did’ (C2C)

> ‘They were offered the direct payment [in the first place]… But they were going through so much trauma… That they couldn’t, I suppose they just didn’t feel as if they could be taking on board anything else at that time’ (SW2F)

As in previous research (Glendinning et al., 2008), difficulty in presenting direct payments at crisis point was a key issue raised by social work staff, who suggested that service users and their families needed time to process their current situation before they could absorb new information and consider this option. Practitioners identified that they felt uncomfortable offering direct payments at what they perceived as an inappropriate time. They suggested that if they were trusted in their judgement as professionals, there would be increased scope and flexibility to present this option at a more suitable time when service users were more open to and ready to consider the idea, which may increase uptake. Some social workers made a point of revisiting service users once any crisis had passed and when fully managed care was in place, so that they could offer direct payments at a time when families were more able to consider this option.

> '…sometimes it's a case of saying well these are direct payments, this is what it's about, but then a few months later when things are more settled, going back and re-talking about the possibility' (SW1D)

Offering direct payments once a care package had been set up was a positive approach in some cases, possibly as families were more able to see the potential benefits of this choice once they had encountered any issues with fully managed care. However, pressure to close cases quickly meant that offering direct payments at a later date was not always possible.

> '… the pressure on us is to open a case, assess the case, review the case, close the case. And that doesn't allow you another window of opportunity maybe three months down the line when somebody could go back… [because service users] just disappear into the reviewing system…' (FG2G)

Social work staff noted that in some cases, direct payments were not re-offered to service users when their case was reviewed annually. They proposed that this could be due to organisational issues, whereby service users 'disappeared' into the system and the option of direct payments was not raised by other practitioners. Alternatively it was suggested that practitioners may believe that after a year service users would still not be interested in this option, for example if they appeared satisfied with their existing care. This indicates that there may be missed opportunities within the system to re-offer direct payments and potentially increase uptake.

However, even where direct payments were offered at the review stage or once care had been set up, this was acknowledged as problematic by social work staff, who were faced 'too late' with service users already in receipt of the default option of a managed care package (which unlike direct payments could be put in place immediately in an emergency). Families in this situation tended not to want to change their existing arrangements unless they had experienced problems:

> '… in most cases once people [have] tried fully supported they are quite happy with that and they'll just say "Better the devil you know"' (SW2E)

In line with this, social work staff identified that direct payments may even be rejected by service users who had made the decision to take up this option, but had an interim package of care in place in the meantime which they became satisfied with and did not want to change.

Having time to decide whether to take up direct payments was a further influence on the decision-making process, with some social workers describing service users and carers as ‘coming round’ to the idea over time. In addition, the complexity of direct payments meant that some families preferred to receive information in stages, so that they did not become confused and overwhelmed with a large amount of material. In line with this, some social workers reported finding it useful to mention direct payments to service users and leave information for them to absorb, giving them time to generate questions, before revisiting the idea at a later date. However it was acknowledged that although this was effective in some cases, some service users who were initially open to the idea of direct payments changed their minds after having time to think about this option. Moreover, allowing time for service users to make this decision was difficult for social workers to fit into an already busy workload.

5.1.3 Precedence

Whether direct payments were offered as a first, equal or secondary option influenced the extent to which service users and their carers were enabled to make a genuine choice about how their care was managed. In some cases, direct payments and fully managed care were presented as equal options by social workers, with a balanced outline of the benefits and drawbacks of each. However it emerged, in line with previous research (Clark et al., 2004; Vick et al., 2006), that direct payments were not always presented initially (as social work staff acknowledged was the official policy), but sometimes only as a fallback option after service users had experienced problems with their existing care, or where more hours of care were needed than could be provided via statutory services.

> ‘… originally they asked for some day care and some respite so we looked at that, and then when that, that didn’t really work, we, y’know I decide-, well ok instead we can, we can do direct payment, just as easily, and you’ll have more choice in what you want to do…’ (SW2B)

> '… we tried all the other options, and [direct payments] was like the final thing really' (SW2F)

This suggests that service users who do not first experience problems with fully managed care may not always be given the opportunity to consider direct payments as an alternative option. Nevertheless, in some cases even where direct payments were offered initially by their social worker, service users and carers themselves did not consider this option until they had experienced problems with their care and approached their social worker again to ask for a solution.

> '[The care] wasn't being done properly, it was rushed, er [Mum and Dad] were getting nerved to hell, they didn't want it at all, they were like, "No, I'm sick of this, and I don't want it. Just cancel it all". And I thought, there's no way we can cancel it all, we need, I need help, I was bloody exhausted. So it was a bit of… a cry to help to [the social worker], just to say, what the hell are we gonna do?... And she just said, "You're better off doing it yourself… There is an option… Have you thought more about the direct payments?"' (C2C)

Social work staff acknowledged that direct payments being viewed as a second option was particularly the case in older persons' services, as previously highlighted (Newbronner et al., 2011; Vick et al., 2006), as this group were seen as less inclined to want control over their care. This was the case for some (although not all) service users and their partners in this research, who tended to pass on decisions to their children due to anxiety or a lack of desire to take on the management of their own care.

> 'My perception is that [in physical disability services it is] much more towards, "We'll do a direct payment… but if we can't do that we'll do fully supported". Whereas I think [in older people's services], we have a tendency to do fully supported, oh if we can't do that we'll do a direct payment. So I think there, there's a different emphasis there. But I think that's a drive from the physical disability lobby… whereas older people traditionally I think are less vocal about how they want their services delivered' (FG1E)

Consistent with this, evidence (Clark et al., 2004) suggests that direct payments are not embedded in the culture of older persons' social work teams, with practitioners working with this service user group identified as particularly risk averse (Glendinning et al., 2008).

5.1.4 Promotion

The way in which direct payments were presented to service users and carers by their social workers was a key influence on their decision-making. In support of this, previous research suggests that where direct payments are poorly presented this can be a barrier to uptake (e.g. Henwood & Hudson, 2009; Kinnaird, 2010; OPM, 2010). In all cases in this research where direct payments had been taken up, this option had been actively promoted by the social worker involved. However, promotion of direct payments varied amongst practitioners, with some highlighting the potential benefits and providing encouragement to service users, while others gave little information about this option.

Where social workers positively promoted direct payments they tended to emphasise the benefits of this route while outlining the drawbacks of managed care. Often comparisons were drawn between the flexibility and spontaneity allowed by direct payments, and the constraints of a set care package. The financial advantages of direct payments were discussed, with social workers highlighting that service users could procure more hours of care for their money using a direct payment than via a fully supported package. Promoting the benefits of direct payments was shown to be an effective approach in some instances, encouraging families to take up this option:

> '… when the social worker said we'd be able to get more hours for our money, I thought well let's try it' (C2E)

Some social workers tailored promotion of direct payments to the individual situation of the service user and their family, outlining how this option could address any problems they had experienced and benefit them personally:

> '… they were on fully supported… and it felt very comfortable for them… However, the downside of that was they were unhappy with the times, they were unhappy with the inconsistency, the, the carers coming in. I said a direct

> payment would put you in control and give you the flexibility… so I promoted it from that stance' (SW2C)

Using examples of cases where direct payments had worked well was an effective approach, as it allowed service users and carers to relate the potential benefits of direct payments to their own situation, and could persuade them to take up this option as it had worked well for others. However, this method was more open to social workers with first-hand experience of supporting direct payment recipients than to their less experienced counterparts. In some instances direct payments were perceived by families as the only option in any case, for example where more hours of support were needed than could be provided directly by the Local Authority.

Drawbacks of direct payments tended to be glossed over in favour of the potential benefits, with one social worker describing the difficulty in providing a balance between a realistic portrayal of the issues service users may need to consider (such as arranging cover for staff sickness and holidays) and presenting direct payments positively:

> '… if you start talking about those kind of intricacies at the start, it puts people off. That's the trouble. So it's, there's a happy medium about being realistic about it, but um putting a positive light, and not saying too much about the n-, the possible drawbacks' (SW1C)

In order to overcome this issue, social workers focused on the advantages of direct payments, with minimisation of or reassurance given relating to the more daunting aspects. Where drawbacks of direct payments were presented they tended to be discussed in a positive light. For example, in one case having to take on the responsibility of being an employer was promoted as giving the family carer the opportunity to be in control and to know that tax and national insurance were being paid correctly.

The persistence of social workers was helpful in encouraging take-up of direct payments, with examples identified of service users who were re-offered and took up direct payments at a later date after refusing this option initially. Some practitioners revisited service users to explain direct payments for a second time if they had difficulty understanding this option, which was found to be a successful approach. In addition, some social workers who picked up new cases for review were proactive in encouraging service users to consider direct payments where they were already receiving managed care, for example by highlighting how direct payments could solve any problems they were experiencing. In some cases practitioners went to great lengths to think creatively about how direct payments could work for service users in complex situations, although they recognised that this made their work more difficult. These social workers seemed to have a particularly positive attitude towards direct payments, which influenced the effort they put into encouraging service users to take up this option.

It was highlighted by service users and carers that face-to-face discussions with social workers would be their preferred way of being offered direct payments. In line with this, social workers successfully supporting families to take up this option reported that rather than providing written information alone, giving time to service users to provide reassurance, encouragement and to answer questions was invaluable.

Although promotion and encouragement to take up direct payments was effective in encouraging some families to select this option, others chose not to take up direct payments despite the presence of an encouraging social worker, in consideration of other factors such as the additional work direct payments would mean for them.

While presentation of direct payments was generally positive, in some cases social workers did not provide service users and their families with any information about this option, or introduced the idea as an afterthought with little discussion of the choices available. The way in which and indeed whether social workers presented direct payments to service users was influenced by their perceived role in offering options for social care. For example, some saw their role as being to promote take-up of direct payments and to discourage service users from taking up managed care, while as previously discussed others acted as gatekeepers, making judgements as to the best option for service users.

> ‘…obviously we are also being encouraged that really everybody should be having a direct payment. We should be discouraging people from having fully supported, unless absolutely necessary’ (SW2A)

> '[I would] consider that maybe a direct payment might be the best route, but also… think, right, ok professional judgement: you know, maybe it's not… I would consider a direct payment, if… it's the right way to go' (FG2E)

Furthermore, while no social work staff in this study disclosed a negative attitude towards direct payments (although this may have been due to sampling or social desirability response bias), some viewed this option as less appropriate with an older service user group. For example, they proposed that older people may be less willing to take up direct payments than their younger counterparts, less able to manage their own care, or that they would gain little benefit from this option. Even social workers who presented direct payments positively to some service users acknowledged that they would not promote direct payments for others they did not consider suitable, for example those they did not consider capable of managing their own care. Previous research has suggested that this may mean direct payments are not always offered to older service users (e.g. Newbronner et al., 2011; OPM, 2010; Routledge & Carr, 2013; Vick et al., 2006), in turn resulting in lower uptake amongst this group. However, there is evidence to suggest that the majority of older people opt not to take up direct payments even where this option is offered (Clark et al., 2004).

Some social workers in this research did report that they offered direct payments even to service users they considered unsuitable or to those they thought would not benefit from this option. Nevertheless, in three of the four cases where service users were receiving fully managed care, the carer or service user initially claimed not to have been offered direct payments. However, in some cases after further discussion it was acknowledged that direct payments had in fact been mentioned by their social worker. This suggests that practitioners not considering direct payments for particular service users may present direct payments in such a way that this is not considered as a real option by the service user. For example, direct payments may be briefly mentioned and dismissed, and not offered again at a later date.

> 'Um, so the conversation [with the social worker went] like, "Well you wouldn't want direct [payments] would you? Because it's pointless having them (laughs). Because you were just getting… the service and the service could be paid for internally"… I can't really remember. But it wasn't anything

> more than just a c-, a comment I would think… It was like an assumption that [fully managed care] is the best way to pay for what you're doing, right. For me, it would've been quite useful to've known all the different ways and what the choices were' (C1C)

Social workers' confidence and experience in presenting direct payments was a key influence on the way they carried out this task. For example, one social worker acknowledged that she had started to offer direct payments more often as she became more confident in her ability to give the correct information and answer any questions that arose. In addition, those with experience of supporting service users on direct payments reported that observing the resulting benefits first-hand had encouraged them to promote this option to other service users, and was useful in providing them with real examples to illustrate how direct payments had worked well. Social workers with such experience tended to be overwhelmingly positive about direct payments:

> 'I think I [get more job satisfaction] when people [take up] direct payments… you come out of that house you know with a smile… a sense of achievement… and once [it] is set up you know you can actually see the benefits as well and then you can get the feedback from the family that "Oh, this is working really well" and you know you'll be proud of yourself' (SW2E)

Furthermore, those who had previously experienced issues with agency care identified that this motivated them to promote direct payments, in order to prevent other service users encountering similar problems:

> '… if you're going straight down the fully-supported route, you're gonna end up with… We can all look at the list of agencies and I'll go, "Oh, well we're gonna get a few phone calls about that one". So… sometimes you really do say… "Now come on folks, this is good for you! This is really gonna work really, really well"… Because you're aware of some of the pitfalls if they just go down that fully supported route' (FG2G)

Contrary to previous research (Henwood & Hudson, 2009; Ridley et al., 2011; Spandler & Vick, 2004; Wilberforce et al., 2012), which suggests some resistance to direct payments on the part of practitioners due to concerns about the potential for an increased workload, no evidence of this attitude was found in the current study. This may have been due to social desirability response bias; however self-reports of social workers' behaviours and experiences in practice situations were in line with the attitudes they disclosed. In addition, they were open in disclosing 'non-desirable' behaviours in some instances, such as that they did not promote direct payments to all service users, despite acknowledging that this practice was contrary to official policy. Therefore, the identified lack of resistance to direct payments may have been due to the fact that participating social work staff, particularly those with experience of supporting direct payment recipients, were genuinely positive about the benefits of self-directed support. This may have in part been a result of sampling bias, whereby those who held a positive attitude towards direct payments may have been more likely to volunteer to take part in the research. Some social work staff identified themselves as being 'pro' direct payments, despite their acknowledgement that the processes involved could add to their workload. They suggested that due to the increased work involved in setting up direct payments, social work staff who did promote this option to service users would need to be particularly proactive and positive. Conversely, it was highlighted in some cases that direct payments could actually reduce practitioners' workload, as service users who took up this option tended to raise fewer complaints about their care:

> 'I used to get a lot of phone calls… from the daughter, complaining about the care agency coming late, maybe no carer turning up at weekends… so we did direct payments and um… I've never had a call since after the last review! (laughs)' (FG2I)

5.2 Acceptance of current situation

Service users and carers' acceptance of their current situation was an influence on direct payment uptake, specifically their satisfaction with the care they were receiving and their desire for change; two factors which are discussed in this section.

5.2.1 Satisfaction

Service users and carers who had opted not to take up direct payments tended to cite satisfaction with their current care as a contributory factor to their decision. Chiefly this was due to their satisfaction with the carers who visited rather than with the care organisation itself, which was often a source of dissatisfaction. This is consistent with previous research (e.g. Glendinning et al., 2008; Lakey & Saunders, 2011; Sense, 2008), which indicates that service users who are satisfied with their existing care may often be reluctant to make changes. In this research, the relationship between agency carers and the person with dementia was a particularly important consideration, with the rapport and familiarity built up meaning that service users had become more comfortable accepting care, and were more responsive to visiting carers. Although continuity of agency carers was commonly an issue, there were some instances where this had been maintained well:

> ‘[Clara’s] brilliant. She’s been coming ever since er we started the care. She knows Auntie Myr… and they’ve got a good relationship now. Auntie Myr thinks she’s known her all her life. “Oh I’ve known her for years” she said, you know. I mean she’s only been coming since er Christmas, but that’s the sort of… relationship that they’ve built up. And that’s what you need’ (C1D)

However, it was difficult to determine whether service users were satisfied or grateful that they were receiving care per se, or that they were particularly happy with the care they personally received and could not have been more satisfied had they taken up a direct payment.

> ‘I have very good care, you know… they come, they do what they want to do, help me a lot. I can’t say any more than that, can I? I’m very pleased with them anyway. Um, I can’t fault ‘em at all. So that’s something isn’t it?... I’m happy anyway, as I am I think’ (PWD1A)

Satisfaction was reported in general rather than specific terms: ‘they’re pretty good’ (C1A); ‘they’re very good girls’ (PWD1B), which may not give an accurate reflection of the actual care experienced. It is proposed (Willis, Evandrou, Pathak & Khambhaita, 2015) that global ratings of satisfaction can mask negative experiences, as respondents may tend to consider the best and minimise the worst experiences of the service they are rating. Furthermore, reported satisfaction in social care settings is generally high, even where service users’ needs are not met (Allen, Hogg & Peace, 1992), with older people tending to report higher levels of satisfaction than those in younger age groups (Judge & Solomon, 1993; Khayat & Salter, 1994). Further research (Callaghan et al., 2012) indicates that older service users in particular may tend to tolerate unsatisfactory services. Bauld, Chesterman and Judge (2000) suggest that as satisfaction ratings given by older service users are uniformly high, they may not always accurately reflect service quality. They propose that older people tend to be more prone to social desirability bias, providing responses that they believe are desired by the researcher, giving several possible reasons for this. First they suggest that older people may be fearful of reprisal from their service provider should they criticise the services they are receiving. For example, there may be particular reluctance to give any criticism of individual home carers (Allen et al., 1992), due to anxieties about making this relationship difficult in the future. Second, those receiving care funded by the Local Authority may be less willing to report dissatisfaction as they do not feel entitled to comment on the quality of their services. Lastly, older people's often low expectations of service quality (Nocon & Qureshi, 1996), possibly due to a lack of knowledge of the quality they should expect or the standard of available alternatives, may mean that they report higher satisfaction as their expectations have a higher likelihood of being met.

Where service users and carers saw no need to change the care they were already receiving they were unlikely to agree to move to direct payments, and in some cases this option was only contemplated after service users had experienced considerable problems with their existing care. Samuelson and Zeckhauser (1988) identified that in decision-making, people disproportionately choose to maintain their present situation, terming this the 'status quo bias'. Therefore, even where other options could provide a better outcome, people tend to prefer their existing service (Hartman, Doane & Woo, 1991). Without any 'push factors' causing consideration of direct payments, some social work staff too could not see any reason for service users to take up this option:

> 'The package of care that she's got is stable, she likes it, the family… are fine, they think that Mrs Jacobs' care needs are being met, I don't see there would be any benefits at all at this stage to go down the direct payment route'
> (SW1A)

No examples were observed of service users and carers who were satisfied with their care but still chose to take up direct payments, while all those who had moved onto direct payments following fully managed care reported some level of dissatisfaction with the care they had previously received. This was not always wholly due to issues with the care provided per se, but in some cases where Local Authority care was not suited to the particular family, for example where the person with dementia preferred having family members rather than agency staff as carers.

Family carers of direct payment recipients who had previously experienced care managed by the Local Authority cited a range of problems they encountered, which had contributed to their decision to take up self-directed support. A major issue identified was the lack of continuity and therefore familiarity of care agency staff, where the person with dementia had been visited by a large number of carers and was unable to get to know them well, and did not know who would be visiting next. This caused particular problems as new carers needed to learn routines and find their way around the service user’s home, which took up valuable limited care time and resulted in lower quality care for the person with dementia. Social workers and family carers suggested that service users with dementia tended to be more responsive to familiar carers, and that continuity was particularly important for this group.

> ‘... if they’re new carers, er that’s a problem... if she sees a new face... she’s more resistant I think to, to support with new people, basically. Until she gets to know ’em’ (SW1D)

> ‘... we found with the agency that you know, there could be twenty different people coming... it is much better just having... a few people I think, anyway. Especially with people with dementia... like my father... he can recognise the three ladies that are there all the time, but he, with the agency... he wouldn’t know one from the other really’ (C2E)

In addition to the person with dementia getting to know the carers, it was important for the carer to become familiar with the person with dementia and how they liked to carry out their daily activities, to ensure that care was provided in a person-centred way.

> ‘...when the agency brings in... somebody new, that tends to cause a bit of er mayhem, in the household there. Because, y’know, Mike’s not used to them. Um, and that person isn’t used to Mike... it has caused problems’ (SW2B)

Lack of carer continuity also had an effect on family carers living with the person with dementia. Some found that simply having agency carers in their home was a source of stress, describing this as invading their space and privacy, and fearing a loss of control.

> '… we went through a period… where I had that many different people coming in this house, two at a time, three times a day, I mean I've had as many as six or eight people in this house in three days. Different people. And I used to be w-, s-, worried who the hell was coming and my wife was that frightened she didn't know who she was attending to. And I got fed up… well I got to feel that the house didn't belong to me!' (C1C)

A further source of dissatisfaction with agency care was the inconvenient or inconsistent timings of care visits, for example carers visiting too early in the evenings to put the service user to bed, or too late in the mornings to assist with washing and dressing.

> '… they don't get the wife up in the morning 'til eleven o'clock. And to come in at half past six, which is only six hours away, it means she's spending seventeen hours a day in bed. I mean I don't agree on that' (C1C)

Family carers saw the inflexibility of agency care as a compromise, as they had to fit in with the available times of the agency rather than arranging visits to suit their own routine. Travelling time was often not taken into account when agencies organised visits; therefore carers were inevitably late. This had meant that service users with dementia had experienced irregular meals, were sometimes left in bed in the morning for long periods, or went to bed fully dressed where carers had not arrived to assist them in getting ready for bed. Furthermore, carers often travelled a long way from outside the local area, which meant that there were sometimes problems in bad weather and that some service users had difficulty in arranging shorter calls to suit their needs.

In addition, agency carers did not always complete their allotted time or the tasks required of them, which was often only discovered by the family carer by chance while on surprise visits or following reports from neighbours. Even where carers did stay for the allocated time, this was sometimes inadequate for them to be able to satisfactorily meet the service users' needs. This was a particular problem for service users with dementia:

> ‘… somebody with dementia takes a long time to do a task, and a care agency… only have a certain amount of time… and they’d come in and they’d try and get that person to go in the bathroom, to have a shower, to have a wash, and… David wouldn’t always co-operate, but that was because of his dementia. So, really, the time that it took was a lot longer than what the care agency had, but they fit them into (sigh) a time slot’ (SW2F)

In some cases, simply having more expensive care managed by the Local Authority (rather than the more cost-effective option of direct payments) meant that the time allocated to meet service users’ needs was inadequate, as the budget could only cover limited hours of care.

Safeguarding issues were raised where agency carers were not carrying out their job adequately. For example, service users with dementia were not always able to identify where the required care was not being provided, such as when carers missed visits, only stayed for half the allotted time, or did not complete necessary tasks such as changing soiled linen, cooking meals or giving medication. There was therefore often a reliance on the family carer to check that the care provided was adequate, and to step in to provide back-up care when necessary, for example where no food had been prepared for their relative or friend.

In some cases, service users personally disliked some of the carers provided by the agency. Some found it difficult to relate to younger carers in particular, and were more resistant to receiving care from less experienced and confident carers. Furthermore, family carers suggested that some agency carers were not adequately trained to understand the needs of people with dementia, and that they were not sufficiently caring or conscientious, seeing their role just as a means of paid work rather than a vocation.

Although the majority of families with experience of care managed by the Local Authority expressed dissatisfaction to some extent, not all chose to change to direct payments. This difference in decision appeared to relate to their level of acceptance of the problems with their care, as all reported experiencing the same issues, relating to visit timings, continuity of carers and care tasks not being carried out adequately. Service users may be more accepting of problems where their care is funded by the Local Authority, if for example they do not see themselves as consumers (Barnes, Harrison, Mort & Shardlow, 1999) and feel obliged to act as grateful recipients of the care they depend on. In all but one case in this research where families had not opted to take up direct payments, some level of acceptance of the issues they had encountered was expressed, possibly increasing satisfaction and meaning that they were less likely to want to change the way their care was provided. In the remaining case, the family were dissatisfied with the care they received, but felt that taking on a direct payment would be too much responsibility. It was noted that while it appeared that service users and carers only needed to be accepting of rather than satisfied with their existing care in order to choose to continue receiving fully managed care, they needed to be dissatisfied or actively desiring change in order for direct payments to be considered. This suggests that decision-making may be weighted in favour of fully managed care.

Those who accepted problems with their care tended either to minimise any issues, for example as ‘one or two little niggles’ (C1A), or accept them as inevitable:

> ‘… one or two [carers] come now you think, “Oh it’s her again”, you know, “I could do without her!” But… you’re bound to get a bit of that’ (PWD1B)

> ‘But of course, I’m only too grateful for what they do, so I have to put up with it [inconvenient timings]’ (C1C)

It is proposed (Oliver, 1980) that satisfaction is dependent on the gap between a person’s expectations and their actual experiences. Thus satisfaction is reached where experiences are better than anticipated, and dissatisfaction where experiences fall below what is expected. In the present study it was expected (and therefore accepted) by fully managed care recipients that in receiving care from an agency, they would have to make some level of compromise (e.g. in relation to visit timings) in order to fit around other care recipients. As this group had not received care procured via direct payments, they may have accepted any problems as an inevitable part of receiving care, and not have envisaged how things could be different if they were to take up self-directed support. In contrast, families opting to take up direct payments after experiencing Local Authority managed care had been less accepting of any issues encountered:

> '… trying to deal with the Council has been laughable' (C2D2)

> 'It just didn't, it just did not work, didn't work at all' (C2F)

This group were more aware of the benefits direct payments could afford, possibly due to their prior knowledge of the care system or to greater promotion or explanation of this option by their social worker. They therefore felt that taking on the management of their relative's care could improve things, even where problems with Local Authority managed care were not insurmountable:

> '… it wasn't a decision to say we can't live with this system, it was the decision knowing that there's a better system' (C2D2)

Those dissatisfied with their care also considered the extent to which direct payments could solve the problems they were experiencing. Primarily, direct payments were viewed as a solution to the allocation of inadequate care hours, as service users could secure more care for their money if they managed the budget themselves. In some cases, direct payments enabled the service user to stay in their own home where this would not have been possible had they continued to receive fully managed care. Furthermore, by allowing service users to employ carers directly, direct payments were seen as reducing some of the problems associated with agency care, as families could choose who to employ, giving them direct control over the quality of care provided. For those experiencing difficulties due to unfamiliar carers visiting, direct payments could reduce the stress of this by allowing them to employ regular, familiar carers with whom they could build a rapport, or their own family members if this was the preferred option. Employing regular carers via direct payments also addressed practical issues relating to continuity, meaning for example that carers became familiar with the service users' routine and knew where to find and put away items in their home, which reduced the burden on the family carer. Direct payments were seen in some cases as a solution to the inflexibility of agency care. For example, whereas care agencies could not always organise care visits at a convenient time for service users, those employing their own carers via direct payments were in more of a position to dictate this.

In rural communities, direct payments were utilised as a solution to the problem of agency carers needing to travel long distances to reach clients. For example, as identified by Clark et al. (2004), they could enable service users to employ local carers with low mileage costs who could reach their home in bad weather or at short notice, and provide shorter care visits if required. In addition, whereas there may not always be a choice of care agencies able to take on clients in remote areas, direct payments could enable service users to employ local people, thus giving an element of choice.

However, where families felt that they would need to utilise a care agency if they were to take up direct payments (e.g. if they felt unable to organise rotas for a large number of carers, or wanted carers who were already trained and insured), this option was not seen as a solution to the problems they were experiencing. For example, many of the issues cited (such as lack of flexibility, having carers they disliked, expensive care costs, or carers not turning up on time or travelling from far away) would still exist if a chosen agency was used. Nevertheless, it was acknowledged by family carers and social workers that in these cases, direct payments would enable service users and carers to choose which agency to utilise and to communicate directly with the agency about any problems or changes they would like to make, giving them some level of choice and control. In some cases agencies allowed service users to request particular carers, meaning that they could be visited more often by those with whom they had a good relationship.

Participants acknowledged that direct payments could not always fully resolve service users' problems, even where they employed their own carers directly, dissuading some from taking up this option. For example, personal assistants would not necessarily be able to provide flexible care that was fully responsive to the needs of the service user, as they would still take holiday and sick leave when they would need to be replaced by other carers, thus not completely solving the issue of carer continuity.

> '… I just feel that you probably couldn't [solve the issue of carer continuity with direct payments], because… if you demanded the same people you could never have the same people. Because… they've gotta have time off… I can't see that you could ever demand that you could have the same people all the time' (C1C)

It was also acknowledged that the extent to which direct payments could solve cited problems with agency carers would depend on the quality of the personal assistant employed:

> ‘Researcher: So do you think [direct payments] could solve any of the problems that you’ve had with the care…?
>
> C1D: Um, hmm. Huh (laughs), well… only… time would tell. I mean… if the carers came at the right time and, you know, things like that, then yeah it’d be… fine. If they didn’t, then I wonder how easy it would be to get another… carer (laughs)!’

Furthermore, social work staff and family carers pointed out that direct payments alone could not provide a complete solution to the issue of service users needing 24-hour care, as the budget allocated was still inadequate to pay for this level of support. The only cases in which this was secured were where the service user received a high level of care from relatives or friends, or where care funding from the Local Authority was supplemented with personal funds.

5.2.2 Desire for change

As found in previous research (e.g. NAO, 2011; Routledge & Carr, 2013; Wood, 2010), desire for change amongst older service users and their carers in this study was generally low, with the exception of cases where there was considerable dissatisfaction with existing care. This was a clear barrier to the take-up of direct payments for those already receiving social care. It was suggested by social work staff that many service users, particularly those in the older age group, simply do not like change (rather than direct payments per se) as it provokes anxiety. It is proposed in the literature (e.g. Baxter & Glendinning, 2013; Henwood & Hudson, 2007; Manthorpe & Stevens, 2008) that this may be due to fear of losing existing services that are working well, or apprehension about unknown alternatives.

