

How Do Peer Networks Enable Service Users and Informal Carers to Obtain and Manage Personal Budgets?

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*“Though I climbed up the highest mountain in view,
Yet contentment was not mine,
For beyond a mountain still higher was looming.”*

Moondog (2017) Moondog Monologue
from *The Viking of 6th Avenue*

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ABSTRACT

Background:

Since 1997, a growing proportion of United Kingdom citizens have been able to obtain a personal budget (PB) and spend it on their own support instead of using state-run health and social care services. Early studies of PBs found schemes that involved disabled people's organisations and other peer networks (PNs) had significant advantages. However, the rapid increase in the use of PBs led to support being commissioned from a much wider range of organisations, and such schemes dwindled to a small proportion.

Literature review:

A systematic search of research databases and cascade search supplemented by expert suggestions identified forty-five relevant research reports published between 1997 and 2016. Data were aggregated and then subjected to a thematic analysis. The scheme developed to aggregate data shows that the supports provided by PNs could be grouped according to the different stages of obtaining and managing a PB. The approaches PNs used included fostering collaboration between individual PB users and between local agencies, enhancing communication with PB users, increasing people's confidence about managing a PB, and applying specialist knowledge typically derived from lived experience.

Focus group study:

Applying the principles of emergent design within a critical constructionist framework, a secondary focus group study was developed. Three groups with a total of sixteen participants were held in the autumn of 2015, using a topic guide drawn from the literature review. Thematic analysis was again used to interpret the data.

Results:

While the collective approaches of PNs remain characteristic, there is considerable variation in practice between individual PNs. The support they provide can be characterised

by two principal roles. Firstly, people are supported practically and emotionally to develop the skills necessary to manage PBs. Secondly, PNs mediate between the individual personal budget user and the agency funding the PB. To achieve this, they must manage competing tensions in their relationships with members and external bodies.

Practice theory development and modelling:

Bourdieu's practice theory is applied and extended to model the relationship between peer identity, organisational culture and the support provided by peer networks. Peer support is conceptualised in terms of social capital. The characteristic approaches evolved by PNs are interpreted as cultural capital, often developed as cultural artefacts. The educational and emotional dimensions of peer support are interpreted respectively in terms of shared social practice and emotional capital. The empowering effect of PBs can be thought of as moving economic capital from the social field of health and care systems to that of the PN, where the field rules are more closely aligned with the life goals of PB users. PNs' success in mediating between PB users and statutory bodies is dependent on social capital, which itself is derived from economic capital invested by both statutory bodies and network members. The impact of progressive cuts to the funding of PNs and the sums allocated to individual PB users has depleted the cultural capital within PNs and the wider social field of health and care systems.

Conclusions:

The theoretical approach can be seen in the context of a revival of interest in Bourdieu. It provides an alternative to naïve market models to account for the emancipatory potential of personal budgets, and supplements activist models for the effectiveness of user-led organisations. Reversing a recent policy of disinvestment in PNs would allow them to play a positive role in the implementation of personalised care in the English NHS and the continuing transformation of adult social care services, and many of the approaches they have developed could be learned and applied successfully by others working in health and social care services.

DEDICATION & ACKNOWLEDGEMENTS

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ABBREVIATIONS

ASSIA	Applied Social Sciences Index and Abstracts
CHC	Continuing health care
CIL	Centre for Independent Living
CINAHL	Cumulative Index to Nursing and Allied Health Literature
COREQ	Consolidated criteria for reporting qualitative research
DP	Direct payment
DPULO	Disabled people's user-led organisation
HACT	Housing Associations Charitable Trust
ILT	Independent Living Trust
LTID	Long-term limiting illness or disability
NCIL	The National Centre for Independent Living
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
PB	Personal budget
PHB	Personal health budget
PN	Peer network
ODI	Office for Disability Issues
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SDS	Self-directed support
UK	United Kingdom of Great Britain and Northern Ireland
ULO	User-led organisation

CHAPTER 1: BACKGROUND AND INTRODUCTION

The aim of this section is to provide a brief introduction to personal budgets (PBs) and the role of peer networks (PNs) in their delivery, and to explain how the present study is relevant to themes emerging from earlier studies. Further material relating to the United Kingdom policy contexts will be presented in the literature review. For a more detailed analysis of the policy background the reader is referred to Glasby and Littlechild's *Direct Payments and Personal Budgets* (2016), or Leece and Bornat's *Developments in Direct Payments* (2006).