> ‘Change is hard for anyone isn’t it. It’s like moving house, I don’t like it, you know what I mean, I hate it. But you get someone sixty plus, oh, it’s like the end of the world, isn’t it? So anything that’s like that, it’s like a major change,

> they think, “Oh, well I’ve never done this’, and “I won’t be able to do this”. They would be up at night worrying about it’ (C2C)

> ‘Mr Jones is very, I mean, he’s older than Mrs Jones in fact, but he… doesn’t adapt well to change, so he doesn’t like change… any change in any part of his life, he’s very um unreceptive to. So Mr Jones himself is a barrier [to the family taking up direct payments]… even if p’raps he could see that it could be of some benefit, I think the anxiety it would cause him just thinking about change, he wouldn’t go ahead with it’ (SW1C)

This suggestion was corroborated by older service users themselves, who appeared anxious about the prospect of change:

> ‘PWD1A: I’m happy with th- with things as they are (coughs). [Inaudible] altering.
> C1A: This is nothing to do with altering anything.
> PWD1A: Oh, that’s alright then’

Although direct payments was not a change per se for those new to receiving social care, it represented a move away from the traditional model of care that families expected to receive. Social work staff suggested that some older service users had outdated expectations of the social care system as a whole, with a view that their care would be provided for them. These preconceptions may affect the likelihood of direct payment uptake. It has been recognised in previous research that both older service users and practitioners working with this group tend to be relatively conservative when making decisions about their care, often favouring traditional services (Brookes et al., 2013; Laybourne et al., 2014; Newbronner et al., 2011; Routledge & Carr, 2013).

> ‘[When personalisation] came into place it, it was exciting to think about it, to give people more… choices… more ways of enjoying life… it seemed like a great idea. Instead of a basic wash, dress… medications and out the door… it sounded really like a major str-, step forward. But when it came down to talking about it with people who were elderly people, that wasn’t really what they had in mind at all’ (SW1A)

For some who did not wish to change the way they received their care this seemed more of a negative choice, made because they wanted to avoid change, rather than due to a particular desire to maintain their existing situation. Others simply did not see the need for change as they were already receiving an adequate package of care. Where service users and their families had become familiar with agency carers and support being provided in a particular way, they were sometimes uneasy at the thought of change. It is argued (Kahneman & Tversky, 1984) that potential losses have a greater impact on decision-making than potential gains. Therefore, once service users are receiving a traditional care package they may be more reluctant to make changes, as the fear of a potential loss of existing services may tend to outweigh the perceived potential benefits of a direct payment. In line with this, social work staff reported that there was a small 'window of opportunity' in which direct payments could be promoted before service users went on to a fully managed package of care:

> 'I think if Sue had wanted to take it on board, direct payments could've worked quite well from the start. But as soon as um they had the home care in and as soon as they got used to that and that everything was working well, that's when Sue [inaudible]. If people've got a stable home care package they don't want to change it, basically. So, you lose that kind of… window of opportunity if you've got stable care going in, generally people tend to say, "Well, actually I'm happy with what I've got. It's working fine. Why would I wanna mess about with it?"' (SW1C)

Keeping familiar carers was of particular importance where service users had advanced dementia, suggesting that change might be more difficult for this group.

> '… when we did try the other agency a few weeks ago, Mrs Jones was totally unresponsive, you know, more unresponsive than normal if you like. So she obviously still has some recognition of the current carers…' (SW1C)

However, although some service users and carers expressed a dislike of change and acknowledged that setting up a direct payment was daunting in the first instance, with encouragement from their social worker some overcame these initial anxieties and went on to take up direct payments successfully. Carers also played a role in reassuring their older relative about any changes and in talking through the benefits of direct payments with them, although this was not always successful.

5.3 Evaluating net benefit of direct payments

Social work staff proposed that service users and carers went through a process of weighing up the potential benefits and drawbacks of direct payments when making decisions about their care, in order to decide whether this option would be of overall benefit to them and their family. Practitioners and family carers suggested that this presented a choice between the extra flexibility and value for money of direct payments together with the extra work this would entail, or the more straightforward but potentially less beneficial option of fully managed care.

> '… the social worker did stress that... it would be a… bit more work for me, but that ultimately we would be able to get more care, you know, more hours of care, by doing it ourself, which was the important thing really…' (C2E)

> 'If there is no family member who is quite active or willing to do managing the money, keeping the receipts, then most of the family just say "I don't really want that responsibility". You might actually find some families who are quite willing to do that because they feel that you know the advantages kind of er outweigh the disadvantages…' (SW2E)

Factors such as the budget available for service users' care were considered, with those eligible for little funding unlikely to take on the extra responsibility of direct payments for potentially limited benefit.

Although family carers in this study appeared to make a considered judgement regarding the option of direct payments, it is argued (Simon, 1957) that individuals do not always make fully rational cost-benefit analyses when faced with such decisions. For example, Simon (1957) proposes that there is a tendency to choose the first satisfactory alternative rather than spending time and effort analysing all possible options. Thus if fully-managed care is presented or considered as the primary option, families may tend to select this route rather than fully assessing the benefits of direct payments as a potential alternative.

Nevertheless, where the perceived benefits of direct payments were judged to outweigh the drawbacks, it was observed that families in the present study were more likely to take up this option. For example, in one case a service user agreed to take on the responsibility of a direct payment if it meant that he could change the timings of care visits to suit him. One family carer decided to take up direct payments because he wanted to have more direct control over the care his mother was receiving, although his initial preference had been to have the care managed by the Local Authority as he perceived this as being less work. In a further case, although the family carer found the thought of direct payments daunting, she took up this option as it enabled her to choose who to employ.

Flexibility was a key benefit of direct payments cited by participants, enabling both service users and carers to be more spontaneous in taking trips out or changing their routine. For example, changes to timings could be negotiated with personal assistants directly rather than needing to be arranged in advance via a care agency manager. This was also made easier where service users employed local carers who were more able to change visit times at short notice.

> ‘Nora knows, if there’s a football match on… she won’t get Mum into bed, no way. She’ll wanna watch it. So… she’ll say to, to Mum, “Instead of coming at five, I’ll come at half six. And then I can put you to bed at like ten, is that alright?”… You wouldn’t have that connection with an agency, would you?’ (C2C)

Being able to organise care flexibly allowed family carers to arrange more care when needed, for example when they went on holiday, and less when they were able to take on more caring responsibilities themselves. This was also a key benefit for service users with fluctuating needs, enabling them to procure more care on ‘bad’ days and less when they were more able. In addition, social work staff suggested that being able to arrange a smaller number of longer care visits rather than three calls every day could be beneficial in creating less confusion for service users with dementia, or in freeing up a larger block of time for family carers.

Familiarity was also highlighted by social work staff and family carers as a particularly important advantage of direct payments, in allowing families to recruit regular carers, which provided a more settled routine, greater continuity and less confusion for the person with dementia. This also allowed a relationship and trust to build up between families and paid carers, resulting in less stress for family carers and more security for the person with dementia.

> '… it's been very good, because [the carer is] familiar… Mrs Westlake knows her face, might not necessarily remember her name, but she knows her face. And she trusts her… That's one of the most important things really' (C2D2)

Family carers acknowledged that personal assistants' familiarity with the routine of the person with dementia and their likes and dislikes enabled higher quality, more personalised care to be provided, and in some cases meant that the person with dementia was less resistant to receiving care. One carer who used a combination of directly employed personal assistants and agency carers identified a difference in the quality of care her parents received from each set of staff:

> '… my ladies… they take more pride in, in looking after them, because they've got to know 'em, they're quite fond of Mum and Dad… it's more of a personal thing, whereas the agency staff… they just come in, do their, what they think they've got to, and then off' (C2E)

The enhanced choice offered by direct payments meant that service users could choose who they wanted to support them, which was highly valued. For example, this option enabled the recruitment of family members or friends as paid carers, which allowed service users to receive care from someone they knew well and who understood their needs.

Another recognised benefit of direct payments was that they afforded families greater control over the care provided, and the ability to resolve any problems directly or to replace carers they felt were unsuitable. Some felt that this gave them greater control over the quality of care and enabled them to procure exactly the care they wanted to suit the needs of the service user.

> '… it's the best care for Dad. That he could ever have, really... we can have [his] care tailor made for him' (C2F)

> ‘[Direct payments has] made it a hundred percent better... We know she’s being looked after properly... it’s up to us to make sure she gets the best. Whereas with the Council, you don’t even have a choice of even which local agency you use... you’re stuck with it. And now we have a choice, she gets looked after properly’ (C2D1)

Having greater control also made having outside help easier to accept for some carers:

> ‘It’s made my, my Mum’s life so much easier. She’s just less I say worked up about who’s gonna come into the house, an’ y’know, having strangers in the house and, she’s just so much more relaxed about um accepting the care I think. Because she’s in control of it’ (C2F)

For some, the deciding factor was that direct payments could enable them to procure more care. For example, they could employ personal assistants at a lower hourly rate than agency carers, or combine payments for two family members to employ joint carers for a greater number of hours. This included in some cases being able to arrange live-in care, where service users needed someone there at all times to enable them to stay in their own home. Family carers suggested that remaining in their own home was particularly important for people with dementia:

> ‘[After leaving hospital] the rise in her perception, understanding, comfort, and all the rest of it when, once she got home in familiar surroundings, was very noticeable’ (C2D2)

However, even where service users and carers could see the potential benefits of direct payments, it was not always possible for them to take up this option, as their ability to do so was dependent on the support available to them, as discussed in the next section.

When weighing up the extent to which direct payments could benefit them, a number of limitations were identified by service users and their families. For example, those who chose to continue receiving fully managed care tended not to envisage directly employing personal assistants themselves when considering direct payments, but utilising a care agency, which limited the benefits direct payments could afford. Even those who had experienced problems with agency care felt that there was little difference between agencies so did not foresee that being able to choose could significantly change the care they received. In some areas, a lack of available alternative services meant that direct payments could provide little additional choice. Furthermore, participants opting to receive fully managed care suggested that they would not make any changes to the care provided if they were to take up direct payments; therefore this option would not change the service users' life in any meaningful way. Previous research (Henwood & Hudson, 2007; Ipsos MORI, 2011; Routledge & Carr, 2013; Wood, 2010) has indicated that this is the case for a significant proportion of service users, particularly older people (Bartlett, 2009). Furthermore, retrospective studies (Glendinning et al., 2008; Wood, 2010) suggest that around a third of those in receipt of self-directed support do not make any changes to their care following uptake of this option. In the present study, some carers felt that any changes made may not affect the person with dementia in any case, for example as they did not notice the lack of carer continuity or if carers arrived late:

> '… it would be better to have the same carers but I don't think mother-in-law bothers. She doesn't seem to, to mind' (C1A)

In addition, it was suggested by family carers and social work staff that some of the benefits associated with direct payments, such as choice and control, could be experienced by those on managed care. For example, some who took this option reported that they had been able to choose from a range of agencies (although this was more limited in rural areas) or request preferred carers, and communicated directly with the agency to make changes or resolve problems.

A number of organisational barriers to the success of direct payments were also identified. For example, those who wished to continue using agency care or attend a day centre via direct payments could be charged more than those on managed care, due to block booking discounts negotiated by the Local Authority. Some care agencies charged mileage only to clients who were in receipt of direct payments or who were self-funding, which could increase the cost of care considerably, particularly for those living in rural areas, creating inequity for this group. Furthermore, whereas block booked respite care could be booked several months in advance, direct payment recipients could only book the same care around a fortnight ahead, which made it difficult for carers to arrange holidays. In certain instances, block booking meant that direct payment recipients were not able to access particular services. For example, one service user in this study received in-house specialist dementia care via the Local Authority, which could not be procured through direct payments. This appears to be an issue across local authorities, with block Local Authority contracts highlighted in a number of studies (e.g. Priestley et al., 2010; Ridley et al., 2011; Spandler & Vick, 2004; Vick et al., 2006) as a major issue affecting uptake of direct payments.

Some service users overcame the issue of block booking through using a combined direct payment, whereby they received a direct payment to pay for part of their care (such as to employ personal assistants) and had the remaining part of their budget managed by the Local Authority, thus enabling them to access block booked services such as day centres. Others in this situation simply chose to have their budget fully managed.

> ‘… they can’t have all their money as a direct payment if they want to access a specialist service like that. So it would mean them having some of the money separately and some fully supported. And once you start having to have that conversation with people, people say, “Well why would I, why would I want [a direct payment] then? You just do it all”’ (FG1E)

Where the drawbacks of direct payments were considered by the service user and their family to outweigh any benefits, they were unlikely to take up this option. The biggest drawback of direct payments cited by the majority of family carers was the extra work and responsibility involved, particularly in the light of their existing caring responsibilities. Social work staff pointed out that not all carers were willing to take on this role, even where they had identified that direct payments had the potential to benefit their relative.

> ‘[Her daughter] rang me up, and she said, “I’ve been on the Internet. Mother could have a lot more care… if we… do it ourselves. Organise it ourselves”. So I said… “Well do you want to see to it?” She said, “No!”… I said, “If you want to go down that road… then… you sort it out… but… I’m not gonna be responsible”’ (C1D)

This was particularly the case for older carers, who in some cases did not want to embark on managing a direct payment in later life unless a younger relative could take on much of the responsibility. Social work staff and family carers suggested that older people may be more anxious and less able to cope with arranging care and dealing with paperwork. This is supported by previous findings, which highlight the concerns and difficulties reported by older people themselves in relation to their ability to take on the responsibility of direct payments (Dewar et al., 2005; Moran et al., 2013; Newbronner et al., 2011; Wood, 2010). Where family carers did decide to take up this option in the present study, it was acknowledged by social workers and carers themselves that this could be beneficial for the service user but detrimental to the carer.

> '… it has been quite stressful, 'cause you know, you're employing people… it's not just um straightforward really… but… it's definitely better for Mum and Dad…' (C2E)

This is consistent with previous research, which suggests that direct payments may create extra work and stress for carers (e.g. Newbronner et al., 2011; Sense, 2008; Williams et al., 2003), particularly those who are older people themselves (Ellis, 2007). However, evidence suggests that despite the additional responsibility and work involved, direct payments may be beneficial to carers in some cases, for example in offering increased flexibility and freedom (Laybourne et al., 2014). In a randomised controlled study, it was found that carers supporting service users in receipt of individual budgets reported significantly higher quality of life and participation in their chosen activities than those caring for service users who were receiving traditional care (Jones et al., 2014).

Carers and service users mentioned a number of worries around taking on direct payments, the majority in relation to becoming an employer, which was viewed as a significant drawback of this option.

> '… you know, it's so complicated, you've got to have insurance, you've got to employ people, you've got to advertise for people… you know… everything, and if they get ma-, made redundant, er they've got redundancy, and, if they're pregnant they're allowed to have time off, and all sorts of things. Well I didn't

> wanna do that. I didn’t wanna be an employer. I didn’t want er the hassle of all that…’ (C2A)

> ‘… it would be more convenient to have the same person [as a carer]. But o-, but of course, they’d want holidays and so forth, so presumably we’d employ more than one. I don’t know how, how it would work out at all’ (PWD1B)

Using direct payments to purchase agency care rather than directly recruiting personal assistants was a popular halfway option, which allowed service users and carers more choice and control (albeit limited) without having to take on the responsibilities of being an employer. It is estimated that only one third of direct payment recipients in England employed their own staff directly in 2013 (Skills for Care, 2015).

> ‘At best [older people] might take a direct payment and use it to… purchase an agency… we don’t get many opportunities I s’pose where they actually appoint er personal assistants. Which er-, would actually give them more flexibility. ’Cause they’ll be paying less money to a PA than they will to an agency. So it’ll actually give them more time, more flexibility as well. But most people don’t wanna know about PAs…’ (SW1C)

For some, agency care was the preferred option as it was pointed out that care agencies could carry out checks on employees, ensure cover in the case of illness or holidays, and provide necessary training and insurance cover.

> ‘… they do have to have a certain amount of training and they do have to have insurance don’t they. Agencies… when you’ve got all… this medication that she has… you’ve got to have somebody who knows a little bit about it. Now I believe that they do have somebody in to talk to them about diabetes’ (C1A)

In addition, families were often more willing to take on direct payments for respite care, which was relatively straightforward to manage but provided the advantage of greater choice and control (although some preferred to leave this to their social worker).

Despite concerns expressed by family carers, in all cases in this study where service users were in receipt of fully managed care, the carer was confident that they would be able to take on the management of the care via direct payments in a practical sense; however they did not wish to take on this responsibility.

> '… I mean yeah, w-, we could do it [take on direct payments]. Wouldn't be a problem, but, as I say I didn't want the responsibility' (C1D)

Some families who had taken up direct payments saw this as the only option in their situation, for example in enabling the person with dementia to stay in their own home where a high level of care was needed, which was seen as important by service users and carers alike. A maximum of four calls a day could be provided via Local Authority managed care, which would not have been sufficient in some cases where the service user needed up to 24-hour provision. For some families this was the 'deciding factor' that led them to take up the more cost-effective option of direct payments.

> '… there was not any other way that family would have managed at home without direct payments... [they had] two options, direct payments or go to nursing home' (SW2E)

> 'I think it was probably their desperation [that made them decide to take up direct payments], because… what they'd got was not working. What they wanted they couldn't afford. So they thought that [direct payments] would probably be a way of achieving it… I think they felt that it was a last resort… I think it was a matter of hav-, this has gotta work' (SW2D)

Those who saw direct payments as the only option did not appear to weigh up the benefits and disadvantages of this, although they tended to be positive about the benefits.

> 'I didn't really consider [managed care]… It wasn't an option… [Direct payments] gave me the opportunity of organising things, and if anybody's gonna do it then I'd rather do it than somebody that is from the Council or something' (C2B)

Likewise, in one case where the family felt that a direct payment was not an option (as they would not be able to continue receiving a specialist dementia care service from the Council), they too had not weighed up the benefits and drawbacks of this route, although they were able to identify a range of potential benefits of direct payments.

Where the benefits and drawbacks of fully managed care and direct payments were viewed as equal (i.e. where both options would provide a similar quality of care), families tended to opt for fully managed care, with direct payments only considered where they could provide additional benefits. Thus fully managed care was the default option, automatically taken up unless service users and carers made an active choice to receive direct payments. It is argued (Sunstein & Thaler, 2003) that even where people appear to be granted free choice, the presence of a default option is a strong influence on their decisions. McKenzie, Liersch and Finkelstein (2006) suggest that the default option set by policymakers (in this case fully managed care) conveys an implicit message that it is the recommended choice. Furthermore it is pointed out (Shevchenko, von Helversen & Scheibehenne, 2014), as is the case here, that default options tend to maintain the status quo and require less effort to take up, making them more likely to be selected.

5.4 Perceived ability to manage direct payments

Service users and carers considered their capacity to take on the management of their care in deciding whether to opt for direct payments, including the presence of an able and willing family carer, confidence in their own ability to manage, and the availability of suitable contacts or services. This suggests that while fully managed care is open to all service users, direct payments is a more selective option limited to those with sufficient support, contacts or ability to take this route.

5.4.1 Availability of support

By far the biggest factor affecting service users' perception of their ability to manage direct payments was whether they had available support to help them do this, specifically a family carer. In support of this, previous research has highlighted that assistance from relatives is vital in enabling uptake of self-directed support (e.g. Kinnaird, 2010; Spandler & Vick, 2004; Williams et al., 2003). In all cases in this research, service users were supported by a family carer who was the key decision-maker regarding their care, as it was acknowledged that they would be responsible for managing a direct payment if it were taken up. Therefore, even where those with dementia themselves expressed a preference for direct payments, the final decision rested with their carer, with service users deferring to what they decided. For example, in one case the person with dementia said that he would like to employ his own carers so that he could have personal assistants he liked visiting every day; however he was reliant on his carer who did not want to take on the additional responsibility of employing people. There were no cases in this research where it was felt by the social worker or the family carer that the person with dementia would have been able to take on the management of direct payments alone. Therefore, it is likely that in some cases family carers may act as gatekeepers, preventing their relative from accessing direct payments where they could not manage this option without support.

> '… at the end of the day, it'll, it'll be down to [the carer] it's whether she wants to take on that er responsibility. Certainly [the service user] herself couldn't do it. She wouldn't be able to manage the financial aspects of it. Um, so it would be down to [the carer], so it, it's really about whether she feels she wants to go down that line' (SW1D)

> 'I don't think I'd have anything to do with [managing direct payments]. [My wife] would really run that side' (PWD1B)

In the majority of cases in this research, service users with dementia were not involved in the decision as to whether to take up direct payments or care managed by the Local Authority. It was suggested by practitioners that those with dementia sufficiently advanced to mean that they were eligible for care would not have the capacity to understand or engage in discussions about how their care was provided. In line with this, the only two service users with dementia able to take part in an interview for this study were eligible for care due to their physical needs rather than their dementia. Furthermore, some service users did not believe they needed any care, which was an additional barrier to their involvement in related discussions.

> '… he is aware that people come and take him out. But he would not understand the ins and outs of a direct payment and why that's there, and why

> that needs to be there to support him. Um, because, for as far as he's concerned, he's managing ok really' (SW2A)

In cases where service users were involved in the decision-making, this tended to be when their carers presented them with simplified options relating directly to the care they received.

> '[I said to Dad], "Look, this is the options. You can either [have direct payments] and then you will get certain people that you want at certain times of the day. Or, you… leave it as it [is], with the agency coming in"' (C2C)

Where possible, the carer sought agreement from the person with dementia before taking up a direct payment on their behalf, but this appeared to be on a superficial level rather than as a result of any discussion about how the care budget could be managed.

In line with previous research (Clark et al., 2004; Spandler & Vick, 2004, 2005, 2006), some social workers acknowledged that they would not have offered direct payments to service users they perceived incapable of managing, if they had not had a carer available to administer the budget on their behalf. They suggested that even service users with early stage dementia would be unable to organise and oversee their own care, for example arranging rotas and managing the financial aspects. Furthermore, both social work staff and family carers argued that service users with dementia would be unable to cope alone at home in any case.

> '… I think with dementia you definitely have to have a support system there, really… they obviously can't manage [direct payments] themselves' (SW2B)

Practitioners argued that where service users with dementia could hypothetically take up direct payments with the help of their social worker or local support organisation, they would need to sacrifice flexibility, putting in place a more rigid care package to ensure they received regular support. However, concerns were expressed that no-one would be there to oversee the care and check that personal assistants were turning up regularly. The social work staff in this research could not identify a person with dementia who had taken on direct payments independently, or whom they thought might be able to take on this role, even with the help of a support organisation.

Where service users with dementia did take up direct payments with the support of a family carer, the carer took on a management role, for example organising recruitment, troubleshooting and taking on all the associated paperwork such as payslips and timesheets. Family carers and social work staff suggested that older carers in particular may find some of these tasks difficult and experience apprehension about the financial management of the budget. Consistent with this, previous research (Dewar et al., 2005; Wood, 2010) has highlighted a number of concerns expressed by older service users related to their own ability to take on direct payments, particularly regarding the financial and employment aspects (Moran et al., 2013; Newbronner et al., 2011). Social work staff identified that it tended to be the younger generation (children or nephews or nieces) rather than the spouse who managed the direct payment on behalf of older service users, due to a perception that they would be more capable of doing so, or that the spouse would not wish to take on more responsibility than they already had.

> '… some of the things, you do need a bit of help with, I think if you're a pensioner… especially setting up the insurance… we did it on the Internet, and Mum was there, but she wouldn't have the knowledge to be able to put the Internet on. Some people do, don't they, they do these silver surfer courses, but to shop round and get a good deal on the um, liability insurance, they wouldn't do that. And they wouldn't pick up the phone and give someone their bank details over the phone to pay for it, would they? And there's nowhere you can walk in. And buy employment liability insurance, is there?' (C2C)

> '… if it was just Mum on her own… I don't think she would've [been able to manage direct payments]… Mum has got more than enough on her plate, managing Dad, than starting to worry about paying people… at her age' (C2F)

However, while wider family support is available to some service users and carers wanting to take up direct payments, not all may wish to draw on this. For example, one older carer identified that she would need the help of her children if she were to take on a direct payment on behalf of her husband, but did not want to hand on any of the stress or responsibility to them.

Although all service users in the present study had a family carer, not all were able or willing to take on the management of direct payments on behalf of their relative. Some lived too far away to be able to be involved in the day-to-day management, while others did not wish to take on the additional work and responsibility. This was particularly the case where carers felt that they should not have been left to take on the main caring role in the first place, for example where there were closer relatives who were not providing any support. It was suggested by some carers that managing direct payments was a full-time job, although others fitted it in around full-time paid employment.

> ‘How the hell can I do [direct payments] and work full time? There wasn’t the option. I was lucky that my husband was working, and that, you know, we could do it… but some families wouldn’t have that option…’ (C2C)

Social work staff proposed that a certain type of carer would be needed to take on the responsibility of direct payments. Primarily it was identified as important that they were willing and enthusiastic about doing so, for example where they could see the potential benefits.

> ‘[The gentlemen who manage the direct payment are] really good. Really. And I think that’s, that’s what you need, you need somebody willing to take it by the horns, don’t you, and really get involved with it. And they are very willing… They were just really dead keen on, they really were wanting to keep her at home, so they really wanted this to work’ (SW2D)

> ‘… the fact that [the carer] wanted to do [direct payments], that’s what made it successful… you know you want that eagerness… She wanted it to work’ (SW2C)

The experiential capital of carers was also a key factor. Existing research (Hamilton et al., 2015) suggests that for service users with high support needs, the presence of an active and informed carer substantially increases their potential to utilise personal budgets effectively.

Consistent with this, social work staff in the present study identified it as advantageous if carers were able and motivated to seek out and understand the relevant information relating to direct payments, or identify possible services to procure. Those with prior knowledge of Social Services due to previous work experience in a related field appeared to find the system easier to navigate. In some cases, carers also had experience of employing people and sorting out the related paperwork and tax, which increased their confidence in taking on a direct payment.

As family carers took on the management of care in the majority of cases, the availability of support for this group was of key importance, as acknowledged in much previous research (e.g. Hitchen, 2012; Kinnaird, 2010; Lakey & Saunders, 2011). Some received this from their social worker who provided reassurance, signposting to possible care agencies or support organisations, and practical help with paperwork. Others identified that having a good support network of family members was helpful, for example to share the workload of direct payments or to take on some of the management of the care if the main carer became ill (although not all had this advantage).

Those using the local support organisation to assist with the management of direct payments found this particularly useful, for example in providing general advice, assisting with the recruitment of personal assistants, ensuring tax and national insurance were paid correctly, writing contracts, and processing timesheets. Carers valued being able to telephone the support organisation for advice relating to specific legal issues as they arose, such as regarding their responsibilities when employees became pregnant or when they needed to make personal assistants redundant. Some acknowledged that they would have been unable to take on direct payments without the help of the support organisation, due to a lack of understanding about some of the processes involved. In addition, it was highlighted that without this support, some carers managing direct payments would have opted to use a care agency rather than employing their own personal assistants.

The support organisation provided reassurance to carers considering direct payments that they could help with any difficult issues and provide support with a range of tasks. Social workers acknowledged that raising awareness of the support organisation could result in service users being more likely to take up direct payments, as they were comforted to know that there was support available to help them. This was corroborated by service users and carers themselves:

> ‘I wasn’t sure how [direct payments] would work, how much time it would take. Because when I saw [all the information], I thought, I’m gonna be on this every day. It’s gonna take hours to sort all this out. And the legal side of it, and the wages, and all that… and then Mary [from the support organisation] came out, she said “Well look, we can do the payroll… We can d- help you with the, the tax… And that’s when I thought, “Yeah, alright, we’ll go for it”’ (C2C)

Social work staff suggested that service users with dementia could possibly take on direct payments themselves, with a high level of support from the support organisation, although they could not identify any examples where this had been the case. However, practitioners and family carers acknowledged that the charges of the support organisation would result in a reduction in the funds available to pay for care; therefore a high level of support may not be feasible. While some carers saw the support organisation charges as an acceptable cost, others felt that they would prefer to handle tasks such as payroll themselves, in order to maximise the hours of care they could procure for their relative.

> ‘… we pay for the privilege of [having support]. But I don’t mind that. I wouldn’t have a clue! I would not, I would’ve been on the phone for hours, and the Internet for hours, trying to sort it all out. And I still wouldn’t’ve been a hundred percent sure that what I was doing was legal and correct. So that’s why it’s good to have that legal knowledge and background…’ (C2C)

> ‘[The support organisation] did offer that. Um, to do the payroll and everything. But I think we sort of dismissed that quite early… saying, “Well, y’know, that’s more hours that Mum could have for care”’ (C2F)

Although the support organisation was helpful in providing reassurance to family carers considering direct payments, social workers did not always refer service users to this provision. Some identified that they would only refer those who expressed a wish to take up direct payments, possibly meaning that some service users who may have been encouraged to take this option if they had seen it as more manageable, did not do so as they were not given additional reassurance or support. In support of this, Arksey and Baxter (2012) cite several cases where service users' level of awareness of available support determined whether they opted for direct payments.