The use of personal budgets has a long history in the United Kingdom (UK), and occupies an important position in at least two related policy fields. Firstly, they can be linked to the community care reforms of the 1990s, which can themselves be seen as part of a wider policy agenda of marketisation and later modernisation and personalisation of health and social care services (Paton 1990, Department of Health 2003, Needham 2011). Personal budgets are an example of 'cash for care' schemes, which have developed independently in many post-war welfare states as a de-centralised mechanism for purchasing personal social services at an individual level (Ungerson 2004). Goals of such schemes often include promoting clients' autonomy and choice, and filling gaps in the provision of centrally provided and commissioned services (Timonen et al. 2006). Secondly, the availability of personal budgets in the UK can also be seen as the product of a sustained effort by disabled people's organisations to gain control over the assets used to provide their support (Evans 2002, Leece & Bornat 2006).

Nomenclature in UK public policy has varied, and terms such as Direct Payment, individual budget and personal budget often have precise legal definitions and bureaucratic usages that have changed over time. At the present moment, the term 'personal budget' is probably the most widely used. It is used throughout this document as a collective term for the whole spectrum of mechanisms for devolving state spending on health and adult social care to individuals.

1.1 The background to Direct Payments

The National Health Service and Community Care Act 1990 followed two white papers. The first advocated the division of the National Health Service (NHS) into purchasers and providers, creating the 'purchaser-provider split' and implementing an internal market (Department of Health 1989a). The second was aimed at reinvigorating the policy of closing long-stay institutions and creating alternative provision for people in their own homes (Department of Health 1989b). Another intention of the 1990 legislation was to devolve some purchasing decisions from local authorities to individual social workers, though this was not widely implemented (Wistow et al. 1994).

At the same time as the community care reforms were coming into force, disabled people's organisations were achieving some success in pushing for individual control over state resources. The Independent Living Fund had initially been set up in 1988 to replace discretionary top-up payments lost through reforms of Supplementary Benefit, but by 1993 it had been reformulated with explicit links to eligibility for adult social services (Glasby & Littlechild 2009). At the same time indirect payment schemes had been established in one Scottish local authority and several English counties (Witcher et al. 2000). These had been created to bypass the restrictions on making payments directly to users of adult social care services imposed by the National Assistance Act 1948 and retained in the 1990 legislation. Following research which showed that such schemes could increase autonomy and save the state money (Zarb & Nadash 1994), the British Council of Organisations of Disabled People successfully lobbied the government to change the law. The *Community Care (Direct Payments) Act 1996* created discretionary powers for English and Welsh local authorities to make payments directly to adults who had been assessed as eligible for publicly funded social care. Statutory instruments were used to create very similar provisions in Scotland and Northern Ireland, where the legislative bases were slightly different (Her Majesty's Government 1997a, 1997b). The purpose of Direct Payments was to allow many adult users of social care services to purchase their own care and support, instead of relying on services provided or commissioned by local authorities. The new powers became available on the first of April 1997.

1.2 Extending Direct Payments across the UK

Initially the uptake of Direct Payments was low, and in 1998 the white paper *Modernizing Social Services* committed the incoming New Labour government to increasing availability in the context of enhancing independence (Department of Health 1998). In the first part of the following decade, new regulations removed the exclusions for older adults and required all local authorities to make Direct Payments available (Her Majesty's Government 2000a, 2000b, 2000c, 2000d). The government's policy of devolution meant that health policy within the UK began to diverge at this point. Because the UK government retained control in many policy fields, devolved matters such as health and social care received proportionately more attention from the newly devolved executives (Jervis et al. 2003, Ham 2009). Lines of accountability were also shortened, meaning that elected representatives of the various assemblies were routinely involved in decision-making (Jervis et al. 2003). Despite these differences, policy developments in relation to direct payments were broadly consistent across the UK. The general direction of travel was to mandate the relevant authorities to provide direct payments instead of simply allowing them the discretion to do so, and to extend availability to carers and to a greater proportion of adults (including those with cognitive impairments who might have difficulty managing them). The term 'cognitive impairment' is used throughout this document as a general term to include intellectual impairments, mental distress and dementias.