In the first six months of 2012, only 2.7% of those referred to Worcestershire County Council Social Services were referred to the local support organisation for direct payment information or support. Referrals were substantially less likely for older people (1.8%) and people with mental illness (2.4%) than for adults with physical (14.1%) or learning (23.9%) disabilities. This may be because these groups were less interested in taking up direct payments initially, or due to selective referral by social work staff. Of those referred, a large majority (85.8%) took up direct payments, suggesting that the support organisation was highly effective in encouraging take-up.

5.4.2 Confidence

Carers' confidence in their own ability to manage direct payments on behalf of their relative or friend was an important influence on their decision-making. Those who did choose to take up direct payments tended to be relatively confident in their ability to manage the budget and found it straightforward with the exception of a few minor problems. Social workers reported that carers working in management roles or those with experience of managing their own business (as was the case for half of carers of direct payment recipients in this research) tended to be more confident and easily able to manage their relative's direct payment. On the whole, carers of direct payment recipients also tended to be younger than those of service users receiving fully managed care, with current or more recent work experience, which gave them more confidence in taking on the management of something new. However, not all carers confident in their ability to manage direct payments chose to do so, primarily due to the extra work and responsibility entailed. Others acknowledged that the thought of managing direct payments was daunting at first, which led to some rejecting this option. As in previous research (e.g. Homer & Gilder, 2008; Kinnaird, 2010; Routledge & Carr, 2013), becoming an employer was the most daunting aspect of direct payments, particularly in relation to recruiting or replacing carers, and arranging cover in the case of emergencies.

> '… they worry about the responsibility… What if something happens? What if I'm liable? W-what… if the person is ill? What if the person wants to leave?... It's just really, the, the responsibility of it, that what's, what worries her… "I've never employed a person in my life"' (SW2A)

In line with existing research (e.g. Manthorpe & Stevens, 2008, 2010; Newbronner et al., 2011; Ridley et al., 2011), carers and social work staff acknowledged that recruitment could be particularly problematic in rural areas, where travelling time and costs tended to be high for potential personal assistants. This was also a concern in the two cases where service users were funding their own social care, with both utilising a local care agency, as they did not know how they would recruit their own carers:

> '[Without the care agency] I really don't know what we'd've done… I don't know… I'd've been enquiring at the GPs and everything else, you know, to see if they could give us any contacts…' (C3B)

Consistent with this, Sense (2008) and Spandler and Vick (2004) report that anticipated difficulties with the recruitment of personal assistants is a major reason for service users choosing not to take up direct payments. It has been highlighted in previous research that people with dementia in receipt of direct payments may experience particular difficulties in recruiting personal assistants with a good understanding of dementia (Henwood & Hudson, 2009; Kinnaird, 2010). Service users and family carers in the present study worried about how they would recruit good quality carers in the first instance, for example identifying the right people for the job and ensuring they were trustworthy and suitably qualified. This was partially due to concerns around having to terminate the contract of unsuitable carers.

> '… you don't know that [carers you interview are] going to be any good… that was my biggest worry… just like hairdressing you know, somebody comes and they give you a, er their um CV and it sounds great. And then they do somebody's hair and it's awful. Well that can be the same with a carer' (C1D)

Family carers found the thought of advertising for and interviewing potential employees particularly daunting.

> '… the disabled people I was saying about at this group, I mean they'd had some awful, awful ex-, you know, they'd adverti-, um interviewed a few people and… this particular man had given the job to somebody, and he had a couple of the other people ringing up and saying well, why hadn't they got the job… I thought oh my god, that'd be really frightening wouldn't it?' (C2E)

The issue of arranging cover for carers who were sick or on holiday was also identified as a key reason for rejecting direct payments, with the acknowledgement that using a care agency provided security in these instances. This was a specific concern expressed by service users and carers in previous research studies (e.g. Clark et al., 2004; Dewar et al., 2005; Sense, 2008), echoed by practitioners (Manthorpe & Stevens, 2008).

> '… my biggest worry about [taking up direct payments] is if... the carer rings up and said, "You know I'm really poorly today, I'm not gonna be able to come"… Then it would be up to me to cover for that, or get somebody to cover for that. And, you know, I think that could be potentially a very big problem… That was the reason I didn't really want to take [direct payments] on' (C1D)

To overcome this issue, one family carer employed a combination of agency carers and personal assistants on behalf of her parents who required double-up calls, to ensure that a carer would always be in attendance; a strategy previously identified by Henwood and Hudson (2009).

Some family carers lacked confidence in their ability to manage the financial or paperwork aspects of the direct payment, particularly around tax or national insurance. Carers and social work staff suggested that older people in particular may experience anxiety around taking on legal employment responsibilities, procuring liability insurance over the telephone or via the Internet, or handling large, possibly overwhelming quantities of paperwork.

> '… it is definitely more difficult I find, with older people. For them to accept a direct payment really. Once it's set up, they're not so bad. But, the set-up process they find very, they find it a very anxious time, I think' (SW2B)

> ‘… the social worker’s assured me that once [the direct payment is] set up … it’s quite easy. But it’s just for me… to take everything on board is quite difficult I think. You know. ’Cause I haven’t worked for quite a while, and I’ve been out of touch with all these sort of things… you lose your confidence really, you know, when you’re sort of at home and you, you’re not involved in work or anything…’ (C2A)

Some carers who were daunted by the thought of direct payments still chose to take them up, for example in cases where they felt that this option would improve things for their relative by enabling more care to be provided. In these cases, once the initial set-up of direct payments was complete, carers found them relatively straightforward to manage.

> ‘I thought oh, I can’t do this… it almost seemed quite overwhelming… I thought, this is gonna be really full on, I’m gonna be working on this every night, working it out. But really it’s not, it’s three days out the month, and it’s only an hour or two hours out of that day that you’re actually doing it’ (C2C)

Social workers played a role in reassuring carers that they would be able to cope with direct payments, particularly during the initial stages when they were taking in a large amount of information. They acknowledged that extra support was needed initially to reassure carers that once the direct payment had been set up it would be relatively easy to manage.

> ‘… what this family needs, is somebody to… reassure them, that [direct payments] is actually fine, and doable. And not as difficult perhaps. Maybe difficult to start up, but once it’s up and running, it should be fairly straightforward’ (SW2A)

Practical support was also provided by some social workers, who answered queries addressing specific anxieties, clarified how the budget could be spent, and helped family carers complete initial paperwork.

5.4.3 Availability of suitable contacts and services

Where service users and carers were aware of suitable contacts and services they could procure using direct payments, they were more confident about taking up this option. As discussed in the previous section, family carers' confidence in their ability to recruit personal assistants was a key concern. Some carers reported that they would not wish to 'advertise blindly' (C2E), but to employ only personal assistants already known to them or recommended via their personal contacts. In some cases, the service user or carer wished to employ family members or friends to deliver care. Therefore, the social capital of the carer (i.e. the extent of their connections and influence) affected their recruitment ability, with carers with few suitable personal contacts less likely to be able to employ previously known or personally recommended personal assistants. Research (OPM, 2010) suggests that service users' social networks are a key factor in encouraging take-up of self-directed support, with the majority of direct payment recipients employing someone previously known to them as a personal assistant (IFF Research, 2008).

> 'I wouldn't actually advertise, no. No, er, it'd have to personal ref-, it would have to be recommendation, that someone's really good, so no I wouldn't advertise. 'Cause… you don't know what you're gonna get (laughs). No' (C3A)

All of the direct payment recipients in this research who utilised personal assistants employed those previously known to them or recruited via word of mouth. For example, carers were recruited from a pool of agency or day centre staff who had previously cared for the service user, friends and family themselves, those who were already employed by the family (e.g. as a cleaner), or following recommendations from family or friends.

> '… Jane was er, Mum and Dad's old carers… when we were with the agency that they didn't really like, she was like a shining star, and she um left the company… So I said to her if she wanted a few months' work… then, you know, she could do that' (C2C)

This enabled families to employ trusted people who had an existing relationship with the person with dementia, so that they did not have the worry of potentially employing and having to dismiss unsuitable carers. Those who did recruit based on personal recommendation acknowledged that advertising for personal assistants may have been difficult in their rural community due to a lack of an available local workforce.

> ‘… we didn’t have to do it, but I think we might have had trouble advertising. I mean the ladies that we’ve got don’t live too far away, but I don’t know how they, how we’d have got them. Because they wouldn’t’ve had the local p-, you know there’s no local paper to where they are’ (C2E)

Conversely, it was suggested that word of mouth recruitment could be particularly successful in close-knit rural communities.

> ‘… my sister said there was a, a lady who lived near her, that’s been a carer for forty years, who’d retired, and was after a few hours’ (C2C)

> ‘… my brother knew somebody that dealt with dem-, dementia, and he had a word with her, and she knew of, of a few people… that’s how we took them on, word of mouth rather than advertising’ (C2E)

Those utilising care agencies via direct payments similarly chose those they were already aware of or that had been recommended to them via personal contacts. Where local care agencies were available this was considered a particular advantage as it enabled family carers to make arrangements or deal with any problems in person, and meant that agency carers themselves were more likely to be local, although this was not always the case.

Service users or carers who were not aware of any suitable contacts or services may have been less likely to take up direct payments as they could not envisage how they would manage to procure the care that they needed.

> ‘I don’t think [direct payments] would have been successful ’cause we don’t know enough pe-, the sort of people who’d want to come in… I mean we get girls here from, you know… everywhere. I don’t know how we would have found them’ (PWD1B)

Some families experienced delays in arranging care or a lack of choice as there were few care agencies providing services in their rural community. Consistent with this, previous research has highlighted that the care market is insufficiently developed to offer a choice of dementia support services, which has acted as a barrier to personalisation (Goodchild, 2011; Kinnaird, 2010; Lakey & Saunders, 2011). In the present study, it was suggested that the absence of alternative options may affect direct payment uptake where those taking up direct payments stand to gain little additional choice.

> '… it's quite a rural area so um, you're quite limited on, on the agencies and the people who're around and that doesn't make any difference whether you're self-financing, whether you're direct payment, or whether the Local Authority is organising it, 'cause it's, it's the same pool of, if you're going to an agency, it's the same agencies, isn't it' (SW3A)

Conversely, some carers chose to take up direct payments on behalf of their relative despite or even because of the fact that there were no established services in their rural area. For example, it was noted that direct payments enabled the employment of local staff, while those on managed care may experience problems due to personal assistants travelling from some distance to visit them. In support of this, it is proposed (Priestley et al., 2010) that a lack of suitable in-house services in rural communities may actually lead to social workers encouraging service users to take up direct payments so that they can procure appropriate support themselves.

Some carers chose not to take up direct payments despite being well informed about a suitable range of available local services, primarily because they did not wish to take on the responsibility of becoming an employer. It was noted that although all service users in this study lived in the same Local Authority, families' level of awareness of local services was variable. For example, those who had experience of working in a relevant field or who were proactive in finding out about alternative options tended to be more aware of what was available. Again, those with the necessary experiential capital were advantaged in this respect.

Social work staff reported that not all service users kept themselves informed of new services, in part due to outdated expectations that a single care service would be provided by the Local Authority.

> '… there's been a long history in this area: you go into Morwood Hall for respite, you go into Morwood Hall for day care. So you've also got to break that perception… it's… educating people that there are other options out there' (FG2G)

This may be due to 'institutionalised conservatism', as proposed by Henwood and Hudson (2007), who suggest that some service users find it difficult to envisage new methods of support outside traditional services. It is argued (Routledge & Carr, 2013) that older service users in particular may require help in conceiving of innovative, non-traditional support options. In addition, as acknowledged by Ipsos MORI (2011) and Lakey and Saunders (2011), finding out about available services may be particularly difficult for service users without access to the Internet. Internet access is relatively low amongst older people, with only a third of those aged 75 and over reporting having used the Internet in the first quarter of 2015, compared to the majority of those in younger age groups (ONS, 2015). Furthermore, adults aged 75 and over with a disability were considerably less likely (27%) than their non-disabled counterparts (40%) to have accessed the Internet in the same three-month period (ONS, 2015). Therefore, older disabled people appear to be particularly disadvantaged in their access to a range of relevant information when considering alternative forms of support.

5.5 Outline of theory – Direct payments as a second option (DPASO)

In line with the first aim of the research, findings were used to develop a theory to explain direct payment uptake by service users with dementia living in rural communities. The theory is underpinned by the core category **'second option'**, as receiving social care via a direct payment was often a second option both in terms of the way it was presented by social workers and considered by service users and family carers. There also appeared to be a two-tier system whereby the default 'choice' was care managed by the Local Authority, which was an option open to all, whereas direct payments could only be accessed by those with sufficient social capital.

Four categories represent the key influences on the decision-making process of people with dementia and their carers, encompassing individual, organisational and societal factors.

‘Offering’ refers to the way in which direct payments are offered to service users and their families by their social worker. Four themes were identified within this category. Firstly, *‘selective offering’* of direct payments was observed, whereby social workers made decisions as to which service users would be offered direct payments. The *‘timing’* of the offer of direct payments at the optimal point in the service user’s journey through the social care system was significant, as was the *‘precedence’* given to direct payments as an option. Finally, the quality and extent of the *‘promotion’* of direct payments by the social worker was an important influence on the decision-making of service users and family carers.

‘Acceptance’ relates to families’ acceptance of their current situation. There were two themes within this category, namely service users and carers’ *‘satisfaction’* with the care they were receiving, and their *‘desire for change’*, observed to be particularly low amongst this service user group.

‘Evaluating net benefit’ refers to the weighing up of the perceived benefits and drawbacks of direct payments by service users and their carers during the decision-making process.

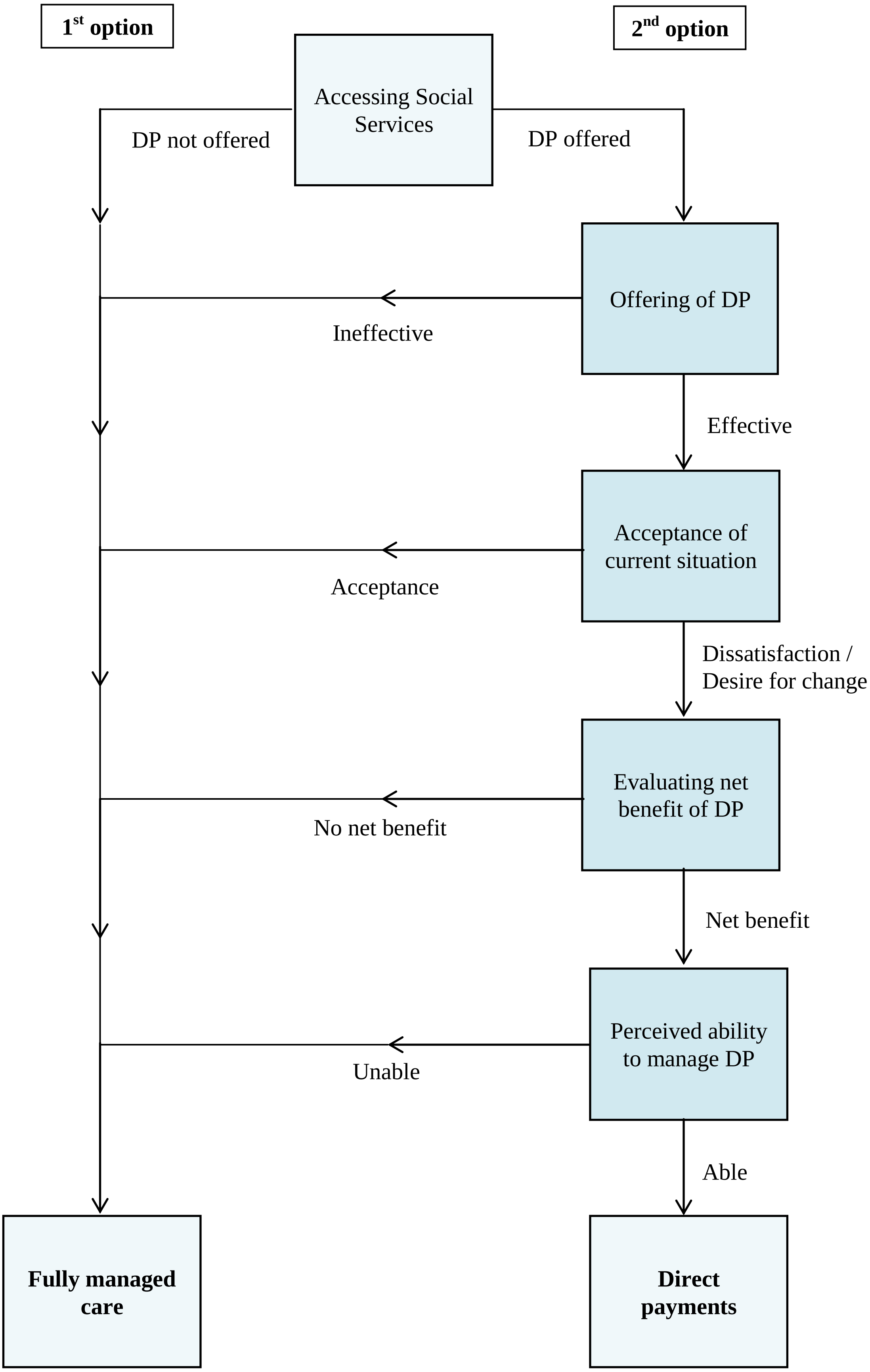
‘Perceived ability’ relates to the judgement of service users and carers as to whether they would have the ability to manage direct payments. Three themes emerged within this category. Families considered the *‘availability of support’*, for example of a family carer or a support organisation, ‘*confidence’* in their own ability to manage direct payments, and the *‘availability of suitable contacts and services’* to procure.

Figure 10 illustrates how the social care decision-making process of people with dementia and their carers is weighted towards fully managed care, with direct payments a **‘second option’**. Initially at the point of accessing social care services, some service users embark immediately on the default option of fully managed care without entering the decision-making process, as the alternative route of direct payments is not offered. If the **‘offering’** of direct payments is carried out effectively (i.e. at the optimal time and with the benefits of direct payments promoted by the social worker), service users and their families are more likely to consider this option. Conversely, if offering is ineffective, service users are more likely to move back to the default option of fully managed care. The subsequent three (interchangeable) stages of the decision-making process involve service users and carers evaluating their current situation (**‘acceptance’**), the potential benefits and drawbacks of direct payments (**‘evaluating net benefit’**), and their ability to manage direct payments (**‘perceived ability to manage’**). Here, those dissatisfied with their current situation and desiring change, holding the perception that direct payments would be of overall benefit to them, and confident in their ability to manage direct payments, are more likely to take up this option.

It was noted that families’ decision-making was weighted in favour of fully managed care. For example, it appeared that families only needed to be ‘accepting of’ rather than ‘satisfied with’ their existing situation to be more likely to take up fully managed care, while they needed to be ‘dissatisfied’ or actively ‘desiring change’ in order to be more likely to take up direct payments. Likewise, it was observed that service users and carers only needed to perceive that direct payments would be of ‘no net benefit’ to them rather than perceiving an actual ‘net loss’, in order to be more likely to take up fully managed care.

Furthermore, while in general an accumulation of several factors was necessary in order for families to make the decision to take up direct payments, it was observed that it may take only one influencing factor to lead them not to take this option. For example, service users and family carers may be offered direct payments effectively, perceive themselves able to manage this option, and be dissatisfied with their existing care, but decide that the work involved with direct payments outweighs the potential benefits, and therefore choose to take up managed care.

Figure 10: Direct payments as a second option (DPASO) - A model of the social care decision-making process of service users with dementia and their carers



5.6 Case studies

Two case studies are presented in order to illustrate the decision-making process of two families, one of whom opted to take up direct payments (see Box 3) and the other where the service user was in receipt of fully managed care (see Box 4).

Box 3: Decision-making process of a family who chose to take up direct payments

David was diagnosed with dementia 11 years ago. He lives with his wife Helen, who is his main carer, and the couple receive a lot of support from their children and grandchildren. A year ago, David’s needs increased dramatically and when Helen reached crisis point, their daughter Claire contacted Social Services to ask for help. Initially the family started receiving fully managed care, which was a big step for Helen who was anxious about outside involvement. They did not feel that they could consider direct payments at that time, although they were given information to read about this option.

However, the care the family received was not suited to their needs. The fixed times of morning visits were not compatible with David’s irregular sleep pattern, and he did not respond well to unfamiliar carers. Helen also felt uncomfortable about carers visiting their home, so the family cancelled the care package although they were still in need of support. Their social worker suggested that a direct payment could solve some of the problems they had experienced with David’s care. The family agreed that a direct payment would be beneficial for David and Helen, as it would enable them to employ familiar carers and to have the flexibility to arrange care when it was needed.

Claire took on the management of the direct payment on behalf of her parents, and reported that she found this straightforward. However, she did not think that Helen would have taken on direct payments had she not had family support. The family utilised the local support organisation to explain the process of taking up a direct payment, and Claire was made aware of the payroll support they could provide, although she has not needed to use this. The family identified a number of relatives and friends who were willing and able to provide care, who they have employed using the direct payment. This has worked well for the family, who describe the direct payment as ‘life-changing’, and report that it enables them to give David the ‘best possible care’.

Box 4: Decision-making process of a family in receipt of fully managed care

Eleanor has dementia and lives alone with the support of her daughter-in-law Caroline and other family members who live nearby. When it became apparent that Eleanor needed daily support at home, Caroline contacted Social Services and a social worker visited to complete an assessment. Following the assessment, a fully supported care package was put into place, with care visits organised at times to suit Eleanor. Although Caroline had previously worked in a related field, she was unaware of direct payments and said that this option had not been offered by the social worker involved. Conversely, their social worker reported that she had offered direct payments to the family two years after they had started receiving care, once this option had become more open for people with dementia. However, she felt that direct payments were not generally desired by older people, and did not feel that they would benefit Eleanor or Caroline in any way.

Eleanor and Caroline were both satisfied with the care provided, and accepting of any issues, describing these as ‘one or two little niggles’. Caroline reported that she would have liked to have had the option of direct payments explained to her, but like Eleanor had no desire to make any changes to the existing care.

When asked by the researcher to consider the option of direct payments, Caroline could not see that this would be of overall benefit to herself and Eleanor. She acknowledged that direct payments would give them more control, but identified a number of potential drawbacks, chiefly relating to the extra work and responsibility involved. Although she felt that having familiar carers visiting would be preferable, she did not think that Eleanor noticed the lack of continuity in her care.

Caroline felt that if she were to manage direct payments on Eleanor’s behalf she would need help to organise this, and noted that she might have problems recruiting the right people as personal assistants. She was not aware of any support organisation that could help her do this, and did not identify any possible employees from her personal contacts.

5.7 Summary

There were four key influences on the decisions made by people with dementia and their families as to whether to take up a direct payment. Firstly, the way in which direct payments were offered had a considerable effect on uptake, with evidence that some social workers presented this option selectively only to service users they considered suitable. Effective offering of direct payments occurred where the offer was made at the optimal time, where benefits of this route were promoted, and where it was presented as a primary or equal option. Secondly, service users and carers' acceptance of their current care situation was a key influence on their decision; specifically those who were satisfied with their care and had no desire to make any changes were less likely to choose to receive direct payments. Thirdly, families went through a process of weighing up the potential benefits and drawbacks of direct payments, in order to decide whether the extra flexibility and value for money they could gain were worth the extra work and responsibility involved. Finally, service users' and carers' confidence in their own ability to take on direct payments was an important factor in determining uptake, with those with perceived sufficient support and an awareness of suitable alternative services or potential employees appearing to be more likely to take up direct payments.

It was identified that direct payments tended to be a secondary option to the default route of care managed by the Local Authority, open only to those with sufficient social and experiential capital. The decision-making process of people with dementia and their carers in relation to the management of their care was weighted against direct payments. For example, those who were accepting of their current situation were likely to take up the default option of care managed by the Local Authority, while only those dissatisfied or actively desiring change tended to be more likely to take up direct payments. Furthermore, while an accumulation of several factors (such as being offered direct payments effectively, dissatisfaction with existing care and confidence in ability to manage) was necessary in order to facilitate direct payment uptake, only one unfavourable factor (such as the belief that the work involved in taking up direct payments outweighs the potential benefits) could lead to rejection of this option. In line with the second aim of the research, the next chapter outlines the methods utilised in developing, piloting and evaluating an intervention aimed at maximising access to direct payments.

Chapter 6

Part 2 – Pilot Intervention

Research Methods

Research findings from part one of the study were utilised in order to inform the building and piloting of an intervention aimed at maximising access to direct payments. It was originally intended that the intervention would focus on improving direct payment access specifically by people with dementia living in rural communities. However, due to sample limitations and time constraints, the focus was widened to include all adult social care service users living in the community. The intervention was implemented in one community social work team in Worcestershire, and was evaluated using pre and post questionnaires, interviews and statistical analysis of direct payment uptake data.

The aim of this chapter is to outline the methods utilised in building, piloting and evaluating the intervention. The chapter comprises four sections, starting with the intervention aim in section one. Section two focuses on the building of the intervention, providing an outline of the selection of an area for intervention, subsequent negotiations with Worcestershire County Council and the design of the intervention itself. This is followed in section three with an overview of the practical implementation of the intervention and details of intervention participants. The chapter concludes in section four with a description of the methods employed to evaluate the intervention.

6.1 Research aim

The aim of this part of the research was to build and pilot an intervention that can be utilised in rural communities to help ensure that access to direct payments by people with dementia is maximised.

6.2 Building the pilot intervention

6.2.1 Selection of a focus for intervention

Following analysis of findings from the initial study, three potential areas for intervention were identified (see Table 13), all of which were designed to reduce the likelihood of direct payments being presented or viewed as a second option. These areas were selected because they encompassed issues that had frequently been cited by participants as problematic in relation to direct payment uptake, and each addressed one or more of the key influences on service users' decision-making identified in the first part of the research. In addition, it was considered that an intervention with the potential to increase uptake of direct payments could be practically implemented by the researcher in each area. As the implementation of the selected intervention would need to be supported by Worcestershire County Council, the potential areas for intervention were presented to senior Council staff for feedback (see Table 13), which informed the final selection.

It was decided that social work staff (rather than people with dementia and their carers) would be the focus of the intervention and subsequent evaluation. A limitation of this approach was that it removed the focus from the specific group of service users at the centre of the research (i.e. people with dementia living in rural communities), and that the voice of individual service users with dementia and their carers was missing from the intervention evaluation. However, focusing the intervention on social work staff meant that it could have a much wider impact, as each individual staff member would come into contact with a large number of service users over the intervention period.

Table 13: Intervention ideas

Problem / area to address	Intervention idea	Council response
Some service users are using combined direct payments[18] to overcome issues such as block booking, or in instances where they would like to have more choice and control over their day activities but are reluctant to employ their own care staff. However, this option is not routinely offered by all social work staff.	Encouraging social work staff to offer combined direct payments as an option to service users who are reluctant to take up full direct payments.	This sounds a really positive approach.
Although the vast majority of service users (85.8%) who are referred to the local direct payment support organisation go on to take up direct payments, only 2.7% of all new service users are referred to this support by their social worker.	Encouraging social work staff to increase referrals to the support organisation, even where service users appear reluctant to take up direct payments.	We have always referred service users to the support organisation. Social work staff should be aware of this; however we will send a reminder.
Due to block booking of services by Worcestershire County Council, service users in receipt of direct payments may have to pay more for particular services (or be unable to access them), and are not able to book respite stays in residential and nursing homes more than a few weeks in advance.	Negotiating equitable rates and booking procedures with service providers so that service users in receipt of direct payments have the same access to services as those receiving social care managed by the Local Authority.	Commissioners are already working hard with service providers to negotiate more equitable rates for direct payment recipients.

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[18] Service users in receipt of combined direct payments receive part of their personal budget as a direct payment, while the remainder is retained and managed by the Local Authority.

As indicated in Table 13, Council staff reported that two of the three suggested areas for intervention were already being addressed internally. Therefore, it was decided that the remaining area (encouraging social work staff to offer combined direct payments as an option) would be the most appropriate for intervention. This was also the researcher's preferred approach, as it addressed a number of the barriers to direct payment uptake identified in the initial study. For example, offering combined direct payments to service users reluctant to take up full direct payments may give self-directed support more prominence in the offering process, where fully managed care was the default option. Combined direct payments could provide a more inclusive option for service users lacking the confidence, ability or necessary support to take on the full management of their care package initially. In addition, they could allow service users dissatisfied only with particular aspects of their care to make limited changes where desired, while retaining the remainder of their care package, helping to overcome issues related to block booking for example. The additional flexibility afforded by this option could enable service users to access the benefits of direct payments, such as increased choice and control, while removing some of the perceived drawbacks. For example, a service user daunted by the responsibility of becoming an employer could choose to receive domiciliary care provided by the Local Authority, while selecting and paying for their own choice of activities outside the home.

During the initial study, the researcher identified several examples of people with dementia and their families using combined direct payments flexibly to meet their needs and overcome barriers to full direct payments. For example:

- David was receiving excellent care at a specialist dementia day centre block booked by the Local Authority, but his family wanted more flexibility and control over the care he received at home. They therefore utilised a combined direct payment so that David could continue to attend the day centre twice a week while employing family members and friends to provide care in his own home.
- Paula uses a combination of agency carers and carers she employs herself to provide care at home for her parents who receive double-up calls. This makes it easier for her to organise rotas and to arrange cover if a carer is on holiday, while also ensuring her parents receive personalised care from familiar carers.