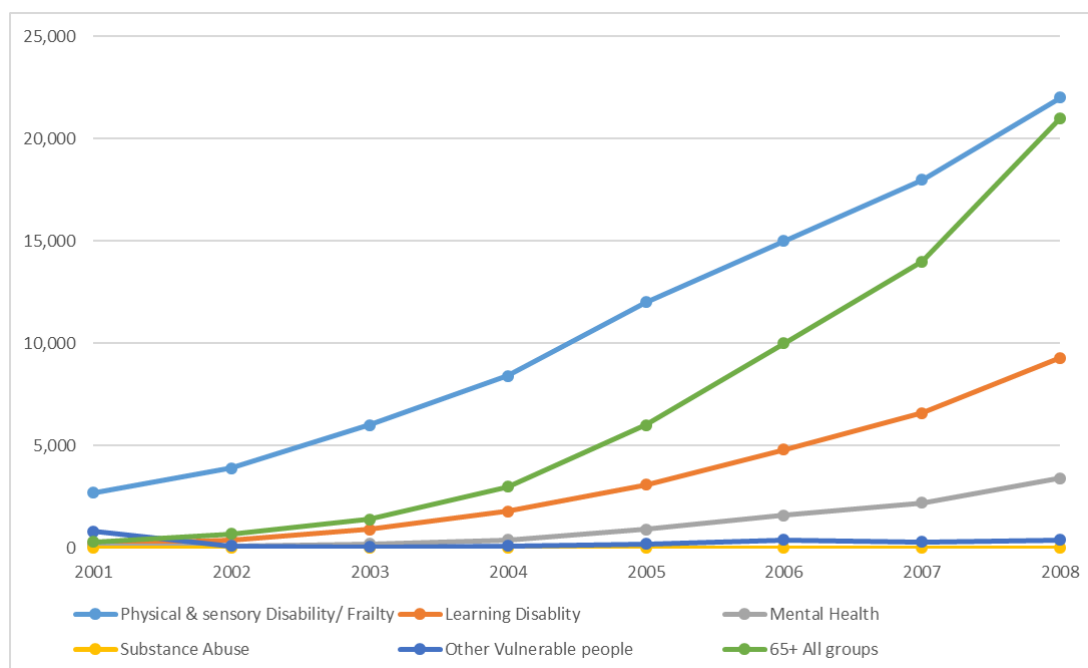


Figure 1: Numbers of Direct Payment Users in England, 31/3/2001 - 31/3/2008

Data sources: Community Care Statistics, Referrals, Assessments and Packages of Care (RAP Return), 2000-1 to 2007-8.

In England, the *Carers and Disabled Children Act 2000* gave parents of disabled children the ability to obtain payments by amending s 17 of the *Children Act 1989*. The *Health and Social Care Act 2001* changed the discretionary power to provide Direct Payments to users of adult social care services into a duty (with some exceptions), and extended payments for disabled children to 16 and 17-year-olds. New regulations implemented in 2003 were accompanied by guidance that Direct Payments should “...always be considered when deciding how to meet a person’s care needs.” (Department of Health 2003a, Para.5). Over the same period, the annual reports of the Social Services Inspectorate show an increasing emphasis on direct payments as an instrument of policy (Department of Health 2001, 2002 & 2003b); after only a brief mention in the 10th report, the 11th contains a dedicated section, and the 12th discusses direct payments at length in the sections relating to individual care groups, local initiatives and strategic priorities.

Uniquely amongst the home nations, Scotland accepted the recommendations of the Sutherland Commission (Parliament 1999) to provide free personal care. Alongside measures to implement this decision, the *Community Care and Health (Scotland) Act 2002* followed England and Wales by converting the enabling power to provide Direct Payments into a legal duty (again with some exceptions), extended their availability from “a person in need” to “any person”, and amended the Children (Scotland) Act 1995 to allow payments to parents of disabled children. Section 8 of the *Community Care and Health (Scotland) Act 2002* brought Scotland into line with the rest of the UK in terms of the duty to provide support for carers giving a “...substantial amount of care on a regular basis...”, but excluded them from receiving this support as a Direct Payment (Scottish Executive 2003a, Para. 137).

The Welsh Assembly was not able to legislate separately and raise taxes to pay for services until after the *Wales Act 2014*. As a consequence, the Welsh Direct Payments regulations published in 2004 were issued under UK law and were virtually identical to those for England (Her Majesty’s Government 2003a, 2004a). Northern Ireland gained independence for health policy in 1999. It had initially tried to follow Scotland in making personal care free, but lacked the funds to do so (Jervis et al. 2003). Following the suspension of the Northern Ireland Assembly in 2002, health and social care policy reverted to the Westminster government, which issued Direct Payment regulations for the province in 2004 (Her Majesty’s Government 2004b). These brought Northern Ireland broadly into line with the rest of the UK.