6.2.2 Negotiations with Worcestershire County Council

Although some staff members at Worcestershire County Council were positive about the selected intervention idea, senior managers within Social Services expressed concerns about social work staff offering combined direct payments as an option, as they felt that this could ‘dilute’ the Council’s promotion of full direct payments. Therefore, the researcher attended a meeting with the senior managers to address their concerns and discuss the proposed intervention in more detail. At this meeting, the researcher emphasised that social work staff participating in the proposed intervention would only be encouraged to offer combined direct payments to service users who were reluctant to take up full direct payments. It was also highlighted by the researcher that, as identified in Worcestershire County Council’s direct payments policy (WCC, 2011b), combined direct payments can ‘provide the service users or carer with the opportunity to gain experience of using Direct Payments before taking on the responsibility for arranging services to meet all their needs’ (p.5). The senior managers made several requests and suggestions, which were incorporated into the intervention by the researcher, namely:

- That part of the intervention should comprise discussion with social work staff as to how service users who take up combined direct payments could subsequently be encouraged to move on to full direct payments.
- That during the intervention the researcher should also highlight existing Council initiatives aimed at increasing direct payment uptake.
- That the Self-Directed Support Officer should be invited to intervention sessions to respond to any operational issues or queries raised by attendees, and in order to ensure that the correct messages were presented about the Council’s priorities in relation to direct payments.
- That social work staff selected for participation in the intervention should be consulted on its content to ensure it is useful in informing their practice.

It was agreed that a detailed outline of the intervention would be submitted to the Self-Directed Support Officer for approval prior to its commencement. Negotiations with the Council took around three months, which meant that the intervention was implemented later than originally planned. Following the above negotiations, the intervention and evaluation were granted research governance approval from Worcestershire County Council one month after application.

6.2.3 Ethical approval

A University of Worcester ethics checklist was completed by the researcher and signed off by the researcher’s supervisor. No major ethical issues were identified. The approved form was submitted to the Institute of Health and Society Ethics Co-ordinator, and ethical approval for the intervention and evaluation was granted.

6.2.4 Building the intervention

It was decided that the intervention would commence with an interactive session delivered by the researcher to participating social work staff. This would mark the start of a six-month intervention period, during which participants would be asked to offer combined direct payments as an option to service users reluctant to take up full direct payments. Intervention participants were requested to offer this option to all service users reluctant to take up full direct payments, rather than only those with dementia living in rural communities. This substantially increased the reach of the intervention, which would otherwise have been limited due to the small number of service users in this group. The relatively short time period available to assess the impact of the intervention also meant that it was important to maximise participation.

It is suggested (Grimshaw et al., 2001) that active intervention approaches such as educational outreach sessions are more likely to be effective than passive methods such as the dissemination of guidelines. Therefore, an interactive session was selected as an approach as it was thought that this would be more effective than written or emailed encouragement to offer combined direct payments, and thus increase staff engagement in the intervention. The session would also allow for discussion and sharing of ideas between social work staff regarding how combined direct payments could be offered to service users, which would be of practical use to them in implementing the intervention. Following consultation with senior social work managers, it was decided that the session would be two hours in duration. This was considered long enough to allow for meaningful discussion and ideas sharing, but short enough to enable social work staff to attend despite a busy workload. A six-month intervention period was selected in order to provide time for participants to change their practice and enable a sufficient amount of direct payment uptake data to be collected in order to evaluate the intervention.

Council staff initially suggested that the session be delivered as part of a pre-arranged masterclass for Advanced Social Work Practitioners and Practice Educators. However, as the target audience was frontline social work staff it was decided that it would be more effective to deliver the session to community social work teams. In order to provide a comparison for analysis, it was proposed that two of the four community social work teams in Worcestershire would participate in the intervention, with the remaining two teams acting as controls. The two teams that had participated in the initial study were selected as the intervention teams, as the researcher was in regular contact with both teams, and team members were already engaged in the research.

Designing the intervention session

Eccles, Grimshaw, Walker, Johnston and Pitts (2005) argue it is important that interventions are theoretically based, and propose three criteria for the selection of a suitable theory of behaviour change to inform intervention design. First they suggest that theories should be demonstrably effective in explaining behaviour change, second that they should include factors that are modifiable (such as attitudes), and third that they should allow for the examination of external barriers and facilitators to change. Three theories of behaviour change were considered, namely the Theory of Reasoned Action (Fishbein & Ajzen, 1975; Ajzen & Fishbein, 1980), Theory of Planned Behavior (Ajzen, 1985; 1991) and Theory of Interpersonal Behavior (Triandis, 1977). Although the Theory of Reasoned Action included modifiable factors (attitudes and subjective norms), it did not address external barriers to change. Both the Theory of Interpersonal Behavior and the Theory of Planned Behavior met each of the criteria proposed by Eccles et al. (2005), however the latter provided a more straightforward, well-defined set of variables to address, and was therefore used to inform the design of this intervention.

The Theory of Planned Behavior proposes that behaviour change has three key determinants: attitudes towards a particular behaviour based on its likely outcomes, beliefs about subjective norms, and perceived control over the behaviour based on an appraisal of potential barriers and facilitators. The intervention session was designed to address each of these determinants. In order to promote the potential positive outcomes of offering combined direct payments (addressing attitude change), a clear rationale for the intervention was presented, supported by research findings and case studies. An interactive session was planned, in which attendees were asked to share ideas as to how combined direct payments could be used creatively and effectively to provide flexible care. It was hoped that this positive, collaborative approach would encourage or reinforce the belief of social work staff that offering combined direct payments was a desired behaviour amongst their colleagues (addressing subjective norms). Barriers and facilitators to offering combined direct payments to service users (perceived control) were addressed during the session through structured ideas sharing activities and group discussions.

The intervention session was designed in collaboration with the two participating social work teams, in order to ensure its content would be useful in informing their practice, and to give social work staff greater ownership of the intervention. O'Leary (2005) proposes that the contribution of practitioners to initiatives aimed at changing their own practice can be effective in empowering them to make improvements. The researcher facilitated an informal focus group with each team, giving an outline of the proposed intervention and asking team members to make suggestions as to what they would find useful in the session, and what would need to happen to make the intervention effective. Members from both teams made similar suggestions regarding the content of the session, which were subsequently incorporated by the researcher (see Table 14). Neither team proposed any suggestions as to what would need to happen to make the intervention work, although several suggestions were made as to what could be done generally to overcome barriers to direct payment uptake.

Table 14: Social work staff suggestions for the intervention session

Intervention suggestion	Action taken
It needs to be made clear that when talking about combined direct payments you are referring to the main care package being managed partly by the Local Authority and partly by the service user, rather than instances where the main package is fully managed by the Local Authority and direct payments are utilised only for respite care.	At the beginning of the intervention session, a definition of combined direct payments was given that made this distinction clear.
It would be useful to share experiences and difficulties regarding combined direct payments, to give team members new ideas and help them to 'think outside the box'. Perhaps attendees could bring examples of challenging cases or of service users using combined direct payments innovatively, to discuss during the session.	At the intervention session, the researcher presented real examples of service users who were using combined direct payments innovatively. Attendees were asked to bring to the session examples of challenging or innovative cases of service users using combined direct payments. A significant part of the intervention session comprised discussion and ideas sharing between social work staff.
It would be useful to have a list of different day opportunities that could be purchased with a direct payment as an alternative to day centres. This is how service users would be most likely to utilise a combined direct payment, as many are daunted by the thought of employing their own carers.	The researcher created a web-based interactive map that could be utilised by social work staff to identify a variety of local day opportunities available for service users to purchase with a direct payment.

A range of delivery methods were utilised during the intervention session, including presentation of research findings and case studies, small group activities, whole group discussion, and question and answer sessions. It was thought that making the session as varied and interactive as possible would capture participants' attention and make the content more memorable, thus increasing engagement in the intervention.

6.3 Implementing the pilot intervention

6.3.1 Organisation of the intervention

Two intervention sessions were organised in collaboration with the Practice Educators of Intervention Teams 1 and 2. The researcher attended a team meeting with both teams approximately one month before the planned sessions in order to explain the research, consult social work staff regarding session content, and give team members the opportunity to ask questions about the intervention. All social work staff from both teams were invited via email and by the team Practice Educator to take part in the sessions. An information booklet about the intervention was attached to the invitation email, including information on the purpose of the intervention, a description of what would happen in the intervention and subsequent evaluation, and researcher contact details (see Appendix 12).

Intervention Team 1 had merged with another team since the initial research, and team members were based in two areas of Worcestershire. Therefore, the researcher proposed to hold two intervention sessions for Team 1, one in each area, located in Council offices where the majority of team members were based. However, senior Council staff requested that the session be held in Council offices in the centre of Worcestershire, and indicated that only one date was available due to team members attending various training courses. Perhaps due to the location of the session and the lack of choice regarding dates, only one team member attended the Team 1 intervention session. As it had taken three months to arrange a date for the session with the team, Team 1 was not included in the intervention, as there was not sufficient time in the research schedule to arrange a new date and conduct an evaluation following the subsequent six-month intervention period. The exclusion of Team 1 from the intervention limited the amount of evaluation data that could be collected from participating social work staff, which may have affected the reliability of results. The session for Team 2 was held in local Council offices where the majority of the team were based, in the centre of Area 2.

6.3.2 Delivery of the intervention session and follow-up

Prior to the beginning of the intervention session, all attendees were asked to complete an attendance slip, which asked for details of their role and experience regarding combined direct payments. A tick box was included on the slip so that participants could indicate whether they would be willing to be contacted by the researcher four to six months following the session, to take part in an interview as part of the intervention evaluation.

The session itself was split into six main parts, the key elements of which are outlined in Table 15.

Table 15: Key elements of the two-hour intervention session

Section	Key elements
Introduction	• Brief outline of session • Outline of existing Council initiatives aimed at increasing direct payment uptake • Definition of combined direct payments • Rationale for chosen intervention • Explanation of intervention evaluation measures
Research findings and case studies	• Presentation of research findings regarding barriers to direct payment uptake • Examples of service users who may be suited to combined direct payments • Examples of service users utilising combined direct payments creatively to meet their needs
Operational considerations	• Outline of when social work staff should offer combined direct payments to service users • Outline of the procedure for moving service users on from combined to full direct payments • Question and answer session
Interactive map	• Demonstration of interactive online map of day opportunities
Sharing of good practice	• Sharing ideas for offering combined direct payments to service users who are daunted by the thought of taking on direct payments • Sharing ideas of how combined direct payments could be used creatively and effectively to provide flexible care
Conclusion	• Summary of intervention • Question and answer session

All attendees were given a small reminder card to refer to throughout the intervention period, with key details of the intervention and the researcher’s contact details (see Appendix 13). Extra reminder cards were given to the team Practice Educator to distribute to the nine team members who had been unable to attend the session. In the week following the intervention session, the researcher sent an email to the whole social work team (including those who had not attended the session), with a brief outline of the key elements of the intervention, and a document containing all the ideas shared by social work staff during the session (see Appendix 14). The researcher attended a social work team meeting three months into the six-month intervention period, in order to remind team members of the intervention.

6.3.3 Intervention session participants

The session was attended by eight Registered Social Workers, one Social Work Assistant and two Student Social Workers; therefore there were eleven attendees altogether. Participants had been in their current role for between two months and ten years at the time of the session (*M* 3.7 years, *SD* 38.6) (one attendee declined to provide this information). Eight had experience of presenting combined direct payments to service users, and nine had experience of supporting service users to use combined direct payments. Five of the eleven attendees had participated in Part 1 of the study.

6.4 Evaluating the pilot intervention

The pilot intervention was evaluated utilising both qualitative and quantitative measures in order to address four key evaluation questions (see Table 16). Mixed methods were used due to the multi-faceted nature of the evaluation; this also enabled the researcher to triangulate data and gain different perspectives of the effect of the intervention.

Table 16: Pilot intervention evaluation questions and measures

Evaluation questions	Evaluation measures
Did the attitudes and planned behaviours of team members in relation to offering combined direct payments change following the intervention session?	Pre and post questionnaires
Did social work staff believe the intervention session was effective?	Pre and post questionnaires Interviews
Did uptake of combined direct payments (and direct payments overall) increase significantly more in the intervention team than in the control teams in the six months following the intervention session?	Examination of direct payment uptake data
What were the experiences of social work staff regarding offering combined direct payments to service users and supporting service users to use combined direct payments?	Interviews

The evaluation was both outcome and process focused, as in addition to the assessment of the outcome or effectiveness of the intervention, evaluation data were used to inform its potential future development. Therefore, a further question considered across the analysis of all data was, ‘How could the intervention be improved?’

6.4.1 Pre and post questionnaires

Pre and post questionnaires were utilised in order to examine whether the attitudes and planned behaviours of social work staff regarding combined direct payments changed following the intervention session. Attendees were asked to complete a short (three-question) questionnaire immediately prior to and following the session (see Appendix 15). The first two questions assessed their confidence in presenting combined direct payments and the likelihood of them offering this option to service users, utilising a four-point Likert scale. A fifth or mid-point was not included on the scale, as this may have created ambiguity as to whether responses denoted neutrality or indecision on the part of the respondent (Coolican, 2004). The third question assessed participants’ belief as to whether offering combined direct payments to service users would increase direct payment uptake overall, with multiple-choice response options of ‘yes’, ‘no’ or ‘maybe’. The questionnaire administered following the session included three additional free-response questions, relating to the usefulness of the session, and attendees’ plans to change their practice.

A strength of using pre and post questionnaires was that they provided a quick and straightforward way to assess and compare attendees' baseline and post-session attitudes. However, taking a quantitative approach was of limited value with such a small number of participants: only nine of the eleven team members who attended the session completed both questionnaires, as two had to leave prior to the end of the session. Nevertheless, including qualitative aspects in the evaluation, such as incorporating free-response questions in the post questionnaires and undertaking semi-structured interviews, allowed for the collection of richer data to complement quantitative findings and add more depth to the evaluation.

Questionnaires were anonymised in order to minimise the effects of social desirability bias; however as respondents completed the questionnaires in the presence of their colleagues and the researcher this bias is unlikely to have been completely eliminated. All those who attended the whole session were asked to complete the questionnaires (and did so), so selection bias was minimised as far as possible. However, those who chose to attend the session may not have been representative of the whole team; for example, they may have generally been more open to changing their attitudes to combined direct payments than others who were not present.

Quantitative data from paired pre and post questionnaires were analysed using Wilcoxon Signed-Ranks tests[19] in order to examine whether attendees' attitudes around combined direct payments changed significantly following the intervention session.

6.4.2 Direct payment uptake data

Direct payment uptake data were obtained from Worcestershire County Council in order to examine whether uptake of combined direct payments (and direct payments overall) increased significantly more in the intervention group than the control group in the six months following the intervention session. For the purpose of analysis, the intervention group included all social work staff in the team asked to offer combined direct payments as an option as part of the intervention, regardless of whether they had attended the intervention session. All other adult community social work teams acted as controls. Data collected comprised the number of service users on the caseload of each team member who

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[19] A Wilcoxon Signed-Ranks test is a statistical test used to examine whether differences within a group over time are statistically significant, i.e. unlikely to have occurred by chance.

took up a direct payment (and specifically a combined direct payment) during the six months before and after the intervention session.

Direct payment uptake data from control teams not participating in the intervention were included, in order to mitigate the effects of any external factors that may have affected uptake during the intervention period (such as other training sessions or changes in policy). For the purpose of analysis, uptake data from the intervention team was split in order to identify team members who had attended the intervention session and those who had not. Although all members of the intervention team were asked to participate in the intervention by offering combined direct payments as an option, it was thought that those who attended the intervention session may have been more likely to do so. Uptake data for social work staff in Team 1 were also collected separately from data for those in the other control teams, as it was felt that participating in Part 1 of the research may have increased their awareness of direct payments, and thus affected the likelihood of them offering this option to service users.

Direct payment uptake data were obtained in relation to all 161 members of social work staff in Worcestershire who had at least one service user on their caseload who took up direct payments during the six months before or after the intervention. Data relating to two staff members were removed prior to analysis as they had moved teams during the 12-month measurement period; therefore 159 members of social work staff were included in the analysis (see Table 17).

Table 17: Number of social work staff included in the analysis of direct payment uptake, by group

Group		**No. of social work staff**
IS:	Intervention team members who attended the intervention session	9
I:	Intervention team members who did not attend the intervention session	9
CR:	Control team social work staff involved in Part 1 of the research (Team 1)	12
C:	Control team social work staff not previously involved in the research	129

6.4.3 Interviews

Semi-structured interviews were conducted with a sample of social work staff who attended the intervention session, in order to explore their experiences of offering combined direct payments to service users and of supporting service users to utilise this option. The interviews also gave the researcher the opportunity to evaluate the intervention session in more depth through discussion with attendees, and to explore the effectiveness of offering combined direct payments as an approach to increasing direct payment uptake. Social desirability bias may have been an issue, particularly in regards to discussions about the effectiveness of the intervention session, which was planned and delivered by the researcher. However, the collection of quantitative data via anonymised questionnaires meant that findings could be triangulated.

Sampling and recruitment

All social work staff who attended the intervention session completed an attendance slip, which included a tick box so that they could indicate whether they would be willing to be contacted by the researcher to discuss possible participation in an interview. All but one of the attendees agreed to be contacted, and all those who agreed were invited to participate in an interview; therefore sampling was voluntary. Using a voluntary sample was felt to be necessary due to the relatively small sampling frame. This had the potential to introduce bias to the evaluation, as social work staff who felt more positive about the intervention may have been more likely to participate in the evaluation interview. However, the main reasons given for non-participation were that attendees had since left the social work team, or had little frontline experience so would be unable to discuss their experiences of combined direct payments. Therefore, sampling bias is unlikely to have had a substantial effect on findings.

Intervention session attendees were invited to take part in interviews via a personalised email from the researcher, which explained what the interview would involve and included a copy of the intervention information booklet. If attendees did not respond to the initial email, a second similar invitation was sent around one month later.

Participants

Six intervention session attendees were recruited to participate in the interviews. They had been in their role for between two months[20] and seven years at the time of participating (*M* 3.2 years, *SD* 2.6) (one participant declined to provide this information). Five out of six of the interview participants reported having had experience of presenting combined direct payments to service users, and five reported that they had experience of supporting service users to use combined direct payments.

Procedures

It was decided that interviews would be conducted towards the end of the six-month intervention period, in order that participants would have had time to gain a substantial amount of experience in offering combined direct payments to service users as part of the intervention. A limitation of this approach in terms of evaluating the intervention session was that the time between the session and the interviews was relatively long, so participants may have forgotten some details of the session. However, each interviewee was presented with a reminder of the session to read at the appropriate point in the interview, and none had difficulty in recalling the different aspects of the session. All interviews took place between five and a half and seven and a half months following the intervention session. Interviews were carried out at a time and location convenient to participants, all of whom chose to be interviewed in a private meeting room at their own workplace. All interviews were audio recorded for the purpose of transcription using a digital voice recorder, which was placed on a flat surface between the researcher and the participant. The interviews conducted ranged from 23 minutes to one hour 29 minutes in duration (*M* 41.1 minutes, *SD* 24.2).

Prior to the start of each interview, participants were asked to sign two copies of a consent form, retaining one and returning the other to the researcher (see Appendix 16). The researcher reminded participants of the aim of the research and the purpose of the interview. The purpose of audio recording the interview was explained and participants were reminded that only researchers involved in the study would listen to the recording and that they would not be identified in any report of the research findings. The researcher emphasised that they were interested in what participants had to say, and that there were no right or wrong answers. It was explained that participants did not have to answer any

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[20] One social worker was newly qualified and had been a student social worker at the time of the intervention session.

questions they did not wish to and that they were free to stop the interview or have a break at any time. Participants were then given the opportunity to raise any questions or concerns prior to the start of the interview.

Interviews were semi-structured, with a standard set of eight main questions used to guide the discussion, each with a set of follow-up questions or prompts (see Appendix 17). Questions were tailored to take the situation of each participant into account, for example depending on their level of experience regarding combined direct payments. Interviews started with a relatively open question to give participants the opportunity to tell the interviewer about their experiences of offering combined direct payments to service users. Subsequent questions focused on specific aspects of participants' experiences and ways of working, and participants were asked evaluative questions about the intervention as a whole and the intervention session specifically. At the end of each interview, participants were given the opportunity to contribute any additional comments and were thanked for their time. They were again reminded that only researchers involved in the study would listen to the recording of the discussion and that they would not be identified in any report of the research findings. Participants were then given the opportunity to ask any further questions.

Analysis

Interviews were transcribed verbatim and analysed thematically, with the use of NVivo to assist in the organisation of data into key themes. Thematic analysis was selected as this is a flexible, relatively straightforward form of analysis, which can be used to identify and summarise key themes in the data (Braun & Clarke, 2006). It is argued that this method can have 'limited interpretative power' (Braun & Clarke, 2006, p. 97). However, it was felt that it suited the purpose of this evaluation, where the aim was to assess the effectiveness of the intervention (and identify potential improvements) in the particular context in which it was implemented, rather than to produce generalisable findings. In line with this, analysis was at an explicit rather than an interpretative level.

6.5 Summary

It was decided that encouraging social work staff to offer combined direct payments to service users would form the basis of the pilot intervention. This approach addressed a number of the barriers to direct payment uptake identified in the initial study, and received positive feedback from Worcestershire County Council staff. One community social work team participated in the intervention, which commenced with an interactive session delivered to participating social work staff. This marked the start of a six-month intervention period during which team members were asked to offer combined direct payments as an alternative option to service users reluctant to take up full direct payments. In order to evaluate the intervention, social work staff who attended the intervention session were asked to complete pre and post attitudinal questionnaires, semi-structured interviews were conducted with six participating team members, and direct payment uptake data were statistically analysed. The next chapter presents the findings of this evaluation.

Chapter 7

Part 2 – Pilot intervention

Results and Discussion

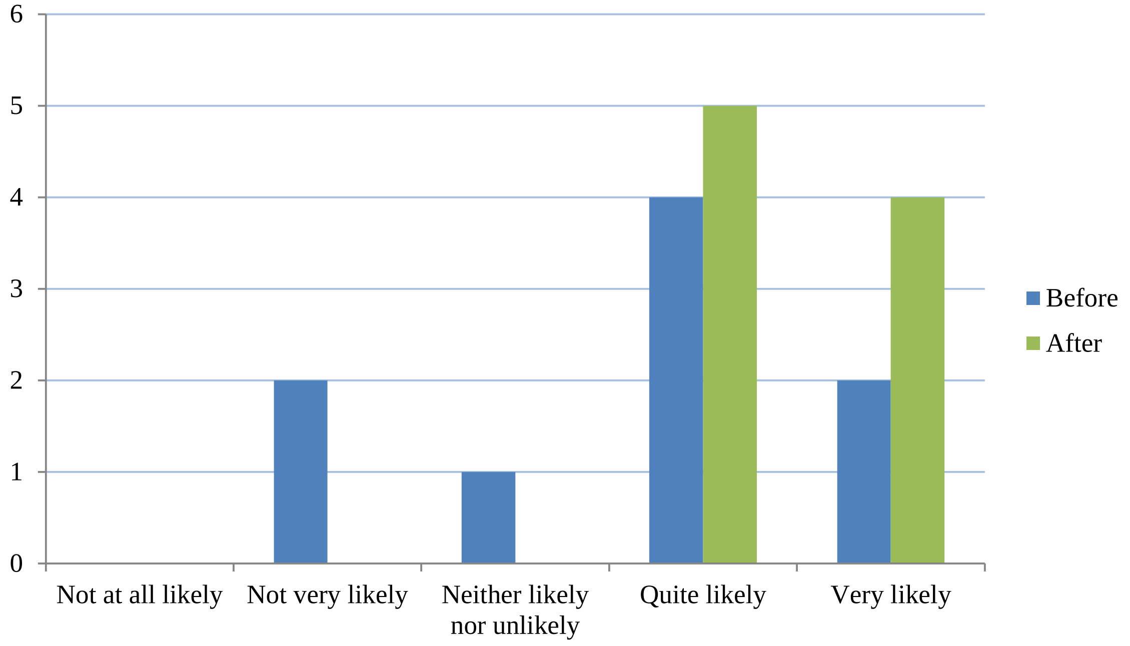
The pilot intervention was evaluated using pre and post questionnaires, interviews and statistical analysis of direct payment uptake data. Four key questions were identified to structure the evaluation, which are addressed in turn in this chapter. A conclusion is then drawn as to how findings could be used to inform the building of any future interventions in this area, and whether the promotion of combined direct payments (and this intervention specifically) is an approach that is likely to be effective in increasing access to direct payments overall.

Section one outlines changes to the attitudes and planned behaviours of social work staff regarding combined direct payments following the intervention session, while section two explores their perceptions as to whether the intervention was effective. Section three investigates changes in uptake of combined direct payments (and direct payments overall) following the intervention session. The chapter concludes in section four with a focus on the experiences of social work staff regarding offering combined direct payments to service users and supporting service users to utilise this option.

7.1 Change in attitudes and planned behaviours of social work staff

A Wilcoxon Signed-Ranks test was used to examine whether intervention team members' attitudes regarding combined direct payments, as reported in the pre and post questionnaires, changed following the intervention session. A significant positive shift in the self-reported likelihood of social work staff offering combined direct payments to service users was found, $T = 0$, $p < 0.5$, although results should be treated with caution due to the small sample size. In addition, social desirability bias may have affected results as social workers completed the questionnaires in the presence of the researcher, so may have felt pressure to indicate that their attitudes had changed. Following the intervention session all attendees reported that they were 'quite likely' or 'very likely' to offer combined direct payments to service users who do not initially want to take up direct payments, compared to two thirds of attendees prior to the session (see Figure 11).

Figure 11: Self-reported likelihood of social work staff offering combined direct payments to service users who do not initially want to take up direct payments, before and after the intervention session[21]



There was no significant difference in responses before and after the session to the question 'Do you think that offering combined direct payments as another option to service users would result in more service users taking up direct payments (both combined and 'full') in total?', with only one attendee changing their response from 'maybe' to 'yes' following the session. There was also no significant difference in attendees' self-rated confidence in presenting combined direct payments to service users before and after the intervention session. However, this may have been because self-rated confidence was relatively high prior to the session, with eight out of nine attendees reporting that they were 'fairly confident' or 'completely confident' in the pre questionnaire.

7.2 Efficacy of the intervention session

In the interviews and feedback part of the questionnaires, social work staff commented that they found the intervention session useful, and outlined a number of ways they benefitted from attending. Some reported that the session increased their knowledge of combined direct payments, and gave them new ideas of how to promote this option and about support

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[21] 'Neither likely nor unlikely' was not offered as a response option on the questionnaire; however one respondent added this response.

planning. One attendee said that the session had inspired him to do some background reading in the area, which had increased his knowledge and confidence regarding combined direct payments. Others identified that the session acted as a useful refresher, which reminded them to offer combined direct payments in their practice:

> '… it's something that's gonna be in your mind isn't it, but it's having sessions like this that kind of remind you in your practice as well' (PI1[22])

Therefore, the session appeared to benefit both less experienced social work staff and those experienced in offering combined direct payments.

The parts of the session attendees found most useful were the group discussions, where they shared knowledge and experiences with their colleagues. They reported that this helped consolidate their own knowledge and gave them new ideas:

> '…it's handy to hear what other ideas people've got… 'cause sometimes people do things and you think well, that's a good way of approaching it… so you just try and remember what they've done and… you adapt it to what you do' (PI5)

The interactive map was also popular:

> '… it's hard to kind of pool all that information. So to… have it there kind of on a plate for you, is really useful… the idea's fantastic' (PI4)

However, although interviewees reported that the map was a useful resource, it was hardly utilised, possibly due to high workload and time constraints. There were only 14 visits to the webpage in the 12 months following the intervention session, despite regular email reminders to social work staff from the researcher and a further demonstration of the map at a team meeting. Attendees did not identify any parts of the session that they did not find useful.

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[22] Quotes from pilot intervention (PI) interview participants have been labelled numerically in order that individual contributions can be identified.

Interview participants made several suggestions as to how the intervention session could be improved; the most frequent was that it would have been helpful to look at the processes and forms involved in setting up a combined direct payment. It was also suggested that social work staff themselves could bring to the session examples of complex cases they had experienced. This was planned initially; however although the researcher requested that team members bring examples to the session, none did so. Other suggestions focused on expanding the group discussions and ideas sharing aspects, with interviewees commenting that it would have been useful to have a greater number of session participants and to mix teams up so that a broader range of ideas and experiences could be discussed.

When asked in the feedback part of the questionnaire what they would do differently as a result of attending the session, only a third of attendees specifically stated that they would offer combined direct payments more frequently, despite this being clearly stated as the main aim of the intervention. This may have been because prior to the session two thirds of attendees said that they were already ‘quite likely’ or ‘very likely’ to offer combined direct payments to service users reluctant to take up full direct payments. Therefore, the majority may have felt no need to change their practice, with one reporting, ‘I believe I already work very well promoting Direct Payments’. This was reflected in the interviews, where a number of participants explained that they had not changed their practice regarding combined direct payments following the intervention session, as they had not felt this was necessary:

> ‘I feel I was doing what was required before. I mean, the session helped highlight areas I think… but I don’t… feel I’ve a- changed the way I’m doing things as such… I felt I had a reasonable um understanding of it anyway… I think as a team we’re generally quite proactive with direct payments generally, whether it’s standard or combined’ (PI5)

One interviewee reported that combined direct payments were offered by team members only when this was considered the most appropriate option for the individual service user, rather than to all those reluctant to take up full direct payments:

> ‘[We make our] decision on the person… the needs… that is what we will do before we will say, oh, definitely full direct payment. Hmm, maybe a combined. Or do combined for that bit, but that bit needs to be fully supported.