1.3 The role of peer networks in promoting the uptake of Direct Payments

While the policy of extending Direct Payments may have been broadly similar across the UK, its effects were not. The first large-scale study of the uptake of direct payments found that the policy was being implemented much more effectively in England (Riddell et al. 2006). The study also found very wide variations within the different countries and province.

Table 1:1 Direct payment users in each country/province of the UK between 2000/1 and 2003: number and rate per thousand people with LTID (reproduced from Table 2 of Riddell et al. 2006, p.7)

Country/ province	Population	% Long Term Illness / Disability	2000/1: number (rate) per thousand people with LTID	2002/3: number (rate) per thousand people with LTID	2003: number (rate) per thousand people with LTID
England	50 million	18	4,900 (0.54)	6,300 (0.70)	9,700 (1.00)
Scotland	5 million	20	207 (0.20)	392 (0.40)	571 (0.57)
Wales	3 million	23	*	185 (0.26)	*
Northern Ireland	1.5 million	23	33 (0.09)	49 (0.14)	128 (0.37)

Notes

**Figures for Wales unavailable for 2000/1 and 2003.*

LTID refers to the percentage of people reporting a long-term limiting illness or disability in the 2001 Census. 10.9 million people in the UK reported LTID with significant regional variations (London & South East 15%; Northeast England 23%).

Alongside devolution, researchers from the *UK Comparative Study* highlighted two additional sets of factors that were potentially impacting uptake (Pearson 2000, Riddell et al. 2006, Priestley et al. 2007). Firstly, the separate national ‘cultures of welfare’ were thought to have been channelled through local differences in commissioning arrangements to create environments that were sometimes more and sometimes less receptive to the new policy agenda. Secondly, and critically from the perspectives of this thesis, partnerships with disabled people’s organisations were found to be pivotal. Nevertheless, many such organisations were struggling to remain viable. The following passage is cited in its entirety because it clearly summarises this process:

“Policy developments were strongest where there were shared goals and direct relationships between members of the disability community and local champions within purchasing authorities. Since the move to mandatory implementation and the expansion of direct payments this picture has changed somewhat. Some user-led organisations have been drawn away from advocacy work towards more operational service provision, and many have struggled to survive in this role. New providers

from the voluntary sector, and in-house support schemes within purchasing authorities, have emerged and there is now some concern about the sustainability of links between the independent living movement and direct payments users, particularly in England.”

(Riddell et al. 2006:22)

The first type of organisation involved with supporting personal budget users were Centres for Independent Living, or CILs. The Independent Living Movement is a political movement of disabled people, which started in the United States of America in the late 1960s and spread to the UK in the early 1990s (Glasby & Littlechild 2009). The aim of the movement was to enable disabled people to live outside of or independently from institutions. The British Council of Organisations of People with Disabilities had campaigned for direct payments before they were introduced, and obtained government funding to set up a National Centre for Independent Living (NCIL), part of the function of which was to support the implementation of direct payments nationally (Evans 2002, Glasby & Littlechild 2006, 2009). The *Creating Independent Futures* review, which looked at independent living arrangements across the UK between 2000 and 2003, reported a rapid growth in the number of local Centres for Independent Living (CILs) during the late 1990s, rising to a total of 69 by 2002 (Morgan et al. 2001). 83% received some or all of their funding from local authorities (Barnes et al. 2001). However, the rapid expansion of direct payments between 2002 and 2005 brought in a new range of support providers who often competed successfully for the contracts to provide services.

The English Department of Health announced a £9M Direct Payment Development Fund in 2002, approximately half of which went to smaller organisations including CILs (Community Care 2003). A similar initiative in Scotland made £530K available 2001, with an additional £650K becoming available between 2003-2006. One aim was to ensure that “Peer support from a local user-led support organisation...” would be available to anyone who wanted it (Scottish Executive 2003b:9). However, the money went to local authorities rather than directly to PNs, and an independent review commissioned by the Scottish Executive in 2007 found no examples of support schemes offering peer support across the whole of Scotland (Homer & Gilder 2008). Commitment in the Welsh and Northern Irish guidance was more

general, merely suggesting that local authorities might wish to partner with voluntary organisations to provide support (Welsh Assembly Government 2004, Department of Health and Social Services and Public Safety 2004). A UK-wide survey of direct payments support schemes carried out in 2004-5 found that commissioners were now purchasing support from a much wider range of organisations, including national impairment-focussed charities (Davey et al. 2007). This may have been because CILs did not exist in all areas, or because of the need to provide support for a rapidly growing number of direct payment users (Davey et al. 2007). Another factor may have been the increase in use of direct payments by people with cognitive impairments, who often needed specialist support not available through CILs (Luckhurst 2005).

CILs and impairment-specific charities were usually legally constituted entities (Davey et al. 2007). However, support was available in many other forms. During the implementation of direct payments and the pilot phase of personal budgets, local authorities and their partner organisations frequently hosted informal support groups (Witcher 2000, Glendinning et al. 2008). With assistance, these groups could sometimes grow into legally constituted organisations such as local CILs or Independent Living Trusts (Luckhurst 2005, Maynard-Campbell et al. 2007). Local groups and organisations not obviously connected with direct payments have collaborated in developing and delivering schemes where this was perceived to be in their members or users' interests. This seems to have been particularly common in rural areas (Dawson 2000, Stanton & Boyce 2004). Between 2002 and 2007, the increasing availability of broadband connections provided a new medium through which disabled people could talk to and support each other (Baines 2007). By 2011, electronic media were providing a wide and growing range of opportunities for collaboration around personal budgets that did not require formal legal organisations (Ayres 2011). Simultaneously, disability activism also began to move from formally constituted disabled people's organisations to looser affiliations, often using new online spaces to organise and campaign (Pearson & Trevisan 2015). Throughout this thesis, the term 'peer network' is used to describe this very diverse range of formal and informal organisations and groups that have provided support to personal budget users.

1.4 Mental capacity and personal budgets

Because Scotland already had a legal definition of mental capacity in the *Adults with Incapacity (Scotland) Act 2000*, the 2003 regulations (Scottish Executive 2003a) were able to make provision for carers with the appropriate powers of attorney to manage personal budgets on behalf of people with cognitive impairments, a development that had to wait for the Mental Capacity Act 2005 in England and Wales. In that year the English Department of Health initiated national trials of a new model for supporting people with cognitive impairments developed by the charity *In Control* (Department of Health 2005a). Field trials were conducted rapidly, and despite mixed results the new process was mandated for all local authorities in England in December 2008 (Glendinning et al. 2008, Department of Health 2008). Like Direct Payment schemes, people were allocated an amount of money and included as fully as possible in the decisions about purchasing (Department of Health 2009a). Those with mental capacity could still access the budget as a Direct Payment and manage the money themselves, but the new arrangements contained additional options. Local authorities, carers or third parties could manage budgets on people's behalves where they lacked capacity, or where they gave consent. The early guidance uses phrases such as 'individual' 'personalised', or 'personal' budget to describe the sum of money allocated, but by 2010 the term 'personal budget' had been settled on (Department of Health 2008, 2009a, 2010).

Between 2008 and 2011 personal budgets became the default mechanism for allocating money for adult social care in England. Here the extension of the use of personal budgets to "...all individuals eligible for publicly-funded adult social care..." was part of a wider process of 'Transforming Adult Social Care' (Department of Health 2008 Para.19). The £511 million made available to local authorities through the Transforming Adult Social Care gives an indication of the scale of change envisaged (Department of Health 2010). The Scottish Executive had set a similar course. The explicit goals also focussed on maximising autonomy and independence but without reference to the *In Control* model, and with a bigger role for services commissioned and provided by statutory organisations (Scottish Executive 2007). Nevertheless guidance issued by the Department of Health in 2009 makes it clear that new regulations north and south of the border were intended to have the same effects in terms

of establishing a wider legal basis for third parties to manage direct payments on behalf of people with cognitive impairments (Department of Health 2009b). In 2011 similar provisions were introduced in Wales (Her Majesty's Government 2011). In Northern Ireland there was no similar change, and following a successful legal challenge to the practice of making direct payments to informal carers, the Health and Social Care Board was forced to implement a more limited set of 'interim arrangements' (Health and Social Care Board 2012).