> And, and that’s how we all kind of work, ’cause that’s the bigger picture than trying to sell something’ (PI2)

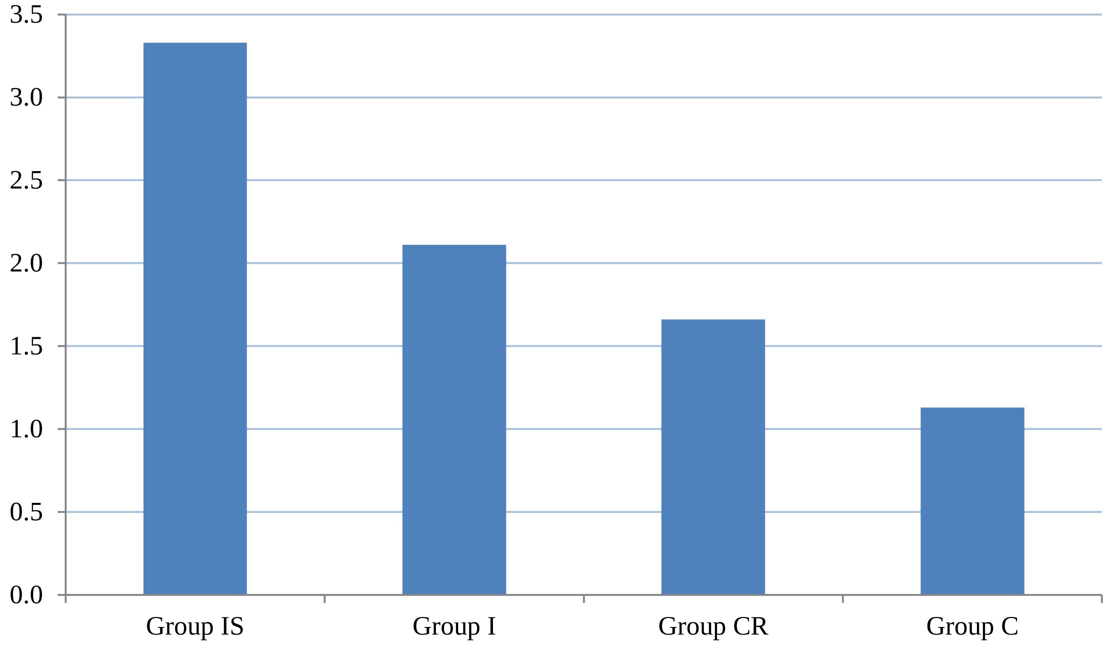
For social work staff using this practice, an intervention simply asking them to offer combined direct payments to all service users reluctant to take up full direct payments is unlikely to be effective, as it does not take individual situations into account. It would be useful to consider how to address this way of working in any future intervention, possibly by focusing more on the advantages of combined direct payments and how they could be used to benefit service users in a range of different situations. Nevertheless, some interviewees did report that they were more likely to offer combined direct payments to service users following the session, as it had served as a reminder of this option and made them think more about using combined direct payments in their practice.

Overall, findings indicate that the session was beneficial to those who attended in terms of increasing or refreshing their knowledge. However, it was less effective in changing the intentions of social work staff regarding their practice, possibly because the majority of session attendees were already proactive in offering combined direct payments. Therefore, a more targeted approach aimed at those who do not generally offer combined direct payments to service users may have had a greater impact in terms of changing attitudes and beliefs about subjective norms. If the session were repeated, it would be useful to include a section on the processes and forms involved in setting up a combined direct payment. In addition, if social work staff could be persuaded to bring examples of complex cases to the session, this may be particularly useful in demonstrating how combined direct payments can work well for individuals in different situations. Adding these components to the session would also enable a greater focus on addressing perceived barriers to combined direct payments.

7.3 Change in uptake of direct payments

It was found that social work staff in the intervention teams set up more direct payments on average than those in the control teams in the six months prior to the intervention (see Figure 12). This suggests a relationship between team members’ inclination to take part in research relating to direct payments and their behaviour around offering direct payments as an option to service users. For example, the number of direct payments set up by intervention team social work staff who subsequently attended the intervention session was higher than the number set up by intervention team members who did not attend the session. Therefore, social work staff with a positive attitude to direct payments may have been over-represented in Group IS. In addition, the increased focus on direct payments resulting from participating in Part 1 of the research may have meant that awareness of and motivation to offer direct payments was higher amongst social work staff in Groups IS, I and CR than amongst their colleagues in Group C.

Figure 12: Average number of direct payments set up by social work staff in each group in the six months prior to the intervention



Key:

IS:	Intervention team members who attended the intervention session
I:	Intervention team members who did not attend the intervention session
CR:	Control team social work staff involved in Part 1 of the research
C:	Control team social work staff not previously involved in the research

As the groups differed at baseline, it was decided to conduct an ANCOVA[23] in order to examine whether uptake of direct payments in the six months following the intervention session was significantly higher in the intervention groups than the control groups, with

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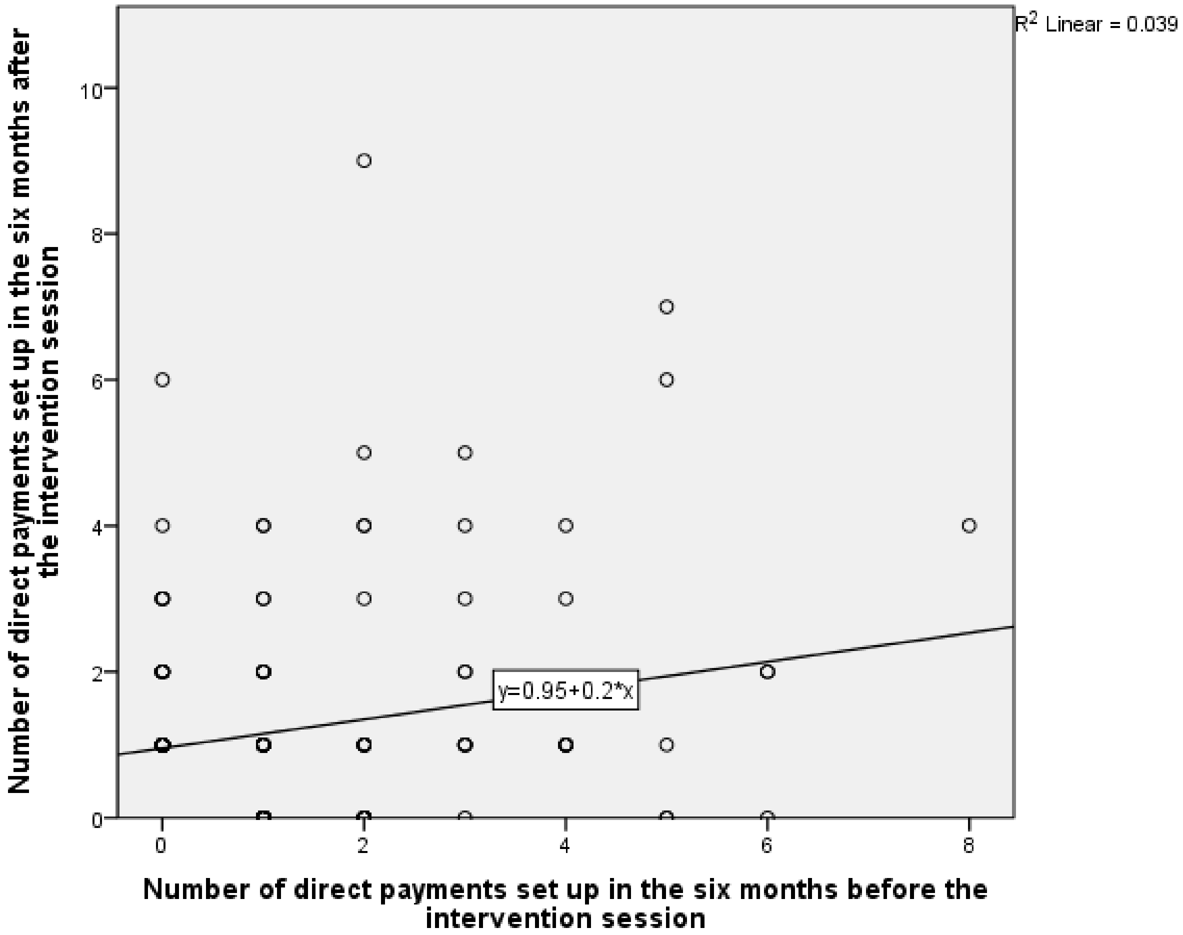
[23] An ANCOVA (analysis of covariance) is a statistical test used to look at the effects of an independent variable (in this case the group that a social worker was in) on a dependent variable (in this case uptake of direct payments), while removing the effect of another variable, or covariate (in this case direct payment uptake per team member in the six months prior to the intervention session).

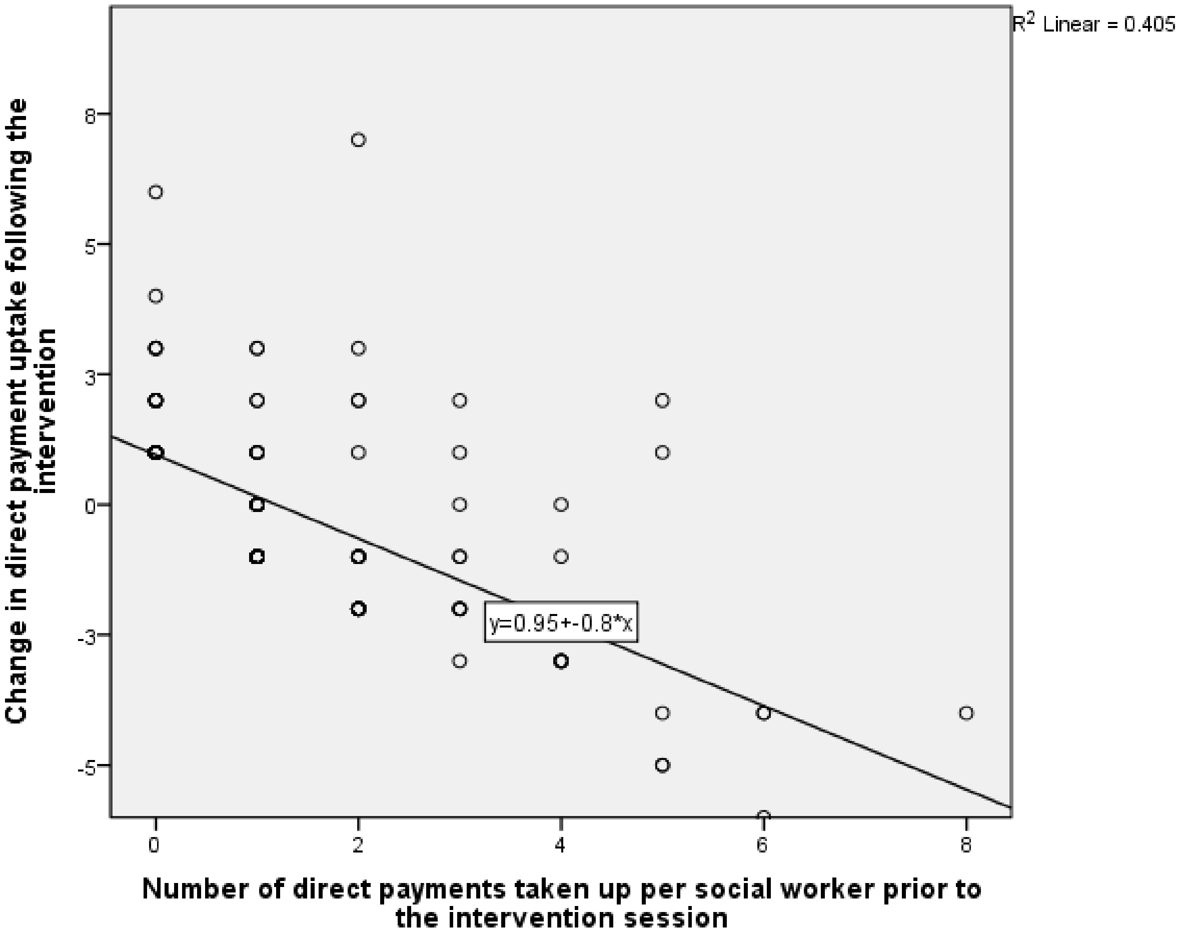
direct payment uptake per team member in the six months prior to the session as a covariate, in order to partial out the effects of this variable. However, prior to conducting the ANCOVA it was found that there was no linear relationship between the number of direct payments set up by each member of social work staff in the six months before and after the intervention session (R-Square = 0.039) (see Figure 13).

Figure 13: Relationship between the number of direct payments set up by social work staff in the six months before and after the intervention session



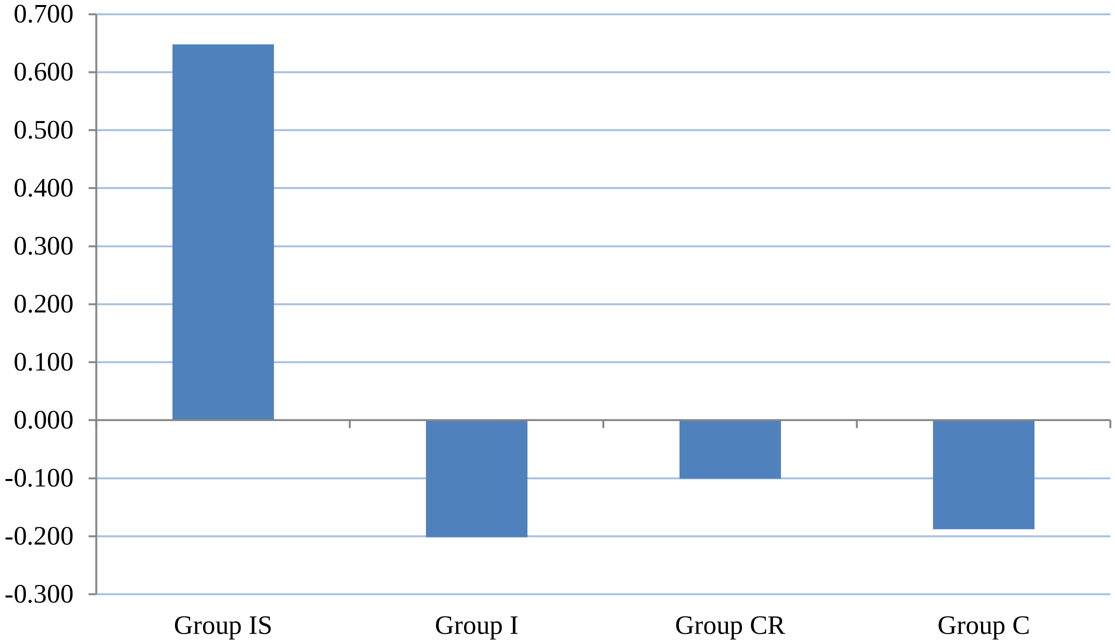
It was therefore hypothesised that there may be a relationship between direct payment uptake in the six months prior to the session and the amount of change in uptake following the session. For example, social work staff who were already proactive in setting up direct payments for service users prior to the intervention session may have found it more difficult to subsequently increase direct payment uptake amongst their caseload. Consistent with this hypothesis, national data indicate that local authorities with high rates of direct payment uptake show a lower year-on-year increase in uptake of direct payments than those with low uptake rates. For example, amongst the 10 local authorities with the highest rates of direct payment uptake in 2011-12, the number of community social care service users in receipt of direct payments fell by 1.48% on average in the following year. In contrast, in the same period the number of direct payment recipients increased by 36.29% on average for the 10 local authorities with the lowest rate of direct payment uptake in 2011-12 (HSCIC, 2013b; 2013c). In support of this, a linear relationship (R-Square = 0.405) was found between the number of direct payments set up by each member of social work staff in the six months prior to the intervention session, and the change in the number of direct payments set up before and after the session (see Figure 14). Social work staff who set up a greater number of direct payments prior to the intervention session tended to show less positive change in set-up rates following the session.

Figure 14: Relationship between the number of direct payments set up by social work staff in the six months before the intervention session, and the change in the number of direct payments set up before and after the intervention session



Therefore, an ANCOVA was conducted in order to examine whether the change in uptake of direct payments following the intervention session was significantly higher in the intervention groups than the control groups, with direct payment uptake levels in each group for the six months prior to the session as a covariate. The assumption of homogeneity of variance was not violated[24]. After adjusting for direct payment uptake levels in the six months prior to the intervention session, there was no significant effect of the between-subjects factor group (F (3, 151) = 0.74), p = 0.53). However although the effect was not significant, on average intervention team members who attended the intervention session showed a small positive change in direct payment uptake following the session (after adjusting for direct payment uptake levels in the six months prior to the session), whereas on average those in the remaining groups showed a small negative change in uptake (see Figure 15).

Figure 15: Average change in the number of direct payments set up by social work staff in each group following the intervention session[25]



Key:

IS: Intervention team members who attended the intervention session

I: Intervention team members who did not attend the intervention session

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[24] The assumption of homogeneity of variance is the assumption that the variance (i.e. spread of the data) in each group is similar. Homogeneity of variance is a requirement of some statistical tests such as ANCOVA.

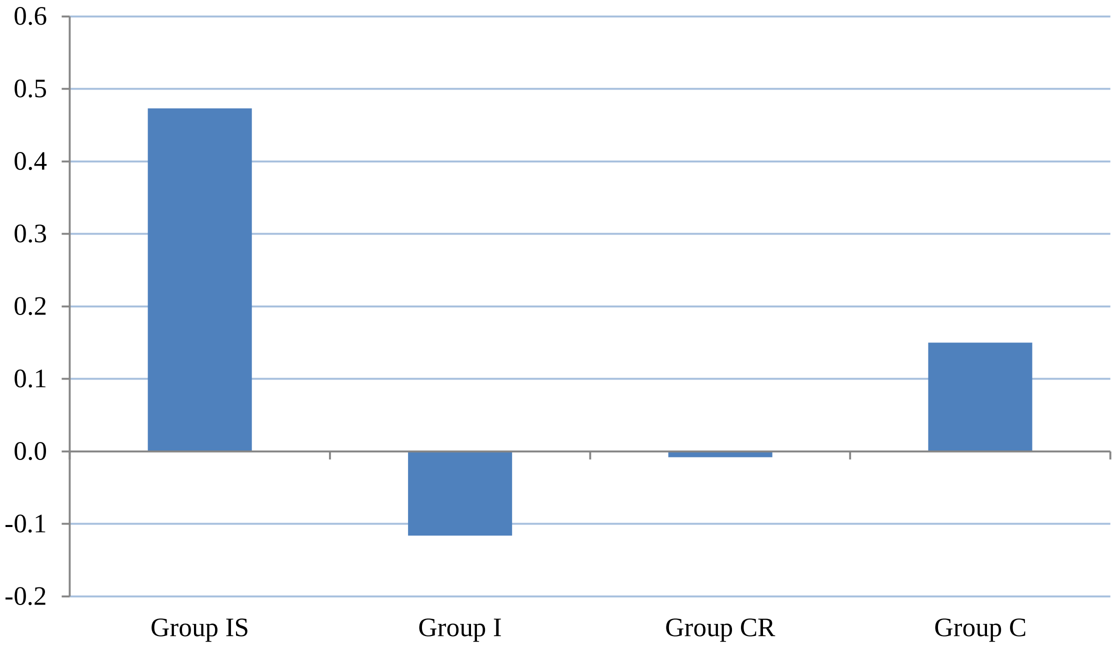
[25] After adjusting for direct payment uptake levels in the six months prior to the session

CR: Control team social work staff involved in Part 1 of the research

C: Control team social work staff not previously involved in the research

An ANCOVA was conducted in order to examine whether the change in uptake of combined direct payments following the intervention session was significantly higher in the intervention group than the control groups, with combined direct payment uptake levels in each group for the six months prior to the session as a covariate. The assumption of homogeneity of variance was not violated. After adjusting for combined direct payment uptake levels in the six months prior to the intervention session, there was no significant effect of the between-subjects factor group (F (3, 151) = 0.912), p = 0.437). However, although the effect was not significant, intervention team members who attended the intervention session showed a greater positive change in combined direct payment uptake on average following the session (after adjusting for combined direct payment uptake levels in the six months prior to the session) than social work staff in the remaining groups (see Figure 16).

Figure 16: Average change in the number of combined direct payments set up by social work staff in each group following the intervention session[26]



The small number of social work staff in groups IS, I and CR (9, 9 and 12 respectively) is likely to have affected the reliability of findings, thus a greater sample size may have

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[26] After adjusting for combined direct payment uptake levels in the six months prior to the session

resulted in a significant difference between the groups being found. A post hoc power analysis indicated that on the basis of the difference between the intervention and control groups (0.83), a sample of 168 social workers (assuming equal numbers in both groups) would be needed to detect an effect of this size (80% chance of detecting the effect at a significance level of 0.05). Although no statistically significant difference between groups was observed in this study, results do indicate that the intervention had some effect. For example, social work staff in Group IS showed the highest (and only positive) change in the number of direct payments set up before and after the intervention session[27] compared to those in other groups.

Although social work staff in Group I were nominally participating in the intervention[28], on average they showed a slightly lower change in the number of combined direct payments set up in the six-month intervention period than social work staff in the control teams. This may indicate that the intervention session was a vital component of the intervention, and/or that social work staff who chose not to attend the intervention session (although in some cases they were unable to do so) were generally less positive about combined or full direct payments initially. In support of this, social work staff in Group IS had set up more combined direct payments on average than those in Group I in the six months prior to the intervention.

The positive change in the number of full direct payments set up by social work staff in Group IS[29] following the intervention was actually greater than the change in the number of combined direct payments set up. Therefore, it is possible that the intervention did not have the effect of encouraging social work staff to offer more combined direct payments per se, but rather that the increased overall attention on direct payments as a result of the intervention had an effect.

7.4 Social work staff experiences of combined direct payments

Interviews were conducted with social work staff who attended the intervention session in order to explore their experiences of offering combined direct payments to service users and of supporting service users to utilise this option. The benefits of combined direct

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[27] After adjusting for direct payment uptake levels in the six months prior to the session

[28] Social work staff in Group I were members of the team asked to offer combined direct payments to service users, but did not attend the intervention session.

[29] After adjusting for direct payment uptake levels in the six months prior to the session

payments, and disadvantages and problems encountered were also two key areas of discussion. Each of these areas will be explored in turn in this section.

7.4.1 Offering combined direct payments to service users

Offering combined direct payments to service users appeared to be an effective approach in increasing direct payment uptake. Participants reported that in their experience, service users were more likely to take up combined than full direct payments:

> ‘I find that people that don’t want the full direct payment, they will consider the combined…’ (PI3)

They felt that this was due to combined direct payments (unlike full direct payments) providing the ‘safety net’ of continued Social Services involvement:

> ‘Yeah, I think [service users are] more open to combined. Because it, it, it gives them s-, it’s the security in their mind the home care staying as it is. And it just gives them that bit of flexibility, organising the day opportunities or the, the respite’ (PI5)

Interviewees also explained that being able to offer combined direct payments to service users was useful as it provided an alternative option that was less ‘intrusive’ and ‘problematic’ than full direct payments, but that still enabled service users to experience some of the flexibility of managing their own care. They saw this approach as ‘a way in through the back door’, which was effective in encouraging service users to consider direct payments where they might not otherwise have done so. Having a third option to present to service users was also seen as positive in terms of increasing choice.

Despite the advantages of offering combined direct payments to service users, this tended to be offered as a secondary option to full direct payments, mentioned only when problems such as block booking prevented the use of full direct payments, or when service users were reluctant to take up direct payments at all:

> ‘… we offer a dire-, direct payment first. That’s our kind of initial goal… And then [combined direct payments are] the next step on, if they’re resistant to having a direct payment… it’s a halfway house isn’t it…’ (PI4)

Interestingly, this was the approach social work staff were asked to take as part of the intervention, due to constraints imposed by senior managers within Social Services, who expressed concerns that offering combined direct payments could ‘dilute’ the Council’s promotion of full direct payments. Interview findings suggested that social work staff viewed a full direct payment as more beneficial to service users than a combined direct payment, as it would give them complete control over their care package; however it would be useful to explore this issue further to gain the viewpoint of senior managers.

Some interviewees explained that they did not take a blanket approach, but offered combined direct payments to service users only when they felt that this would be the most suitable option for their situation. For example, this may be when service users wish to employ family members to deliver their personal care, while also attending a day service block booked by the Local Authority. Interviewees did not report experiencing any particular problems in offering combined direct payments to service users; however one suggested that having specific written information on this option available to distribute would be helpful.

7.4.2 Supporting service users to use combined direct payments

The majority of participants said that the work involved in setting up and supporting service users to use combined direct payments was similar to that involved when full direct payments were used. The only difference identified was that the two different parts of the personal budget (fully managed and direct payment) needed to be worked out and explained to the service user when a combined direct payment was set up. Some social work staff found that service users on combined direct payments needed less support at the set-up stage than those on full direct payments. This was possibly because they only needed to take on the management of part of their personal budget, for example if they were only purchasing day activities and did not need to employ personal assistants themselves. It was suggested that service users taking up combined direct payments may also need less reassurance, as the Local Authority retains some responsibility for their package of care and is therefore available to provide support more readily in emergencies.

All interviewees reported that combined direct payments were more often utilised to enable service users to purchase activities than to arrange personal care, which frequently remained managed by the Local Authority. This was for a number of reasons, for example it was suggested that service users may feel more anxious about ensuring personal care services are in place:

> '… they want something which is protected and something which is unprotected. So we usually try and get the direct payments on day opportunities… So that can be unprotected… where the care… they want it to be protected' (PI2)

Personal care is likely to be seen by service users and their families as more of a necessity than day activities, which may be viewed as an optional extra. Additionally, some service users may wish to use in-house specialist care services (which cannot be purchased with a direct payment) for their personal care, or they may already receive care managed by the Local Authority and not wish to change this. Interviewees suggested that this was particularly the case if it was a long-standing care package and service users were happy with the care they received, as they then felt they had little to gain from managing it themselves. They also proposed that organising the personal care part of the care package was perceived by service users as being more difficult to manage than purchasing day opportunities, due for example to the need to employ carers:

> '… a lot of people like to arrange their own activities… but [don't] necessarily want to arrange the care side of their life… 'cause they can't be bothered with dealing with paying the carer…' (PI6)

Findings from Part 1 of the research indicated that fears about becoming an employer were a major barrier to direct payment uptake; therefore service users may use combined direct payments as a way of avoiding this.

7.4.3 Benefits of combined direct payments

A key benefit of combined direct payments reported by all interviewees was that the continued involvement of Social Services was reassuring to service users and their families as the responsibility for the care package is shared. Having a combined direct payment enables service users to be ‘kept in the system’ of Social Services, which allows them to rely on the Local Authority for support in emergencies, for example if emergency respite care becomes necessary.

> ‘[With combined direct payments] there’s a safety net and the Local Authority has the responsibility. Direct payments, it’s a grey area, you have the money from the Local Authority, but it’s down to you to make sure that you er cover yourself for in-, all eventualities’ (PI2)

Knowing that the Local Authority is still involved in a service users’ care package may help alleviate service users’ and carers’ concerns about managing their care, and thus make them more likely to take up combined direct payments. The continued involvement of Social Services in combined direct payments may also provide reassurance to service users that if they change their minds about managing part of their care, their decision can be easily reversed:

> ‘…the fact that it’s combined and they know that Social Services are involved… it’s… reassuring the individual that when you are taking this direct payment, it’s not a sealed deal that [you] can’t change tomorrow. If you take this and you find that it’s… complicated, and you are struggling to manage the finances, we can change it at any time’ (PI1)

Social work staff also suggested that managing a small part of the personal budget can benefit service users and carers in terms of the increased flexibility, while not being a heavy burden in terms of workload and responsibility. This may be the case particularly where the day-to-day care element of the care package is managed by the Local Authority while the service user purchases their own activities. As the continued involvement and responsibility of Social Services was not an advantage of combined direct payments previously considered by the researcher, it was not discussed in the intervention session. Given that all interviewees identified this as beneficial it would be useful to incorporate this in any future intervention in this area.

A further benefit of combined direct payments identified by social work staff was that they can give service users greater flexibility over how they manage their care package, and enable them to use a wider range of services. For example, combined direct payments allow service users to use services block booked by the Local Authority while having control over other aspects of their care. In this way, they can provide more flexibility than full direct payments:

> '... combined direct payments gives you more options… whereas… direct payments limits your options' (PI1)

As previously mentioned, combined direct payments provide a useful halfway point between fully managed care and direct payments, which may particularly suit some service users:

> '… I think for the combined it's probably looking at like you know, those people who do need that little bit of support but want their independence as well…' (PI6)

Interviewees proposed that combined direct payments may be especially useful for service users with fluctuating needs, such as those with dementia, citing examples of those who had a fixed package of care managed by the Local Authority and organised additional care when needed:

> '… I've got one gentleman… and his needs sort of fluctuate, quite a lot. So he's got the care package that he has, he's got that as fully supported and then he's got the direct payment on top of that, so he can use that when his needs increase, he can use that to, to buy the extra care in. So that works well…' (PI3)

It was reported that this additional flexibility can also be helpful to family carers who are able to provide care at some times but not others. Having combined direct payments could allow them to have the service users' main package of care managed by the Local Authority, while retaining part of the personal budget to procure additional care when necessary, for example when they are at work or on holiday.

In addition to providing a halfway point between full direct payments and fully managed care, it was suggested that the use of combined direct payments was an effective way of moving service users on to full direct payments:

> ‘I think it’s definitely a way in, like I said a lot of people that take up the combined will then go over to the full…’ (PI3)

Participants reported that combined direct payments provide a ‘gentle introduction’ to full direct payments, which alleviates service users’ fears around direct payments as they realise that they are ‘not that hard… to manage’. They also suggested that combined direct payments provide a ‘taster’ that allows service users to experience some of the benefits of full direct payments. Indeed, one team member explained that combined direct payments had been an introduction to direct payments for him as a professional:

> ‘Combined direct payments were probably my way of getting, getting more into direct payments. Because they were… quite daunting at the start. Um for myself, ’cause it… seemed like a really complicated process, so I started off with combined direct payments…’ (PI4)

It was acknowledged that as social work staff only had limited time to work with individuals, it could be difficult to move service users on to a full direct payment. Interviewees suggested that service users may take around six to nine months to ‘get to grips’ with combined direct payments and be ready to move on:

> ‘… If you could work with people a bit longer it would be better, because you could… start off with a, a combined direct payment, and then maybe further down the line… you could maybe say “Right, how do you feel about taking on the full direct payment now?” But by that point… they’ve gone on to Central Reviewing Team’ (PI4)

Participants felt that the Central Reviewing Team (responsible for reviewing the outcomes of support plans) was not ‘geared up towards looking at direct payments’ (PI4), and consequently would be unlikely to suggest that a service user receiving a combined direct payment could try a full direct payment. Targeting future intervention sessions to include social work staff from the Central Reviewing Team may therefore be an effective approach.

7.4.4 Problems associated with combined direct payments

Interviewees reported few disadvantages or problems regarding combined direct payments. They identified that this option does not give service users complete choice and control over their personal budget, which it was suggested can only be provided by full direct payments. However, they also argued that having the option of combined direct payments actually increases service user choice, by providing them with an alternative way in which to manage their care. Some participants reported that having the personal budget split into two parts could be difficult to explain and potentially confusing for service users, particularly where they paid a contribution towards their care. Conversely, some argued that splitting the budget made it easier for some service users to understand. This area may be useful to address in any future intervention, for example through discussion of ways in which combined direct payments can be explained simply to service users.

7.5 Summary

Intervention evaluation findings indicate that the promotion of combined direct payments is an approach that may be effective in increasing access to direct payments overall. For example, it was highlighted that service users were more likely to take up combined than full direct payments if they were daunted by the thought of managing their own social care, and may move on to take up full direct payments once they have experience of using combined direct payments. A number of benefits of combined direct payments were identified, such as greater flexibility and choice for service users, and reassurance due to the continued involvement of Social Services. Social work staff who attended the intervention session showed a more positive change in the number of full and combined direct payments set up in the six months following the session than their counterparts who did not attend. However, this difference was not significant and a larger sample would be needed in order to fully assess the effectiveness of the intervention.

In terms of designing a future intervention in this area, findings suggest that the approach of delivering a session to social work staff was effective. However, the way in which the intervention session was targeted could be improved to maximise its impact. For example, members of social work staff or teams who set up few combined direct payments, or those with low self-rated confidence in presenting this option could be selected to take part. In addition, if the session were made mandatory, social work staff who were less positive about offering combined direct payments (or direct payments overall) would attend rather than only those who were already keen to offer this option. Nevertheless, the presence of more experienced and enthusiastic practitioners was helpful in enabling peer learning and in encouraging colleagues to see combined direct payments as a positive option. Social work staff working in the Central Reviewing Team could be invited to a future intervention session, as it was identified that they play a key role in direct payment uptake, but do not always address this issue at reviews. As suggested, it may also be useful to invite social work staff from several teams to the session in order to enable a broader range of ideas and experiences to be shared.

Regarding the content of the intervention session, findings suggest that it would be beneficial to add a section on the processes and forms involved in setting up a combined direct payment. It could also be highlighted that the continued involvement and responsibility of Social Services in a combined direct payment may make this an attractive option for some service users. It was noted that some social work staff may not respond to an intervention asking them to offer combined direct payments to all service users reluctant to take up full direct payments, as they tend to offer this option only to those they consider suitable. Therefore, in future intervention sessions it may be useful to focus more on the advantages of combined direct payments and how they could be utilised to benefit service users in a range of different situations. This would allow social work staff to see that combined direct payments could be usefully offered to a range of individuals. Finally, it could be helpful to produce an information leaflet for service users specifically about combined direct payments (in consultation with social work staff and service users themselves), as this was identified as a gap in information provision.

The next and final chapter reviews the contribution to knowledge made by this study as a whole and outlines recommendations for practice and future research.

Chapter 8

Evaluation and Conclusion

The aim of this chapter is to review the contribution to knowledge made by this study, with consideration of research implications and limitations, and recommendations for future practice and research in this area. There are three main sections, starting in section one with a discussion of contribution to knowledge, with reference to existing literature. Section two comprises an evaluation of research methods and methodology, while in the third and final section recommendations for practice and future research are proposed.

8.1 Contribution to knowledge

The study sought to explore access to direct payments by people with dementia living in rural communities. Direct payments may afford particular benefits to this group in providing increased flexibility or continuity of care; however uptake is estimated to be relatively low amongst people with dementia. As many people with dementia were ineligible for direct payments until a change in legislation was implemented in 2009 (Health and Social Care Act 2008), relatively little research has been conducted in this area to date. It is thought that no previous research has specifically focused on how the combined factors of dementia and rurality impact on direct payment uptake. The first key aim of the research was to examine the reasons why people with dementia living in rural communities do or do not gain access to direct payments, developing a theory to explain access to direct payments by this group. The second aim was to build and pilot an intervention informed by the research findings, aimed at ensuring that access to direct payments by people with dementia living in rural communities is maximised.

A theory was developed in order to explain access to direct payments by people with dementia living in rural communities, thus meeting the first aim of the research. Direct payments as a ‘second option’ was the core category underpinning the theory, with fully managed care the default option chosen by the majority of service users and their families. Three key factors supported this conclusion. Firstly, the way in which direct payments were presented by social workers meant that they were not always offered effectively or indeed at all to service users, thus not all had the opportunity to select this option. Furthermore, service users and/or family carers who did not make an active choice to take up direct payments simply received fully managed care by default. Secondly, while fully managed care could be accessed by any service user regardless of their ability or support networks, direct payments were accessible almost exclusively to those with the necessary social and experiential capital. Thirdly, service users’ and/or family carers’ own decision-making was weighted in favour of fully managed care. For example, it appeared that an accumulation of several factors (such as effective offering of direct payments, dissatisfaction with existing care and confidence in ability to manage this option) was necessary to facilitate direct payment uptake. However, the presence of only one hindering factor, such as the perception that the work involved in managing this option would outweigh any potential benefits, could lead to service users and their families opting for fully managed care. In addition, acceptance of (rather than satisfaction with) their existing situation appeared to increase the likelihood of service users taking up fully managed care, while only those dissatisfied or actively desiring change tended to be more likely to take up direct payments.

Four key influences on the decisions made by service users and their families regarding the management of their care were identified. Firstly, the way in which direct payments were presented to service users and/or family carers had a considerable influence on uptake, with some social workers offering direct payments selectively only to those they considered suitable. Where the offer was made there was some variation in the way this option was presented, with the timing, precedence and extent of promotion influencing service users' decision-making. A second influence was service users' and/or family carers' level of acceptance of their existing situation, specifically their satisfaction with the care they were receiving and their desire for change. Thirdly, service users and their families appeared to weigh up the perceived benefits and drawbacks of direct payments. The judgement of service users and carers as to their own ability to take on a direct payment, influenced by the perceived availability of support and suitable contacts, was a fourth key influence on their decision-making.

The theory developed was substantive and as such only applies to the context under study, i.e. explaining uptake of direct payments by people with dementia living in rural communities. However, some of the identified influences on decision-making were more broadly applicable to older service users as a whole. For example, there was selective offering of direct payments by some practitioners who made the assumption that this option would not be suitable for older clients, who in turn appeared to be particularly reliant on their social worker for current information. Furthermore it was observed, as in previous research (Callaghan et al., 2012; Judge & Solomon, 1993; Khayat & Salter, 1994), that the older service users and family carers in this study tended to report high levels of satisfaction with the care provided, expressing low desire for change (as found by

Glendinning et al., 2008; Routledge & Carr, 2013; Wood, 2010). Regarding the perceived benefits and drawbacks of direct payments, it was found that this group tended to have limited expectations as to the changes they could make to the care they received, and were particularly anxious about the possibility of taking on the management of their own social care budget. Finally, when assessing their own ability to take up direct payments, it appeared that older participants lacked confidence and particularly valued the support of younger family carers. Therefore, the proposed theory may be useful in explaining the decisions of older service users in general in relation to the management of their care. Although the study was conducted in a single Local Authority, it is thought that findings may be applied more widely, as they are broadly supported by previous research in the field, and diverse perspectives were captured from participants representing a range of roles and situations.

Evidence to date suggests that this study provides the first example of a theory seeking to explain uptake of direct payments by people with dementia living in rural communities, and indeed by social care service users in general. Findings also build on previous limited research into direct payment access by rural older people and service users with dementia, providing some new insights in these areas. For example, it was identified that living in a rural community may actually facilitate direct payment uptake, with this option highlighted as providing a solution to rural issues such as a lack of local services. Word of mouth recruitment of personal assistants was reported to be particularly successful in rural communities, where service users may experience difficulties in attracting staff.

Making changes to their care may be particularly difficult for service users with dementia where they have already built up familiarity and rapport with regular carers, and tend to be more responsive to receiving care from familiar people. Conversely, it was perceived by some family carers that making changes to the care provided would not affect their relative, who they reported did not notice problems such as a lack of carer continuity or late visits. This could affect take-up of direct payments where carers did not consider that this option would facilitate a positive change that outweighed drawbacks such as the extra responsibility involved. Consistent with previous findings (Clark et al., 2004; Goodchild, 2011; Kinnaird, 2010; Lakey & Saunders, 2011), it was suggested that service users with dementia would be unable to manage direct payments without the support of a family carer; therefore the decision as to whether to take up this option was made by the carer rather than the person with dementia themselves.

The study builds on discussions exploring the issue of service user satisfaction with care, for example highlighting that participants' reporting of satisfaction in general terms may mask any negative experiences (Willis et al., 2015). As in previous research (Callaghan et al., 2012; Judge & Solomon, 1993; Khayat & Salter, 1994), it was found that older service users and family carers tended to report high satisfaction with their care. The difficulty in determining whether service users were satisfied because they were receiving care per se, or were particularly satisfied with their own care was noted. Furthermore, while the majority of service users and family carers with experience of Local Authority care were dissatisfied to some extent, not all chose to take up direct payments. Uptake in these instances was influenced by their level of acceptance of the problems they had experienced (with some viewing issues such as lack of carer continuity as inevitable) and the extent to which they considered direct payments could provide an effective solution.

The positioning of fully managed care as the 'status quo' or default option was also discussed in relation to its influence on the decision-making of service users and carers. The phenomenon of 'status quo bias' (Samuelson & Zeckhauser, 1988) appeared to be applicable to the issue of direct payment uptake, with service users and their families tending to show preference for the default option of fully managed care even where they recognised the potential benefits of direct payments. This suggests that the government vision of providing personal budgets 'preferably as direct payments' (DH, 2010, p.4) to all those eligible has not been realised in practice. The findings of this research indicate a need for a review of policy and practice, in order to facilitate direct payment access through the provision of support to those without the social and experiential capital currently required to take up this option. In addition, there is still a need for attitudinal, cultural and procedural change to ensure that direct payments are offered as an option equal to fully managed care.

Findings provide support for existing literature related to access to direct payments in general. For example, as found in previous research (e.g. Hitchen, 2012; Laybourne et al., 2014; Mind, 2009; Moran et al., 2013), direct payments were offered selectively by social workers, some of whom believed that many older service users would be unable to cope with this option (Ellis, 2007; Moran et al., 2013; Newbigging & Lowe, 2005). Findings also confirmed the importance of the offering process in influencing take-up of direct payments (Clark et al., 2004; Henwood & Hudson, 2009; Kinnaird, 2010; OPM, 2010), recognising the significance of the timing of this offer (Glendinning et al., 2008; Newbronner et al., 2011; Vick et al., 2006).

Consistent with previous research (e.g. Glendinning et al., 2008; Routledge & Carr, 2013; Wood, 2010), desire for change amongst older service users and family carers was generally low, with this group tending to be relatively conservative in making decisions about their care (Brookes et al., 2013; Laybourne et al., 2014; Newbronner et al., 2011). Older service users and carers tended to have limited expectations as to the changes they could make if they were to take up direct payments (also found by Goodchild, 2011), possibly due to outdated expectations of the social care system. The most influential factor determining service users' perception of their ability to manage direct payments was whether they had available support, specifically a family carer (as reported by Clark et al., 2004; Kinnaird, 2010; Spandler & Vick, 2004; Williams et al., 2003).

Contrary to previous findings (e.g. Henwood & Hudson, 2009; Ridley et al., 2011; Spandler & Vick, 2004; Wilberforce et al., 2012), there was no evidence of resistance to direct payments from social work staff due to concerns about increased workload. Indeed, it was highlighted by practitioners that direct payments had the potential to reduce workload once set up, as service users taking up this option tended to raise fewer complaints with their social worker relating to the care they received. Further investigation of social workers' attitudes towards direct payments would be useful in order to explore this apparent inconsistency, possibly via analysis of online discussions in order to reduce the likelihood of social desirability bias.

In line with the second aim of the research, an intervention designed to enhance access to direct payments was developed and piloted. The development and evaluation of the intervention contributes to the currently limited literature in this area, although as a small pilot intervention a larger scale implementation and evaluation would be necessary in order to fully explore its potential. Examination of literature to date indicates that this study provides the first empirical evaluation of an intervention aimed at increasing uptake of direct payments through changing the way this option is offered by social work staff. Although it was initially intended that the intervention would focus on improving direct payment access specifically for people with dementia living in rural communities, due to time constraints and sample size limitations the focus was widened to include all adult social care service users living in the community. Following a training session delivered by the researcher, participating social work staff from one community social work team (with three other teams acting as controls) offered combined direct payments as an alternative option to service users reluctant to take up full direct payments. This approach was designed to give direct payments more prominence in the offering process, and to provide a more accessible option for service users who lacked the confidence or ability to take on the management of their whole care package. It was proposed that combined direct payments could provide a more tailored, flexible solution for service users who may be dissatisfied with particular aspects of their care but wish to retain part of their existing care package. In addition, they could enable service users to access some of the benefits of direct payments such as increased choice, while removing perceived drawbacks in some cases, for example relating to block booking issues or the responsibility of becoming an employer.

Findings of the intervention evaluation indicated that this approach may be effective in enhancing overall access to direct payments. The intervention session itself appeared effective in encouraging social work staff to offer direct payments to service users, and participants indicated that it was useful in increasing or refreshing their knowledge in this area. However, as the majority of session attendees reported that they were already proactive in offering combined direct payments to service users, a more targeted approach involving social work staff who do not do this as part of their existing practice (alongside more experienced practitioners) may be more effective. Social work staff who attended the intervention session showed a more positive change in the number of full and combined direct payments they set up in the six-month period following the intervention than those in the control group, although this difference was not statistically significant. Those who took part in the intervention found offering combined direct payments to be a successful approach in encouraging service users to take up direct payments.

8.2 Reflections on the research methods and study limitations

8.2.1 Methodological approach

Grounded theory methodology was effective in facilitating the generation of an explanatory theory in an under-researched area. This approach allowed for the employment of diverse research methods, which enabled the exploration of the research issue from a range of perspectives, encompassing individual, organisational and wider contextual factors. Qualitative methods were used, which suited this relatively new area of study and allowed the researcher to employ an exploratory approach.

The key components of grounded theory development were implemented effectively in the research process. For example, the researcher was able to carry out theoretical sampling through developing interview questions throughout the data collection period, to enable the exploration of issues relevant to the emerging theory. Interview and focus group transcripts were also re-examined, allowing the researcher to develop categories of the theory through re-sampling existing data. As the research progressed, it emerged that widening the sampling frame to include other key stakeholders such as personal assistants, agency carers or frontline staff at the local direct payment support organisation, would have enabled the research issue to be explored in greater depth. However, due to time constraints it was not practical to include these groups in the research.

In order to facilitate an open approach to the generation of theory, conducting a comprehensive literature review on the research issue was delayed until data collection and analysis was complete (see Glaser, 1978). This enabled the researcher to develop the theory creatively and free of preconceived ideas. As acknowledged by Charmaz (2006), an initial literature review was required in order to gain approval for the research; however this was written to provide a brief overview of the research issue and as such did not explore access to direct payments by people with dementia living in rural communities in any depth.

It was felt that theoretical saturation was achieved as far as is possible, as through theoretical sampling all categories were fully defined and developed in terms of their properties and dimensions. Analysis was completed once it was established that no new insights that could add to the theory were emerging from the data.

The core category of direct payments as a ‘second option’ represented the key theme of the research, and as set out by Strauss and Corbin (1998) was able to link all other categories together in an explanatory theory. The theory developed appeared to have explanatory power in that it could explain the decision-making of each case sampled in this research and account for variation. However, it would have been useful to have presented the proposed theory to participants in order to check whether they felt it was a good fit in terms of explaining their experiences. Further confirmation of the theory and its wider applicability could also be obtained through testing it with similar service user groups in other local authorities.

8.2.2 Selection and sampling of research participants

Focusing the research on two adult community social work teams was effective in enabling examination of the factors affecting access to direct payments. This approach also gave the researcher access to service users with dementia and their carers; however this had the potential to introduce bias, as social workers may have been selective in referring potential participants to the researcher, in terms of their perceived ability to take part in the research or the positivity of their attitude towards Social Services. Interviews with social workers provided a key insight into how direct payments were presented to service users, enabled the identification of wider organisational constraints in the process of setting up self-directed support and gave an overview of service users' responses to being offered this option. Participants with dementia offered a direct insight into their experiences of the care they received; however this was limited in terms of the low number of participants in this group and the relatively short discussion time with these service users. It was initially thought by the researcher that service users with dementia themselves may have taken the final decision as to whether or not to take up direct payments; however in this study it was found that their carer made this decision in every case. Therefore, gaining the perspectives of family carers was particularly important for this research in enabling the exploration of their choices around the management of their relatives' care.

The inclusion of triads, both where service users and their carers had opted to take up direct payments and where they had chosen to receive care managed by the Local Authority, was a useful approach in examining the issue of direct payment uptake from both perspectives. Exploring the experiences of those funding their own social care provided an additional insight into the issues of managing care independently, an area that has previously received little research attention.

The 12 triads of service users included in the research were broadly representative of the wider sample from which they were drawn, and represented a diverse range of positions in terms of age, location, care history and household set-up. However, utilising voluntary sampling meant that less experienced social work staff (and possibly those who were less positive about direct payments) were under-represented in the interview sample. The experiences of these groups in offering direct payments to service users may have been particularly useful in exploring the barriers to uptake.

The low participation of service users with dementia in the research was a key limitation. This was chiefly due to the ability of the person with dementia to take part in an interview, although there may have been a small number of cases where carers acting as gatekeepers prevented their relative from taking part where they would have been able to do so. It was observed that people with dementia in receipt of social care tended to be at a relatively advanced stage of the disease in order to be eligible for funded care, unless their eligibility was due to physical needs, as was the case for the two service users with dementia who did take part in an interview. A more inclusive research method such as observation could have enabled greater participation of this group, yet it was thought that this approach would not have provided an effective insight into the research issue. The under-representation of people with dementia meant that their perspectives in relation to decision-making about their care could not be fully explored. However, it was observed that in practice this group had little involvement in these decisions, with their carer taking on the role of key decision-maker.

8.2.3 Methods of data collection

Utilising interviews enabled the in-depth exploration of the experiences of key stakeholders in relation to access to direct payments. This method produced a high response rate, which was an important consideration in a study with a limited number of potential participants. One limitation of interviews as a research method is the potential for bias, as participants may not always give an accurate account of their experiences. However, in this study data could be triangulated due to the inclusion of a range of stakeholders, meaning that findings could be cross-checked and corroborated, and any differences in accounts explored. Although care was taken to ensure that no leading questions were asked and that the researcher presented a neutral, non-judgmental stance during each interview, it was anticipated that social desirability bias may have affected responses. For example, participating social work staff may have felt pressure to present a positive attitude towards direct payments.

The two service users with dementia who were able to participate in an interview found this relatively challenging; therefore this approach did not appear to be suitable for this group. For example, they experienced difficulty in discussing hypothetical situations and in recalling the decisions made about their care. Nevertheless, the inclusion of people with dementia in the research provided a valuable insight into their experiences and own opinions about how they wished to receive care, which differed from that of their social worker or family carer.

Conducting a focus group with each participating social work team enabled the inclusion of a wider range of experiences and perspectives, notably including those of less experienced practitioners who were under-represented in the interview sample. Nonetheless, participants with more experience did tend to contribute more to the discussion, meaning that not all perspectives may have been represented equally.

8.2.4 Pilot study evaluation methods

Both qualitative and quantitative methods were used in order to evaluate the pilot intervention, which enabled the examination of its effectiveness from several different perspectives. Direct payment uptake data were analysed in order to examine the change in uptake amongst the intervention team and three control social work teams before and after the intervention. The inclusion of control teams enabled the minimisation of external factors that may have affected direct payment uptake during the intervention period. The small number of intervention participants meant that quantitative evaluation findings should be treated with caution, although they did provide a useful preliminary indicator of the effects of the intervention. A larger sample would be necessary in order to fully assess the effectiveness of the intervention in increasing uptake of direct payments.

Pre and post questionnaires provided a straightforward way to assess and compare the attitudes of social work staff to combined direct payments prior to and following the intervention session. These were anonymised in order to minimise the effects of social desirability bias, although as they were completed in the presence of the researcher and participants' colleagues this bias may not have been completely eliminated.

Semi-structured interviews exploring social workers' experiences of offering combined direct payments to service users allowed for the collection of richer data to add depth to quantitative findings. Social desirability bias may have been an issue, as interviews were conducted by the researcher who had also designed and delivered the intervention session. However, the inclusion of quantitative methods allowed findings to be triangulated.

8.3 Practice recommendations and areas for future research

A number of recommendations for practice are made resulting from this research. It is thought that the following changes could contribute towards making direct payments more accessible for all and giving this option equal precedence to fully managed care:

- Allowing social workers the flexibility to offer direct payments at a time that suits individual service users, and to re-offer this option at a later date where appropriate
- Offering direct payments to all service users as an option equal to fully managed care, thereby affording everyone the choice as to how their care is managed
- Presenting the benefits of direct payments in a way that is relevant to individual service users, including the potential of this option to solve problems with existing care, and an overview of the positive changes that could be achieved via non-traditional support methods, which older service users in particular may find difficult to envisage
- Ensuring that social workers provide encouragement, reassurance and support to service users considering direct payments
- Referring service users to a local support organisation at the time they are making decisions about the management of their care, in order to ensure they are aware of the support available to them should they choose to take up direct payments
- Promoting combined direct payments to service users reluctant to take up full direct payments, thus providing a more inclusive option for those lacking the confidence, ability or support necessary to take on the full management of their care
- Working to remove inequities caused by block booking, in order to allow direct payment recipients equal access to local services
- Providing service users with a list of approved personal assistants or local support services, so that those without suitable personal contacts or who are less able to carry out their own research can access greater choice, particularly in rural communities

Due to a paucity of existing literature in this area, there is a need for further research exploring access to direct payments by people with dementia in rural communities, particularly that which includes the voice of the person with dementia. Following on from this study, it would be useful to explore the applicability of the proposed theory in other local authorities or amongst older service users in general. In addition, a larger pilot of the developed intervention could be conducted, possibly targeted towards social work staff who set up few combined direct payments, or who lack confidence in presenting this option. It is thought that addressing the following areas in future research may contribute towards increasing access to direct payments:

- Exploration of the way direct payments are offered and presented to service users by less experienced social work staff
- Further examination of the issue of older people's satisfaction with care services, with the aim of identifying how this can be measured more effectively
- Research including people with dementia who manage direct payments themselves, in order to identify the factors that enable this to be achieved
- Further exploration of social workers' attitudes towards direct payments, for example via anonymous online fora so as to minimise social desirability bias

8.4 Conclusion

The initial aim of this study was to explore access to direct payments by people with dementia living in rural communities, and to develop a theory to explain direct payment uptake by this group. It is believed that this thesis provides the first example of such a theory and offers new insights into this previously under-researched area. In line with the second aim of the study, findings were used to build and pilot an intervention aimed at improving access to direct payments. Evaluation findings indicate that the piloted intervention may be effective in enhancing overall access, although larger scale implementation would be necessary in order to fully explore its potential. It is thought that this provides the first empirical evaluation of an intervention that has focused on changing the way direct payments are offered to service users by their social workers.

Although uptake of direct payments is increasing, the government vision of providing personal budgets 'preferably as direct payments' (DH, 2010, p.4) to all eligible service users has not yet been realised. Findings suggest that direct payments will continue to be an option secondary to fully managed care, unless changes in policy and practice giving greater precedence to this route are implemented. This research has highlighted that direct payments have the potential to improve the lives of people with dementia living in rural communities; however in order for this to be realised there is a need to improve the accessibility of this option.

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Appendices

Appendix 1

Focus group information booklet

University of Worcester
Henwick Grove
Worcester
WR2 6AJ
01905 542296
dementia@worc.ac.uk
www.worc.ac.uk/discover/association-for-dementia-studies

Exploring access to direct payments by people with dementia living in rural communities

Information about the research
Focus group

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being carried out and what it would involve for you. Please contact us using the details provided if anything is not clear, or if you have any questions. Talk to others about the study if you wish.

What is the purpose of the study?

The purpose of the study is to find out the reasons why people with dementia and their families living in rural Worcestershire do or do not gain access to direct payments. Direct payments are cash payments that can be paid to individuals eligible for social care services. This allows individuals to arrange their own services rather than the Council arranging services on their behalf. At the moment, very few people with dementia have chosen to manage their services in this way.

Why have I been invited?

As you are working with people with dementia and their families and are involved in presenting their social care options to them, we would like to find out about your views and experiences of direct payments for this client group.

Do I have to take part?

It is up to you to decide whether to take part in the study. If you agree to take part after reading this information sheet, the researcher will ask you to sign a consent form on their next visit. You are free to withdraw from the study at any time, without giving a reason.

What will happen to me if I take part?

A researcher will facilitate a group discussion between you and other members of your team about your views and experiences of direct payments for people with dementia and their families. This discussion will be tape recorded.

What are the possible benefits and disadvantages of taking part?

We cannot promise the study will help you, but the information we learn from this study will help inform future practice in this area. The group discussion will take around an hour of your time.

What if there is a problem?

If you have a concern about any part of this study, please ask to speak to Sarah Milosevic or her supervisor Professor Dawn Brooker, who will do their best to answer your questions.

Will my taking part in the study be kept confidential?

Yes. This means that we will not tell anyone you have taken part in the study, and only researchers involved in the study will have access to records that identify you. What you say during the group discussion may be included in our report but you will not be named.

Everything you say is confidential unless you tell us something that indicates that you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

Any information that is collected about you will be stored securely at the University in a locked filing cabinet or on a password-protected computer. Any information about you that leaves the University will have your name removed so that you cannot be recognised. Information about you will be kept for no longer than five years and will be disposed of securely.

What will happen if I do not want to carry on with the study at any time?

You are free to withdraw from the study at any time, without giving a reason. The information collected up to the point at which you withdraw may be retained and used in the report of the research.

What will happen to the results of the study?

A report of the research findings will be made to Worcestershire County Council. This report will also be submitted as part of a PhD thesis at the University of Worcester and may be published. You will not be identified in the report. If you wish, you can receive a copy of the report.

Who is funding the research?

This research is funded by the University of Worcester and Worcestershire Public Health.

Who has reviewed the study?

This study has been reviewed and given a favourable opinion by Worcestershire County Council and the Social Care Research Ethics Committee. A Research Ethics Committee is an independent group of people who look at research to protect the interests of participants.

Further information and contact details

If you would like any further information about this study, please contact Sarah Milosevic, preferably by email at s.milosevic@worc.ac.uk. Alternatively, please telephone 01905 542295 and leave a message.

Thank you very much

Appendix 2

Focus group consent form

NHS Worcestershire
University of Worcester
worcestershire county council
Association for Dementia Studies

University of Worcester, Henwick Grove, Worcester, WR2 6AJ
01905 542296 / dementia@worc.ac.uk

Consent Form - Focus Group

Exploring access to direct payments by people with dementia living in rural communities

Thank you for considering taking part in this research. If you have any questions please ask a member of the research team before you decide whether to take part. You will be given a copy of this Consent Form to keep and refer to at any time.

	Please tick Yes	/ No
• I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information and ask questions, and have had these answered satisfactorily.	☐	☐
• I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.	☐	☐
• I understand that if I withdraw from the study the information collected up to that point may be retained and used in the report.	☐	☐
• I agree to take part in the focus group.	☐	☐

Name of Participant (please print) ________________________

Signed ____________________________ Date _____________

Name of Researcher (please print) _______________________

Signed ______________________________ Date___________

Appendix 3

Focus group guide

Focus group

Ask group members to introduce themselves and briefly outline their experience of direct payments.

1. What are your experiences of offering direct payments to service users?
   - (Particularly people with dementia, older people and/or those in rural areas?)
   - Ask for examples
   - How do you present direct payments to service users?
   - What have service users' (and carers') reactions been to the option of direct payments (particularly people with dementia/older people)?
   - What is good/not so good about presenting direct payments?

2. What are your experiences of supporting service users who are using direct payments?
   - (Particularly people with dementia, older people and/or those who live in rural areas?)
   - Ask for examples
   - Compared to supporting service users whose support is fully managed by Social Services?
   - What is good/not so good about it?

3. In your experience, how have direct payments worked as an option for people with dementia and/or their carers?
   - (Or older people/people living in rural areas)
   - Ask for examples
   - What is good and not so good about it – for social workers, people with dementia, and carers?
   - Any benefits/disadvantages specific to people with dementia or those living in rural areas?

4. Can you think of anything that would make it easier for you to work with direct payments?
   - In terms of presenting direct payments to service users?
   - In terms of supporting service users using direct payments?
   - Anything specific that would help with people with dementia/older people/people in rural areas?
   - Any other suggested improvements relating to direct payments?

Appendix 4

Sample interview information booklet
(Social workers)

NHS Worcestershire

worcestershire county council

University of Worcester
Association for Dementia Studies

University of Worcester
Henwick Grove
Worcester
WR2 6AJ
01905 542296
dementia@worc.ac.uk
www.worc.ac.uk/discover/association-for-dementia-studies

Exploring access to direct payments by people with dementia living in rural communities

Information about the research:
Direct payments interviews

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being carried out and what it would involve for you. Please contact us using the details provided if anything is not clear, or if you have any questions. Talk to others about the study if you wish.

What is the purpose of the study?

The purpose of the study is to find out about how people with dementia and their families living in rural Worcestershire are using direct payments.

Why have I been invited?

As you are working with people with dementia and their families who are in receipt of direct payments, we would like to find out about your experiences of supporting people who are using direct payments.

Do I have to take part?

It is up to you to decide whether to take part in the study. If you agree to take part after reading this information sheet, the researcher will ask you to sign a consent form on their next visit. You are free to withdraw from the study at any time, without giving a reason.

What will happen to me if I take part?

A researcher will visit you to talk about your experiences of supporting people with dementia and their families who are using direct payments. We are interested in your opinions so there are no right or wrong answers.

This discussion can take place in a private meeting room at County Hall or at the University of Worcester if you would prefer this. You will take part in a separate discussion about each client, but will not be required to take part in discussions about more than three clients. All discussions will be tape recorded.

What are the possible benefits and disadvantages of taking part?

We cannot promise the study will help you, but the information we learn from this study will help inform future practice in this area. Each discussion with the researcher will take around half an hour to an hour of your time.

What if there is a problem?

If you have a concern about any part of this study, please ask to speak to Sarah Milosevic or her supervisor Professor Dawn Brooker, who will do their best to answer your questions.

Will my taking part in the study be kept confidential?

Yes. This means that we will not tell anyone you have taken part in the study, and only researchers involved in the study will have access to records that identify you. What you say during discussions with the researcher may be included in our report but you will not be named.

Everything you say is confidential unless you tell us something that indicates that you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

Any information that is collected about you will be stored securely at the University in a locked filing cabinet or on a password-protected computer. Any information about you that leaves the University will have your name removed so that you cannot be recognised. Information about you will be kept for no longer than five years and will be disposed of securely.

What will happen if I do not want to carry on with the study at any time?

You are free to withdraw from the study at any time, without giving a reason. The information collected up to the point at which you withdraw may be retained and used in the report of the research.

What will happen to the results of the study?

A report of the research findings will be made to Worcestershire County Council. This report will also be submitted as part of a PhD thesis at the University of Worcester and may be published. You will not be identified in the report. If you wish, you can receive a copy of the report.

Who is funding the research?

This research is funded by the University of Worcester and Worcestershire Public Health.

Who has reviewed the study?

This study has been reviewed and given a favourable opinion by Worcestershire County Council and the Social Care Research Ethics Committee. A Research Ethics Committee is an independent group of people who look at research to protect the interests of participants.

Further information and contact details

If you would like any further information about this study, please contact Sarah Milosevic, preferably by email at s.milosevic@worc.ac.uk. Alternatively, please telephone 01905 542295 and leave a message.

Thank you very much

Appendix 5

Sample interview information booklet
(Family carer)

University of Worcester
Henwick Grove
Worcester
WR2 6AJ
01905 542296
dementia@worc.ac.uk
www.worc.ac.uk/discover/association-for-dementia-studies

Exploring access to direct payments by people with dementia living in rural communities

Information about the research
Family member

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being carried out and what it would involve for you. Please contact us using the details provided if anything is not clear, or if you have any questions. Talk to others about the study if you wish.

What is the purpose of the study?

The purpose of the study is to find out about how people with dementia and their families living in rural Worcestershire are using direct payments. Direct payments are cash payments that can be paid to individuals eligible for social care services. This allows individuals to arrange their own services rather than the Council arranging services on their behalf.

Why have I been invited?

As your relative is using direct payments at the moment, we would like to find out about their and your experiences of using it.

Do I have to take part?

It is up to you to decide whether to take part in the study. If you agree to take part after reading this information sheet, the researcher will ask you to sign a consent form on their next visit. You are free to withdraw from the study at any time, without giving a reason. This will not affect the standard of care your relative receives.

What will happen to me if I take part?

A researcher will visit you to talk about the experiences you and your relative have had regarding direct payments. We are interested in your opinions so there are no right or wrong answers. The researcher may talk to you about this on your own or at the same time as your relative if they would prefer this. The discussion with the researcher will be tape recorded.

What are the possible benefits and disadvantages of taking part?

We cannot promise the study will help you or your relative, but the information we learn from this study may help improve access to direct payments by people with dementia and their families in the future. The discussion with the researcher will take around an hour of your time.

What if there is a problem?

If you have a concern about any part of this study, please ask to speak to Sarah Milosevic or her supervisor Professor Dawn Brooker, who will do their best to answer your questions.

Will my taking part in the study be kept confidential?

Yes. This means that we will not tell anyone you have taken part in the study, and only researchers involved in the study will have access to records that identify you. What you say during the discussion with the researcher may be included in our report but you will not be named.

Everything you say is confidential unless you tell us something that indicates that you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

Any information that is collected about you will be stored securely at the University in a locked filing cabinet or on a password-protected computer. Any information about you that leaves the University will have your name and address removed so that you cannot be recognised. Information about you will be kept for no longer than five years and will be disposed of securely.

What will happen if I do not want to carry on with the study at any time?

You are free to withdraw from the study at any time, without giving a reason. This will not affect the standard of care your relative receives. The information collected up to the point at which you withdraw may be retained and used in the report of the research.

What will happen to the results of the study?

A report of the research findings will be made to Worcestershire County Council. This report will also be submitted as part of a PhD thesis at the University of Worcester and may be published. You will not be identified in the report. If you wish, you can receive a copy of the report.

Who is funding the research?

This research is funded by the University of Worcester and Worcestershire Public Health.

Who has reviewed the study?

This study has been reviewed and given a favourable opinion by Worcestershire County Council and the Social Care Research Ethics Committee. A Research Ethics Committee is an independent group of people who look at research to protect the interests of participants.

Further information and contact details

If you would like any further information about this study, please contact Sarah Milosevic. Her telephone number is 01905 542295, and her email address is s.milosevic@worc.ac.uk.

Thank you very much

Appendix 6

Sample interview summary information sheet
(Person with dementia)

What will the research involve for me?

- The researcher (pictured below) will arrange to visit you to talk to you about the decisions you have made about your social care.

- You can choose whether you would like to talk about this on your own or whether you would prefer to have a family member or friend present.

- The discussion with the researcher will be tape recorded.

- You are free to withdraw from the research at any time, without giving a reason. This will not affect the standard of care you receive.

The researcher – Sarah Milosevic

Appendix 7

Sample interview consent form
(Family carer)

NHS
Worcestershire

University of Worcester

worcestershire county council

Association for Dementia Studies

University of Worcester, Henwick Grove, Worcester, WR2 6AJ
01905 542296 / dementia@worc.ac.uk

Consent Form - Interview

Exploring access to direct payments by people with dementia living in rural communities

Thank you for considering taking part in this research. If you have any questions, please ask a member of the research team before you decide whether to take part. You will be given a copy of this Consent Form to keep and refer to at any time.

	Please tick Yes	No
• I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information and ask questions, and have had these answered satisfactorily.	☐	☐
• I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my relatives' care being affected.	☐	☐
• I understand that if I withdraw from the study the information collected up to that point may be retained and used in the report.	☐	☐
• I agree to take part in an interview about the decisions my relative and I have made about their social care.	☐	☐

Name of Participant (please print) ________________________

Signed ____________________________ Date ______________

Name of Researcher (please print) _______________________

Signed ______________________________ Date____________

Appendix 8

Personal consultee information sheet

Association for Dementia Studies
University of Worcester, Henwick Grove, Worcester, WR2 6AJ
01905 542296 / dementia@worc.ac.uk

Personal Consultee Information Sheet

Exploring access to direct payments by people with dementia living in rural communities

We believe your relative is unable to decide for himself/herself whether to participate in this research. To help decide if he/she should take part, we would like to ask your opinion on whether or not they would want to be involved.

We ask you to consider the following information about the study and what you know of his/her wishes and feelings about research. We would like to know whether you feel he/she would have agreed to join the study, if he/she had been able to decide.

If you feel unable to give advice about this, please say so.

If you decide your relative would have no objection to taking part we will ask you to read and sign a Consultee Declaration Form. We'll then give you a copy to keep. You can let us know if you have concerns about the study or if you think your relative should be withdrawn.

If you decide that your relative would not wish to take part it will not affect the standard of care they receive in any way.

The following information is the same as would have been provided to your relative.

Appendix 9

Personal consultee declaration form

NHS Worcestershire
University of Worcester
Association for Dementia Studies
worcestershire county council

University of Worcester, Henwick Grove, Worcester, WR2 6AJ
01905 542296 / dementia@worc.ac.uk

Consultee Declaration Form

Exploring access to direct payments by people with dementia living in rural communities

Please tick

	Yes	No
• I [name of consultee] have been consulted about [name of potential participant]'s participation in this research project. I have had the opportunity to ask questions about the study and understand what is involved.	☐	☐
• In my opinion [name of participant] would have no objection to taking part in the above study.	☐	☐
• I understand that I can request he/she is withdrawn from the study at any time, without giving any reason and without his/her care being affected.	☐	☐
• I agree that the researcher can look at information held about [name of participant] by his/her social worker.	☐	☐

____________________ _________ __________________
Name of Consultee Date Signature

Relationship to participant: ______________________

Person undertaking consultation (if different from researcher):

____________________ _________ __________________
Name Date Signature

____________________ _________ __________________
Researcher Date Signature

Appendix 10

Interview guides

Cohort 1 - Person with dementia

1. Tell me about the care that you have.
   - What care do you have from Social Services altogether?
   - Do you have any care from anywhere/anyone else?
   - Do you have to do anything to organise your care? (Or is it all organised by someone else/Social Services?) If yes, what do you do? Do you have any help from anyone else? (e.g. family/friends/neighbours)

2. Tell me about how you first started receiving care.
   - How did you come to contact Social Services?
   - What happened when you first contacted Social Services?

3. Have you had any problems with your care?
   - Problems with carers – e.g. different/unfamiliar carers, not turning up on time, problems with actual care (e.g. not enough, not the right type of care)
   - Problems with times – e.g. carers not coming at the time you would like
   - Problems with day centres
   - Have you had any other problems?

4. When you first started having social care, did you have any choices/options about the care you received?
   - For example, could you choose when carers came / when you went to the day centre / whether you had care at home or at a day centre?
   - Were you given the choice to have money from Social Services instead of care, so that you could organise and pay for your own care? (e.g. so you could employ people you know as carers / so that you could do something else instead of going to a day centre?)

If yes:
- How did you find out about this? (e.g. explanation from social worker, leaflet, etc.) How did your social worker explain it to you?
- What made you come to the decision not to do this?
- Were there any other reasons?
- What/who helped/hindered your decision? Do you think the way you were offered this option could have been improved? (If yes - How would you like to have been offered this option? – e.g. leaflet, told by social worker, etc.)
- Do you think you would have come to the same decision if ……? (e.g. if you had help? What kind of help would you need?)

If no:
- Did you know that you could do this?
- Would you have liked to have been told about this?
- How would you have liked to receive information about this? (e.g. from your social worker, in a leaflet/letter, etc.)
- Do you think you would have chosen to do this? Why/why not?
- Are there any other reasons?
- Would you still not want to do this if ……? (e.g. if you had help? What kind of help do you think you would need?)

5. What do you think the good points of managing your own care would be? (How important would each of these things be to you? How would this benefit you? Ask for examples)
   - More independence/choice (e.g. someone coming in at times that would suit you, choosing type of care/activities)
   - Improved mood/health
   - Change in day-to-day activities (care related, social, recreational)
   - Having someone familiar to provide care
   - Having more leisure time

   If applicable: Do you think managing your own care would solve the problems you have had with your care?

6. What do you think the bad points of managing your own care would be? (What problems do you think you might have? Ask for examples. Would this be an important factor in deciding whether to manage your own care?)
   - Problems setting up the care at the beginning
   - Problems because you live in a rural area
   - Change
   - Extra responsibility
   - Extra work/paperwork
   - Problems because it is too complicated (e.g. setting up a bank account/employing people)
   - Lack of available (high quality) services to choose from (rural/transport issues?)
   - Lack of information about available services
   - Dementia-related – e.g. memory problems

7. If you started using social care again, is there anything you would do differently?
   - Is there anything you wish you had known?
   - Can you think of any ways in which the care could be improved?

Cohort 1 - Carer

1. Tell me about the social care that …… has.
   - What care does he/she have from Social Services altogether?
   - Does he/she have any care from anywhere/anyone else?
   - Do you have to do anything to organise ……'s care? (Or is it all organised by someone else/Social Services?) If yes, what do you do? Do you have any help from anyone else? (e.g. family/friends/neighbours)

2. Tell me about how …… first started receiving care.
   - How did you come to contact Social Services?
   - What happened when you first contacted Social Services?

3. Have you and …… had any problems with his/her care?
   - Problems with carers – e.g. different/unfamiliar carers, not turning up on time, problems with actual care (e.g. not enough, not the right type of care)
   - Problems with times – e.g. carers not coming at the time you would like
   - Problems with day centres
   - Have you had any other problems?

4. When you first started having social care did you have any choices/options about the care …… received?
   - For example, could you choose when carers came / when he/she went to the day centre / whether he/she had care at home or at a day centre?
   - Were you given the choice to have money from Social Services instead of care, so that you could organise and pay for ……'s care yourself? (e.g. so you could employ people you know as carers / so that …… could do something else instead of going to a day centre?)

If yes:

- How did you find out about this? (e.g. explanation from social worker, leaflet) How did your social worker explain it to you?
- What made you and …… come to the decision not to do this?
- How much was …… involved in this decision?
- Were there any other reasons?
- What/who helped/hindered your decision? Do you think the way you were offered this option could have been improved? (If yes - How would you like to have been offered this option? – e.g. leaflet, told by social worker, etc.)
- Do you think you would have come to the same decision if ……? (e.g. if you had help? What kind of help would you need?)

If no:

- Did you know that you could do this?
- Would you have liked to have been told about this?
- How would you have liked to receive information about this? (e.g. from your social worker, in a leaflet/letter, etc.)
- Do you think you would have chosen to do this? Why/why not?
- Are there any other reasons?
- Would you still not want to do this if ……? (e.g. if you had help? What kind of help do you think you would need?)

5. What do you think the good points of managing ……'s care yourself would be? (How important would each of these things be to you? How would this benefit you? Ask for examples)
   - More independence/choice (e.g. someone coming in at times that would suit you / ……, choosing type of care/activities)
   - Improved mood/health
   - Change in day-to-day activities (care related, social, recreational)
   - Having someone familiar to provide care
   - Having more leisure time

   If applicable: Do you think managing ……'s care yourself would solve the problems you have had with his/her care?

6. What do you think the bad points of managing ……'s care yourself would be? (What problems do you think you might have? Ask for examples. Would this be an important factor in deciding whether to manage ……'s care yourself?)
   - Problems setting up the care at the beginning
   - Problems because …… lives in a rural area
   - Change
   - Extra responsibility
   - Extra work/paperwork
   - Problems because it is too complicated (e.g. setting up a bank account/employing people)
   - Lack of available (high quality) services to choose from (rural/transport issues?)
   - Lack of information about available services
   - Dementia-related – e.g. memory problems

7. If you and …… started using social care again, is there anything you would do differently?
   - Is there anything you wish you had known?
   - Can you think of any ways in which the care could be improved?

Cohort 1 - Social worker

1. Tell me about the social care that …… has.
   - What care does he/she have from Social Services altogether?
   - Does he/she have any care from anywhere/anyone else?
   - Has …… had any choices in the way that his/her care is provided?
   - What is your role in supporting …… at the moment?
   - How much involvement does …… have in his/her care? Does he/she have to do anything to organise it or is this all done by Social Services?
   - If applicable: Does he/she have any help to do this? (e.g. from family/friends/neighbours)

2. Has …… had any problems with his/her care?
   - Problems with carers: e.g. different/unfamiliar carers, carers not turning up on time, problems with actual care (e.g. not enough/not the right type)
   - Problems with times: e.g. carers not coming at the time he/she would like
   - Problems with day centres
   - Could using direct payments help solve this problem/these problems?

3. Have you offered direct payments to …… as an option?

   If yes:
   - When did you offer direct payments as an option? At the first visit? If not, why not?
   - How did you go about offering direct payments to ……?
   - What information did you provide? Format?
   - Tell me about how you helped …… decide whether to use direct payments or have fully managed support.
   - Were there any factors that made offering …… a direct payment difficult?
   - What was ……'s reaction to direct payments as an option?
   - Do you think …… fully understood what direct payments were? Do you think he/she retained this information?
   - Why do you think …… decided not to take up direct payments?
   - Did …… have any initial questions or concerns about using direct payments?
   - Who was involved in the decision of whether to use direct payments?
   - Have you offered direct payments to …… again since? Why? (repeat above questions as applicable)

   If no:
   - Why not?
   - Were there any factors that would have made offering …… a direct payment difficult? (e.g. lack of understanding)
   - Would you have offered direct payments to …… if ……? (e.g. if he/she had help)

4. Does …… use direct payments for respite?
   - If yes: Why has he/she chosen to do this? Why has he/she chosen to use direct payments only for respite?
   - If no, why not?

5. What problems do you think …… might have if he/she used direct payments?
   - Problems associated with living in a rural area
   - Increased paperwork/responsibility

- Lack of available services/high quality services
- Difficulties sorting out financial aspects of direct payments
- Difficulties sorting out employment aspects of direct payments
- Dementia-related (e.g. memory) problems
- Problems with initial set-up
- Change
- Too complicated
- Lack of information about available services

6. How much support do you think …… would need to be able to use direct payments?
   - Can you think of anything that would enable …… to use direct payments?
   - Do you think …… would be able to use direct payments independently after the initial set-up stage?

7. Can you think of any ways in which using direct payments could benefit ……?
   - Increased control?
   - Higher quality/personalised care?
   - More care?
   - More independence/choice?
   - Change in day-to-day activities? / More leisure time?
   - Having someone familiar to provide care?

8. Overall, do you think direct payments would be a better or worse option for …… than fully managed care?
   - Why? What would be better/worse?
   - Can you think of anything that would be better/worse about it?
   - Do you think that if …… had chosen to use direct payments it would have been a success? Why/why not?
   - How would your role in supporting …… change if he/she chose to use direct payments? Would this be more/less work for you?

9. Can you think of anything that would have made it easier for you to offer direct payments to ……?

Cohort 2 - Carer

1. Tell me about how you and …… have used direct payments.
    - How have you chosen to spend the money?
    - Why did you and …… choose to spend the money in this way?
    - Have you employed anyone? If yes, who have you employed? What do they do?
    - Why did you and …… choose to employ this person?
    - Does anyone else help ……? Who? In what ways do they help?
    - What is your role in managing the direct payment?
    - How much is …… involved in managing the direct payment/ making decisions about the direct payment?

2. How did you find out about direct payments? / When did you first hear about direct payments?
    - Did the information you were given about direct payments influence your decision?
    - Do you think the way you were offered direct payments could have been improved?

3. Why did you and/or …… decide to use direct payments? / What made you come to the decision to use direct payments?
    - Are there any other reasons?
    - Were there any reasons you were reluctant to use direct payments?
    - What/who helped/hindered your decision?
    - Do you think you would have come to the same decision if ……?
    - How much was …… involved in the decision to use direct payments?
    - Do you think …… would have still chosen to use direct payments if you weren't able to support him/her? If yes – how do you think he/she would have managed?

4. How has using direct payments affected your lives?
    - Mood / Health
    - Independence / Choice
    - Day-to-day activities - care-related, social, recreational
    - Amount of paperwork, etc.
    - Amount of leisure time – alone/together

5. Have you or …… had any help to use direct payments?
    - Who have you had help from?
    - What kind of help have you had? How has this helped you?
    - Have you had enough help to use direct payments? If no, what kind of help would it be useful for you to have?

6. Have you or …… had any problems using direct payments?
    - Initial/set-up problems
    - Problems associated with living in a rural area
    - Change (if relevant)
    - Bureaucracy/paperwork/increased burden
    - Financial problems
    - Employment issues
    - Interactions with professionals
    - Lack of available (high quality) services to choose from (rural/transport issues?)
    - Lack of information about available services
    - Dementia-related – e.g. memory problems

- How did you feel when [problem] happened? What did you do?
- Did you have any help to sort this problem out? If no, what kind of help would you have found useful?

7. Have you and/or …… benefitted from using direct payments?
   - Increased control/choice/independence?
   - Higher quality care?
   - More personalised care?
   - Do you think using direct payments has been a success for you and ……?

8. [If applicable] How is using direct payments different to having social care services managed by Social Services/the Council?
   - Differences relating to independence/choice/control
   - Quality of care/personalisation of care
   - Financial
   - Employment/paperwork
   - Better/worse?

9. If you and …… started using direct payments again, is there anything you would do differently?
   - Is there anything you wish you had known?
   - Can you think of anything that would have helped you/made using direct payments easier?
   - Can you think of any ways in which direct payments could be improved?
   - Is there any advice you would give to someone who is deciding whether to use direct payments / is about to start using direct payments?

Cohort 2 - Social worker

1. Tell me about your experiences of supporting …… to use direct payments?
   - What kind of support have you provided?
   - How much support has …… needed to use direct payments?
   - Has …… needed any additional support to use direct payments (e.g. from voluntary agencies)?
   - How did/do you feel about your role of supporting …… to use direct payments?
   - What preparation did you have in order to carry out this role? (e.g. training) Did/do you feel adequately prepared/equipped?
   - What support did/do you have to carry out this role?

2. Tell me about how you helped …… to decide whether to use direct payments or have his/her support managed by Social Services?
   - When did you offer direct payments to …… as an option?
   - What information did you provide? Format?
   - Did he/she have any questions or concerns about using direct payments?

3. Have you encountered any problems in supporting …… to use direct payments?
   - How did you feel?
   - What did you do?
   - Did you have any support in resolving these problems?

4. In your opinion, has …… using direct payments been a success?
   - Why? / Why not?
   - If yes, what factors have contributed to this?
   - How do you think ……'s use of direct payments could be improved?

5. Has …… experienced any problems using direct payments?
   - Problems associated with living in a rural area
   - Initial set-up difficulties
   - Interactions with professionals
   - Bureaucracy/increased burden
   - Lack of services/high quality services
   - Financial problems
   - Employment issues
   - Dementia-related – e.g. memory

6. Has …… experienced any benefits of using direct payments?
   - Increased control?
   - Higher quality care?
   - More personalised care?

7. How has supporting …… to use direct payments been different to supporting service users with similar needs to access social care services managed by Social Services?
   - Better/worse?
   - More/less work?

8. Can you think of anything that would have made it easier for you to support …… to use direct payments?

Cohort 3 - Carer

1. Tell me about the social care that …… has.
   - Who provides this care?
   - Is any of ……’s care provided by Social Services?
   - Does anyone else help ……? Who? In what ways do they help?

2. Tell me about how …… first started receiving care?
   - How did you come to contact Social Services?
   - What happened when you first contacted Social Services?
   - What options were you given regarding ……’s care?

3. What is your role in managing ……’s care?
   - How much is …… involved in making decisions about his/her care?
   - Have you employed anyone? If yes, who have you employed? What do they do?
   - Why did you and …… choose to employ this person?
   - How did you go about employing this person? (e.g. advertising, recruitment, tax, contract, etc.)
   - Have you arranged any other sort of care? (e.g. day activities, respite, etc.)
   - Has Social Services given you any help with arranging or managing ……’s care? What sort of help?
   - Have you had any other help with this? What sort of help?
   - Have you had enough help? If no, what kind of help would it have been useful for you to have?
   - Do you think …… would have been able to arrange his/her care if you weren’t able to help him/her? How do you think he/she would manage? / What support would he/she need?

4. Have you and …… had any problems with his/her care?
   - Problems with carers (e.g. different/unfamiliar carers, not turning up on time)
   - Problems with times (e.g. carers not coming at the time you would like)
   - Problems with day centres (if applicable)
   - Problems with care (e.g. not enough, not the right type, poor quality)
   - Have you had any other problems?

5. Were you given the option of having ……’s care fully or partially managed by Social Services?
   - If yes: Did you choose to do this? Why/why not?
   - If no: Would you have preferred ……’s care to be managed by Social Services rather than managing it yourself? Why/why not?

6. What do you think the bad points of having ……’s care managed by Social Services rather than managing it yourself would be/are?
   - Less control/choice
   - Less independence
   - Change in day-to-day activities
   - Lower quality care
   - Less personalised care
   - Less actual care
   - Lack of familiarity with carers

7. What do you think the good points of having ……'s care managed by Social Services rather than managing it yourself would be/are? (How important is each of these things to you? How does/would this benefit you? Ask for examples)
   - Less responsibility
   - Less paperwork/organisation
   - More cost-effective care

8. What do you think the good points are/would be about managing ……'s care yourself? (How important is each of these things to you? How does/would this benefit you? Ask for examples)
   - More independence/choice (e.g. carers coming in at times that suit you, choice over type of care/activities/carers)
   - Improved mood/health
   - Change in day-to-day activities (care related, social, recreational)
   - Having someone familiar to provide care
   - Higher quality care
   - More personalised care

9. What do you think the bad points are/would be about managing ……'s care yourself?
   - Problems setting up the care at the beginning
   - Problems because …… lives in a rural area (e.g. transport issues)
   - Change
   - Extra responsibility
   - Extra work/paperwork
   - Problems with financial aspects (e.g. tax)
   - Problems employing people
   - Lack of available (high quality) services to choose from
   - Lack of information about available services
   - Problems relating to dementia (e.g. memory problems)

   If applicable: What did you do when [problem] happened? Did you have any support to sort this problem out? If no, what kind of help would you have found useful?

10. Do you think managing ……'s care yourself has been/would be successful?
    - How do you think ……'s care would be different if it was managed by Social Services / managed by you? (e.g. Differences relating to independence/ choice/ control? Differences relating to quality of care/personalisation of care? Differences relating to responsibility/workload?)
    - Overall, do you think it would be better or worse?

11. If you and …… started the process of having care again, is there anything you would do differently?
    - Is there anything you wish you had known?
    - Can you think of anything that would have made it easier for you to manage ……'s care?
    - Is there any advice you would give to someone who is about to start managing a relative's care?

Cohort 3 – Social worker

1. Tell me about the social care that …… has.
    - What care does he/she receive altogether?
    - Who provides this care?
    - Does he/she employ anyone? If yes, who? What do they do?
    - Do you know how this person/these people were found / why they were chosen?
    - Has he/she used day centres?
    - Has he/she used respite care?
    - Who manages …… care altogether? Social Services/family/friends?
    - Does anyone else help ……? Who? In what ways do they help?

2. Tell me about how …… first started receiving care / At what point did you first become involved?
    - When did …… or his/her family/friends contact Social Services?
    - What happened then?
    - What options were …… and/or his/her family/friends given regarding his/her care? For example, could they manage the care themselves or have it managed by the Local Authority?

If applicable:

- What information did you provide …… and/or his/her family/friends with about these options? Format?
- Tell me about how you helped …… decide whether to manage the care themselves or have it managed by Social Services?
- Did you present equal amounts of information about both options, or did you feel …… was more suited to one or the other?
- What was ……'s reaction to these options?
- (If not already answered): What did they choose to do?
- Why do you think they decided to do this?
- Who was involved in the decision? Was …… able to be involved in the decision?
- Have you offered these options again since? When? Why?
- Did …… have any initial questions or concerns?
- What does …… have to do altogether to manage ……'s care?
- Does …… have any involvement in managing his/her own care? / How much is …… involved in making decisions about his/her care?

3. What is your role in supporting …… / his/her family/friends at the moment? / What kind of support have you provided?
    - How much support has …… needed?
    - Have you had to support …… with employing carers? What support did you provide?
    - Has …… needed any additional support to manage ……'s care? Where did they get this support? Are they eligible for any support or advice from the local support organisation?
    - Can you think of any other support that it would be useful for them to have?
    - How do you think …… would manage if he/she had no friends or family to help him/her manage his/her care? What/how much support would he/she need? Would this be provided by Social Services?
    - Have you encountered any problems in supporting …… and his/her family/friends? What did you do?

- How much support is generally provided by the Local Authority for self-funders? / What do Social Services have a duty to provide?

4. Have there been any problems with ……'s care?
   - Problems with carers (e.g. different/unfamiliar carers, not turning up on time)
   - Problems with times (e.g. carers not coming at a suitable time)
   - Problems with day centres (if applicable)
   - Problems with respite (if applicable)
   - Problems with care (e.g. not enough, not the right type, poor quality)
   - Problems associated with living in a rural area
   - Lack of available services / high quality services
   - Lack of information about available services
   - Paperwork/extra work/responsibility
   - Difficulties sorting out financial aspects
   - Difficulties employing carers
   - (If applicable): Cover for PAs (e.g. when on holiday/off sick)
   - (If applicable): Training for PAs - Is this difficult to organise?
   - Dementia related (e.g. memory) problems
   - Problems with initial set-up
   - Have there been any other problems?

   - What did you do when …… happened?

5. Can you think of any ways in which managing the care themselves benefits / would benefit …… and his/her family/friends?
   - Increased control/independence
   - More choice (e.g. over the time carers come, care activities)
   - Higher quality/more personalised care
   - More care for the money
   - Having someone familiar to provide the care
   - More flexibility

6. Overall, do you think managing the care themselves / having the care managed by Social Services would be a better or worse option for …… and his/her family/friends than what they do now?
   - Why? What would be better/worse?
   - Can you think of anything that would be better/worse about it?

   - If …… had chosen to manage his/her own care do you think it would have been a success? Why/why not?
   - OR - In your opinion, has managing his/her own care been a success for ……? Why/why not? If yes, what factors have contributed to this?
   - How would your role in supporting the family change if they chose to manage ……'s care themselves / have the care managed by Social Services? Would this be more/less work for you?

7. Can you think of anything that would have made it easier for you to support ……?

Appendix 11

NVivo codes

Code name	Sources	References
Evaluating net benefit of direct payments (DP)	27	946
Perceived disadvantages (or lack of benefits) of taking up DP	27	514
DP difficult or a lot of work to take on	26	215
Finding DP easy to manage	20	55
DP easy to manage	8	21
DP easy to manage once set up	8	11
Carer wouldn't have any problem managing DP	2	7
Carer confident in managing DP	3	6
DP easy to set up	4	4
No reluctance about taking on DP	2	2
No problem recruiting carers	1	1
Recruitment in rural area not a problem	1	1
Service users (SUs) take time to get used to DP	1	1
SUs using DP more independently as time goes on	1	1
DP more work for carer	12	19
DP difficult to understand	6	11
DP more stressful for family carer	5	9
Set up processes and paperwork too onerous	4	9
Set-up difficult	4	9
Easier to manage DP if SUs don't become an employer	6	8
DP more work for social worker (SW)	2	8
Problems with sorting out tax	2	8
Difficult to manage DP when multiple personal assistants (PAs) needed	5	7
Difficulties when family member is the PA	2	6
No clear guidance on how DP can be spent	1	6
Difficult to arrange cover for PAs	4	5
Difficult to work to a budget	3	5
DP no more work for SW	4	5
Like running a business	2	5
Needing to arrange cover for PAs	3	5
SW confused about processes	2	5
DP a full-time job for carer to manage	3	3
Overwhelmed with information	2	3
Problems with separate bank account	1	3
Processes too onerous for small budget	1	3
Advertising for PAs	2	2
DP more complicated to manage	2	2
DP more work for SW to set up	2	2
Fully supported is no work for the carer or SU	2	2
Difficulty recruiting PAs	1	1
Difficulty replacing carers when employing own PAs	1	1
Like doing an admin job	1	1
Older people may need a less complicated DP	1	1
Processes assume that SUs aren't trustworthy	1	1
SU muddling through managing the DP	1	1
SUs having to employ a team of PAs to ensure cover	1	1
SUs take time to get used to DP	1	1
Using an agency a good halfway to being an employer	1	1
Using PA more personalised and flexible than paying for agency with DP	1	1
Not wanting to take on the extra work or responsibility of DP	18	95
Carers not wanting to take on the responsibility	8	20
Carer doesn't want to take on extra work	9	16
Not wanting to employ people	6	12
Carers too busy to take on DP	7	9
Older SUs don't want the responsibility of DP	7	8
Would prefer to use a care agency	3	6

Code name	**Sources**	**References**
SUs more willing to take on DP for respite	3	5
Carer or SU just wanting help and to have care organised for them	3	4
Too much bureaucracy and paperwork putting SUs off	2	4
Wouldn't want to take on employment responsibilities	2	4
Balancing benefits and extra work of DP	2	2
DP more suitable for younger SUs	2	2
Carer not wanting to take on additional caring role	1	1
SUs understood DP	1	1
Wouldn't want to sort out tax	1	1
Organisational barriers to DP	15	81
DP taking a long time to set up	10	22
Block purchasing	6	18
Can't access in-house care with a DP	2	11
Not allowed to use self-employed carers	2	11
Combined DP	4	6
Can't book respite with DP in advance	2	3
SUs not understanding restrictions	1	3
Difficulties when SUs go into hospital	1	2
CHC funding not working with DP	1	1
Payment issues - Council	1	1
SUs not able to use family member as PA	1	1
SWs needing to jump through hoops to set up a DP	1	1
DP wouldn't make much difference	5	18
Safeguarding concerns	10	15
Training for PAs	9	14
DP can't completely solve problems	10	12
Budget inadequate	5	11
Person with dementia (pwd) doesn't want any extra care outside the home	7	11
DP wouldn't benefit pwd	5	7
Extra costs	5	6
Not a secure job for PAs	2	5
Carer liaising directly with care agency	2	4
Lack of monitoring and support for PAs	1	3
Belief that DP would mean SUs get less money	1	2
Care agencies having insurance cover	1	2
Familiar carers only good if carers are good	2	2
Some budgets too small to benefit from DP	2	2
Can do personalised activities with care agency staff	1	1
Can't see why service user would want DP	1	1
DP provides more flexibility even where care agency is used	1	1
Easier for SW to organise respite care	1	1
Inequity in rural areas as DP taken up with transport costs	1	1
Need to use a care agency anyway	1	1
Some choice with agency carers	1	1
Perceived benefits of taking up DP	26	432
Flexibility of DP an advantage	16	51
Familiarity beneficial with DP	17	47
DP gives greater control	18	40
DP giving more choice	17	35
Better to have family member as carer	7	30
DP allowing SU to have more care	8	29
DP allowing SU to procure affordable care	8	21
DP enabling pwd to stay at home	9	21
Continuity an advantage of DP	7	19
DP allowing SU to procure better care	6	12
DP less work for SW once set up	5	11

Code name	**Sources**	**References**
DP can enable person-centred care	5	10
DP better for family	4	8
Merging two DP allowing more care	4	8
Wanting care outside the home	4	8
Important for pwd to remain in their own home	3	7
DP allowing carer to have flexibility and freedom	2	6
More job satisfaction with DP	4	6
DP better for family carer	4	5
DP better value for money	5	5
Flexibility particularly important for pwd	5	5
Balancing benefits and extra work of DP	3	4
DP funded care can be more reactive to needs	4	4
DP would cut down work for the Council	3	4
DP making things easier	2	3
Using DP to provide 24-hour care	2	3
Can always change back from DP	1	2
Carer knows the pwd best	2	2
DP an exciting new way of working	1	2
DP better as it cuts out the middle man	2	2
DP giving people new choices and improving lives	1	2
Need certain type of PA	1	2
No problems related to rurality	2	2
SWs seeing the benefits of DP	1	2
DP a positive experience	1	1
DP allowing more creativity	1	1
DP cheaper for Council	1	1
DP provides more flexibility even where care agency is used	1	1
DP suitable for people with more advanced dementia	1	1
Easier for local carers to be flexible	1	1
Longer visits better than split visits for pwd	1	1
More job satisfaction for PAs	1	1
No SUs have cancelled a DP	1	1
Only advantage of DP is that SU could get more care	1	1
PAs taking more pride in their work	1	1
Privately employed carer might be better	1	1
Satisfaction higher with DP	1	1
Using DP for respite can reduce bureaucracy	1	1
Balancing benefits and extra work of DP	2	2
Perceived ability to manage DP	28	560
Availability of support	28	281
Need family carer	26	123
Need family carer to cover additional care not covered by DP or fully supported package	12	27
Need certain type of carer	5	11
Carer confident in managing DP	4	7
Carer wouldn't have any problem managing DP	2	7
Need younger family carer	5	6
Prior knowledge or experience of carer useful	2	3
Enthusiastic family carer	1	2
Need a good support network	4	6
Possible to have DP with no family carer	1	3
Carer knows the pwd best	2	2
Wouldn't want children to have to take on responsibility	1	1
SU couldn't manage DP without support	25	88
Involvement of pwd in decision making	23	36
Pwd couldn't manage DP on their own	14	23
Pwd believing they don't need care	7	16

Code name	**Sources**	**References**
Need for support	4	5
SU not eligible for care until their dementia is too advanced to manage a DP	4	5
Isolation in rural areas	3	3
Need support organisation	16	61
Support organisation charges	7	14
Referral to support organisation	11	13
Having more than one support organisation would be useful	1	1
Would be useful for support org to link up with SW teams	1	1
Would still have taken up DP without support organisation	1	1
Support provided by SW	7	9
Support it would be useful to have	3	7
Would be useful to have support with tax	1	3
Would be useful to have a database of PAs to recruit from	1	3
Would be useful for SU to speak to people already on DP	1	1
Confidence	24	187
Worries about taking on DP	18	113
DP daunting at first	9	30
Worries relating to PA recruitment	10	29
Wouldn't know how to recruit PAs	5	7
Carer daunted by the thought of recruiting PAs	1	6
Anticipated difficulty recruiting PAs in rural area	3	5
Worries about recruiting suitable PAs	3	5
Advertising for PAs	2	2
Wouldn't know how to select a good care agency	1	2
No anticipated problems in recruiting	1	1
Worries about keeping established PAs when switching to DP	1	1
Worries about becoming an employer	8	20
SW needing to provide reassurance	4	8
SU scared of misusing DP	3	7
Worries about financial management of DP	4	5
Carers overestimating time DP would take to manage	2	4
SU unsure of how DP can be spent	3	3
Concerns about paperwork	2	2
Worries about tax and national insurance	2	2
Carer daunted by the responsibility of DP	1	1
No worries about taking on additional responsibility	1	1
Worries about reviews	1	1
Finding DP easy to manage	20	55
DP easy to manage	8	21
DP easy to manage once set up	8	11
Carer wouldn't have any problem managing DP	2	7
Carer confident in managing DP	3	6
DP easy to set up	4	4
No problem recruiting carers	2	2
No reluctance about taking on DP	2	2
SUs take time to get used to DP	1	1
SUs using DP more independently as time goes on	1	1
Hard for older people to manage	8	15
Hard for pwd to manage	2	4
Availability of suitable contacts and services	23	92
Availability of personal contacts	18	50
Carer using personal contacts to employ PAs	9	20
Agency or PAs already identified	3	7
SU preferring to use recommended PA or PA they know	4	6
Importance of recommendations of care agency	3	5
SUs wanting family member as PA	3	3

Code name	**Sources**	**References**
Advertising for PAs	2	2
Useful to have contacts	1	2
Carer considering poaching agency carers	1	1
Easier to recruit in close-knit rural communities	1	1
Employing family members as PAs	1	1
Important to recruit the right PAs	1	1
Worries that pwd or carer may not like agency carers	1	1
Availability of local care agency	7	10
Less choice in rural communities	9	10
Availability of local PAs	3	3
Important to have PAs trained in dementia	2	3
Isolation in rural areas	3	3
Lack of suitable respite care services	3	3
Limited choice of specialist dementia care	2	3
More services becoming available	1	2
Older SUs not keeping themselves informed of what's available	2	2
Lack of awareness of available services	1	1
Might have problem recruiting certain type of PA	1	1
No anticipated problems in recruiting	1	1
Acceptance of current situation	28	446
Satisfaction	28	400
Push factors causing SUs to consider DP	28	262
Problems with agency care	25	197
Familiarity of care agency staff	18	36
Agency carer timings not convenient	11	22
Agency carers not turning up on time	8	18
Continuity important for pwd	7	12
Pwd not liking agency carers	5	12
Agency care not flexible	7	10
Safeguarding concerns	6	9
Agency carers not skilled or experienced	4	7
Agency carers travelling a long way	5	7
Problems with agency carers	4	7
Agency carers not completing required tasks	4	6
Not wanting to have strangers come to the home	4	6
Agency carers not letting SUs know if they're running late	3	5
Problems in poor weather	5	5
Agency carers rushed or not working for required time	3	4
Pwd can't report when carers are not doing their job	4	4
Agency care plan not being updated	1	3
Agency carers not turning up	3	3
Agency not telling SU which carers will be visiting	2	3
Length of agency care visits inadequate	3	3
Agency carers not caring	1	2
Care agency organisation poor but carers good	2	2
Cultural issues with care agency	2	2
Agency carers not as good as PAs	1	1
Fully supported more stressful for carer	1	1
Problems with agency carers giving medication	1	1
DP allowing SU to procure affordable care or agency care unaffordable	11	27
Transport difficulties	9	12
Less choice in rural communities	9	11
Problems with day centre	8	11
Problems with Council on managed care	1	3
Better for pwd to have care at home	1	1
Familiarity of care agency staff	14	26

Code name	Sources	References
Acceptance of problems with care	7	23
Continuity of agency carers	6	14
Can still have choices with managed care	6	13
Continuity important for pwd	7	12
Flexibility of care agency	3	5
SU not satisfied with alternative care agencies	1	4
Desire for change	15	46
SUs not wanting change	8	21
Older people less likely to want DP	10	13
SU not interested in taking on DP	3	7
Carer or SU just wanting help and to have care organised for them	3	4
SUs outdated expectations	1	1
Direct payments a second option	26	398
Direct payments as a solution to problems	26	292
Problems with existing care	19	59
Continuity of agency carers	6	14
Problems with agency carers	5	8
Problems with day centre	6	8
Agency carers travelling a long way	5	7
Pwd not liking agency carers	4	7
Agency care not flexible	4	6
Problems in poor weather	5	5
Not wanting to have strangers come to the home	2	4
Needing more care	10	44
Familiarity important for pwd	13	29
Better to have family member as carer	7	27
DP a solution to problems	12	26
DP enabling pwd to stay at home	9	21
Transport difficulties	9	12
Continuity an advantage of DP	6	11
Less choice in rural communities	8	9
DP better for family	4	8
DP allowing carer to have flexibility and freedom	2	6
Important for pwd to remain in their own home	3	6
DP beneficial for SUs in rural communities	3	5
Flexibility particularly important for pwd	5	5
Problems with agency causing SUs to consider DP	2	4
DP better value for money	3	3
DP making things easier	2	3
SUs in rural areas more likely to take up DP	2	3
SUs wanting family member as PA	3	3
DP better as it cuts out the middle man	2	2
Better for pwd to have care at home	1	1
Better to have local carer	1	1
Difficulty switching agency as too expensive	1	1
Not many in-house dementia services so need DP	1	1
Problems with existing care an opportunity for SW to promote DP	1	1
Rural SUs employing local PAs	1	1
Direct payments the only option	12	57
DP enabling pwd to stay at home	9	26
Pwd needing 24-hour care	6	10
Would have taken up DP even if it wasn't the only option	2	2
Direct payments a second option	14	49
Offering of direct payments	23	213
Timing	19	92
SUs need time to decide about DP	9	22
Difficult to offer or present DP at crisis point	8	20

Code name	Sources	References
DP not offered initially or at all	8	16
DP offered initially	5	6
Usefulness of setting up interim care package	4	6
Need time to set up or move on to DP	3	5
SUs reluctant to get Social Services involved or engage in services in the first place	3	5
Important for SUs to know about DP at an early stage	2	3
Overwhelmed with information	2	3
Better to present information in stages	2	2
DP not always offered at review	2	2
SUs not wanting DP initially	1	2
Promotion	17	66
Promotion of benefits of DP by SW	9	17
Need SW available to answer questions	4	8
Proactive SW	2	8
SW positive about DP	4	7
Encouragement from SW	4	6
Being able to tell SUs their assessed charge up front would be helpful and could increase uptake	1	3
Overwhelmed with information	2	3
Presentation of potential drawbacks	3	3
SWs confidence in presenting DP	1	3
DP information easy to understand	2	2
Promotion or lack of of DP by health professionals	2	2
Way DP presented by SW is important	1	2
Hearing about good DP experiences makes SUs more likely to take up DP	1	1
Would be useful to have short booklet explaining DP to give to SUs	1	1
Selective offering	20	44
DP not offered initially or at all	8	16
DP offered by SW	7	7
Selective offering of DP	5	7
DP offered initially	5	6
SW assumed fully supported would be best	1	3
Would have liked to have been offered DP	3	3
Paperwork putting SWs off offering DP	1	1
SW more likely to offer DP for respite	1	1
Precedence	6	11
SW only offered DP	3	6
SW didn't give enough info about DP	2	3
Responsibility of encouraging SUs to take up DPs	2	2

Appendix 12

Pilot intervention information booklet

University of Worcester
Henwick Grove
Worcester
WR2 6AJ
01905 542296
dementia@worc.ac.uk
www.worc.ac.uk/discover/association-for-dementia-studies

Part 2: An evaluation of a pilot intervention aimed at increasing direct payment uptake by older people in Worcestershire through offering combined direct payments

Information about the research

We would like to invite you to take part in our research study. Before you decide whether you would like to take part, we would like you to understand why the research is being carried out and what it would involve for you. Please contact us using the details provided if anything is not clear, or if you have any questions. Talk to others about the study if you wish.

What is the purpose of the study?
The purpose of the study is to find out whether offering combined direct payments to service users in some instances is effective in increasing direct payment uptake amongst older people living in Worcestershire. For the purpose of this study, a combined direct payment is defined as one where a service user has part of their personal budget paid directly to them on a regular basis while part is kept and managed by the Local Authority.

Why have I been invited?
You have been invited to take part because you offer direct payments to service users as part of your role.

Do I have to take part?
It is up to you to decide whether to take part in the study. You are free to withdraw from the study at any time, without giving a reason.

What will happen to me if I take part?
A researcher will deliver a session to your team focusing on offering combined direct payments. This session will be developed with input from your team.

Following the session you will be invited to take part in a discussion with the researcher about your experiences of offering combined direct payments to service users. It is up to you whether or not you take part in this discussion. We are interested in your opinions so there are no right or wrong answers. The discussion would take around half an hour and could take place in a private meeting room at your offices or at the University of Worcester if you would prefer this. All discussions will be tape recorded. If you decide to take part in the discussion, the researcher will ask you to sign a consent form.

What are the possible benefits and disadvantages of taking part?
We cannot promise the study will help you, but the information we learn from this study will help inform future practice in this area. The combined direct payments session will take around two hours of your time. If you decide to take part in the discussion with the researcher, this will take around half an hour of your time.

What if there is a problem?
If you have a concern about any part of this study, please ask to speak to Sarah Milosevic or her supervisor Dr Simon Evans who will do their best to answer your questions.

Will my taking part in the study be kept confidential?
Yes. This means that we will not tell anyone you have taken part in the study, and only researchers involved in the study will have access to records that identify you. What you say during discussions with the researcher may be included in our report but you will not be named.

Everything you say is confidential unless you tell us something that indicates that you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

Any information that is collected about you will be stored securely at the University in a locked filing cabinet or on a password-protected computer. Any information about you that leaves the University will have your name removed so that you cannot be recognised. Information about you will be kept for no longer than five years and will be disposed of securely.

What will happen if I do not want to carry on with the study at any time?
You are free to withdraw from the study at any time, without giving a reason. The information collected up to the point at which you withdraw may be retained and used in the report of the research.

What will happen to the results of the study?
A report of the research findings will be made to Worcestershire County Council. This report will also be submitted as part of a PhD thesis at the University of Worcester and may be published. You will not be identified in the report. If you wish, you can receive a copy of the report.

Who is funding the research?

This research is funded by the University of Worcester and Worcestershire Public Health.

Who has reviewed the study?

This study has been reviewed and given a favourable opinion by Worcestershire County Council and the University of Worcester.

Further information and contact details

If you would like any further information about this study, please contact Sarah Milosevic, preferably by email at s.milosevic@worc.ac.uk. Alternatively, please telephone 01905 542295 and leave a message.

Thank you very much

Appendix 13

Pilot intervention reminder card

Combined direct payments intervention

Aim is to offer combined direct payments as another option to service users who do not want to take up full direct payments:

- Offer to new service users
- Offer at annual reviews

Combined direct payments may be a good option for service users who:

- Don’t want to employ anyone themselves but might be interested in an alternative to a day centre (see website for local day opportunities)
- Are daunted by the thought of managing their whole care budget themselves but would like greater control of their care
- Might want to keep attending a Local Authority funded day centre but employ personal assistants themselves
- Are likely to benefit from using direct payments but don’t want to take on the whole responsibility initially

Appendix 14

Pilot intervention session ideas sharing document

Combined direct payments: Ideas sharing

Examples of service users using combined DP

David

- Uses a block booked day centre but employs his own carers.
- This is beneficial as he enjoys going to the day centre so didn't want to change this, but he and his family are able to employ people they know to provide care at other times.

Paul

- Uses agency carers for personal care, and employs people he knows using direct payments for social activities.

Jean

- Uses one care agency, using the fully supported part of her personal budget to pay for day-to-day personal care, and the direct payment to pay for ad hoc carers from the same agency for social activities.
- This means that the family carer can phone up when a carer is needed for extra activities, giving the family more flexibility.

Ways you suggested of offering combined DP

Make direct payments meaningful to the person

- Spend more time if possible on the support plan and getting to know the person better: e.g. finding out about their hobbies
- Don’t start by focusing on the bureaucracy (e.g. by telling them they will have to open their own bank account, etc.)
- Start by making suggestions as to how having a direct payment could work for them, and give them information about suitable day opportunities available in their area
- Give real examples of other, similar service users who are using direct payments.

Think about the existing support network

- If a person already has a good relationship with their carers, or a family member or friend provides their care, suggest that they use direct payments to employ these people, or to pay their current care agency directly so that they have more control and flexibility.

Service users who may benefit from combined DP

Terry

- Uses a care agency three times a day - he could use the same care agency with direct payments.
- This would enable him to organise things directly with the care agency, giving him more flexibility.
- Suggesting that he could use direct payments for more day opportunities might be a way of getting him interested in direct payments.

Pat

- Has a cognitive impairment and currently receives care from the side-by-side service. She has a good relationship with her carers but is wary of social worker involvement.
- With a direct payment she could use her existing side-by-side carers to do activities with her such as cooking, which she enjoys but is unable to do alone for safety reasons.
- Asking the side-by-side carers to discuss direct payments with her might be helpful.

Sue

- Is an insulin-dependent diabetic who has become forgetful, which makes it difficult for her to manage her diabetes herself.
- She wants to try attending a day centre as she would like more social interaction.
- Alongside this she could use direct payments to pay a family member who already provides care to her. This would also enable her to have a contingency plan for when this family member is not available.

Appendix 15

Pilot intervention evaluation: Pre and post questionnaires

Combined direct payments session
Questionnaire 1

Please do not write your name on this questionnaire.

Combined direct payment definition: For the purpose of this questionnaire, a ‘combined direct payment’ refers to where a service user takes on part of the management of their day-to-day care package while the Local Authority manages the remainder.

Please tick this box if you agree to your answers being used for research purposes. All individual responses will be treated confidentially. ☐

Please circle your response to each of the following questions:

1. How confident are you in presenting combined direct payments to service users?

Not confident at all *Not very confident* *Fairly confident* *Completely confident*

2. How likely are you to offer service users the option of combined direct payments if they do not initially want to take up direct payments?

Not at all likely *Not very likely* *Quite likely* *Very likely*

3. Do you think that offering combined direct payments as another option to service users would result in more service users taking up direct payments (both combined and ‘full’) in total?

No *Maybe* *Yes*

Combined direct payments session
Questionnaire 2

Please do not write your name on this questionnaire.

Please tick this box if you agree to your answers being used for research purposes. All individual responses will be treated confidentially. ☐

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1. How useful has this session been for you? (please circle)

   Not at all useful　　*Not very useful*　　*Fairly useful*　　*Very useful*

   Please write any comments you have about the session in the box below:

2. What will you do differently as a result of attending the session?

3. If one of your colleagues asked you to tell them one benefit of attending the session, what would you say?

4. How confident are you in presenting combined direct payments to service users?

   Not confident at all　　*Not very confident*　　*Fairly confident*　　*Completely confident*

5. How likely are you to offer service users the option of combined direct payments if they do not initially want to take up direct payments?

   Not at all likely　　*Not very likely*　　*Quite likely*　　*Very likely*

6. Do you think that offering combined direct payments as another option to service users will result in more service users taking up direct payments (both combined and ‘full’) in total?

   No　　*Maybe*　　*Yes*

Thank you for your participation

Appendix 16

Pilot intervention evaluation: Interview consent form

NHS Worcestershire
University of Worcester
worcestershire county council
Association for Dementia Studies
University of Worcester, Henwick Grove, Worcester, WR2 6AJ
01905 542296 / dementia@worc.ac.uk

Consent Form - Interview

Part 2: An evaluation of a pilot intervention aimed at increasing direct payment uptake by older people in Worcestershire through offering combined direct payments

Thank you for considering taking part in this research. If you have any questions please ask a member of the research team before you decide whether to take part. You will be given a copy of this Consent Form to keep and refer to at any time.

	Please tick Yes	No
• I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information and ask questions, and have had these answered satisfactorily.	☐	☐
• I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.	☐	☐
• I understand that if I withdraw from the study the information collected up to that point may be retained and used in the report.	☐	☐
• I agree to take part in an interview about my experiences of offering combined direct payments to service users.	☐	☐

Name of Participant (please print) ________________________

Signed ____________________________ Date _____________

Name of Researcher (please print) _______________________

Signed ______________________________ Date___________

Appendix 17

Pilot intervention evaluation: Interview guide

Pilot intervention evaluation interview

1. Tell me about your experiences of offering combined direct payments to service users.
   - When do you offer combined direct payments to service users? (e.g. on the first visit, initially, not at all, or only after they have rejected full direct payments?)
   - What information do you give service users about combined direct payments?
   - How do you help service users to decide whether to use combined direct payments, full direct payments, or fully managed care?
   - Have you experienced any particular difficulties in offering combined direct payments to service users?
   - Is there anything that would make it easier for you to offer combined direct payments to service users?

2. How have service users reacted to the option of combined direct payments?
   - Do service users tend to have any particular questions or concerns about using combined direct payments?
   - In your experience, does offering a combined direct payment to service users make them more likely to take up direct payments? Why do think this is/is not the case?

3. Do you offer combined direct payments to all service users? Why / why not?
   - If yes: Are there any situations where you don't or wouldn't offer combined direct payments?
   - If no: In what situations do you tend to offer combined direct payments to service users? (e.g. to a particular service user group, to service users who are reluctant to take up full direct payments, to service users who you think might particularly benefit)
   - In your experience, have you found that combined direct payments are especially useful for any particular groups of service users?
   - In your experience, have you found that combined direct payments are particularly useful for people with dementia?

4. Are there any differences in setting up combined direct payments compared to setting up full direct payments?
   - More/ less/the same amount of work?
   - Do service users tend to need more or less support at the set-up stage, or about the same?

5. Have you changed your practice around combined direct payments following the combined direct payments session in January?
   - If yes: What do you do differently?
   - If no: Why not?
   - Do you think the session was effective in encouraging social workers to offer combined direct payments as an alternative to service users who are reluctant to take up direct payments? Why/why not?
   - If no: Can you think of an approach that might be more effective? (e.g. a session in a different format/with different content, or something different)
   - Were there any parts of the session you found particularly useful?

   - Are there any ways you think the session could have been improved to make it more effective?

   - Do you now offer combined direct payments to service users more often than you did before the session?
   - Are you more confident about offering combined direct payments to service users now than before the combined direct payments session?

6. Tell me about your experiences of supporting service users to use combined direct payments.
   - Are there any differences in supporting a service user to use combined direct payments compared to supporting service users to use full direct payments? More/less/the same amount of work? Do service users tend to need more or less support, or about the same?
   - Have you experienced any difficulties in supporting service users to use combined direct payments?
   - Is there anything that would make it easier for you to support service users who are using combined direct payments?

7. Do you think service users benefit from using combined direct payments?
   - If yes: What are the advantages of combined direct payments over full direct payments or a fully managed budget? Are there any disadvantages?
   - If no: Why not? Are there any advantages to using combined direct payments over fully direct payments or a fully managed budget?

8. Are there any other ways that you think people with dementia could be helped or encouraged to take up direct payments?