1.5 Personal Health Budgets

In 2009, the English NHS began pilot testing 'Personal Health Budgets' (PHBs) for people who required aftercare, which was interpreted as meaning those in the 'continuing care' needs group (Forder *et al.* 2012). The pilot tests were judged to have been successful, and the Health and Social Care Act 2012 created permanent duty to make them available. The regulations that followed gave all Clinical Commissioning Groups discretion to make PHBs available to other groups of patients (H.M. Govt. 2013a). In England the assessment threshold for NHS continuing care is different to but generally higher than that for adult social care. Consequently, many people who are eligible for the former are entitled to both (Forder *et al.* 2012). Initially it had been hoped that personal budgets would provide a way of combining and co-ordinating funding from a range of sources, but the pilot tests had highlighted many bureaucratic and legal barriers (Glendinning *et al.* 2008). This finding was supported by the evaluation of the personal health budget pilots, which found that local systems for delivering personal budgets in health and social care were often incompatible with one another (Forder *et al.* 2012). Consequently when PHBs were introduced, it was as a separate bureaucratic structure operating alongside PBs in adult social care (Alakeson & Rumbold 2013). In 2015, integrating support for PHBs and PBs became a policy goal for the English NHS, and a report in 2017 claimed that 15,800 PHBs were being delivered in this way at that point (NHS England 2017a). In Scotland the different legislative basis meant there were fewer barriers to making direct payments for health services, and the 2007 guidance made it explicit that direct payments could include components for health as well as social care (Scottish Executive 2007). However, the Social Care (Self-directed Support)

(Scotland) Act 2013 only specifies mental health services. Despite a policy goal of complete integration of health and social care in Wales, there are currently no plans to extend direct payments to people in lieu of health services (Welsh Government 2018). A recent Expert Advisory Panel on Adult Care and Support in Northern Ireland focussed heavily on direct payments, but did not propose extending their use to the NHS (Kelly & Kennedy 2017).

Section 2.3.2.2 (p.42) presents the research literature relating to PNs and personal budget users in the context of these policy developments.

1.6 Project aims and objectives

To summarise, PNs have played an important role in the implementation of personal budgets from their introduction in the 1996 through to the present moment. Many studies, including some large multi-site projects commissioned by UK and devolved governments (Riddell et al. 2006, Davey et al. 2007, Glendinning et al. 2008), found significant evidence of their positive impacts. Nevertheless, by the second half of the last decade, they had become marginal providers of support to personal budget users (Davey et al. 2007). Subsequent cuts to social care services and welfare benefits for disabled people have led key figures within the disabled people's movement to question whether progress towards independent living has stalled (Oliver & Barnes 2012, Morris 2014). At the same time, the use of personal budgets across the UK has continued to grow. In the context of an ageing population and a *per capita* reduction in public spending, integration of health and social care services has become a policy priority, and personal budgets are seen as a key element of a wider strategy to support people in their own homes and reduce pressure on secondary health and social care services (Department of Health of Northern Ireland 2016, Scottish Government 2016, NHS England 2017b, Welsh Government 2018).

The present thesis presents a timely review of the role of PNs in supporting personal budget users, and reports an inquiry into whether there were benefits of providing support in this way and if so, how these were achieved. The inquiry proposed to achieve this by pursuing a series of specific objectives, to be investigated in two linked phases of inquiry:

1. To describe the range of organisations and informal groups providing peer support to personal budget users, and explore the contexts in which they operate.
2. To explore the perceived benefits and drawbacks of providing support through a peer network.
3. To describe the features of peer support that personal budget users find helpful or unhelpful.
4. To explore the ways in which individuals in paid or defined volunteer roles use their individual and organisational identities as 'peers' to support people throughout the process of obtaining and managing a personal budget.
5. To develop existing or original theories to explain the ways in which people with and without lived experience of illness or disability utilise peer identity to support people who are managing a personal budget.

The first phase would draw together the existing research, to see if PNs had a characteristic approach that positively impacted on the experiences of personal budget users. This is reported in Chapter 2. A subsequent empirical study (reported in Chapters 3 and 4) would then investigate the operation of peer identity within the support process, and try to determine the impact on personal budget users. It was envisaged that the literature review would contribute to the first three objectives, and inform the development of methods to meet the last two, using a process of emergent design (Lincoln & Guba 1985). The empirical study would then revisit the first three objectives whilst investigating the more complex issues implied by objectives four and five. A theoretical discussion of the findings of the two linked studies is presented in Chapter 5. A short summary of the limitations of the study and its implications for theory, policy and practice are given in Chapter 6.

CHAPTER 2: LITERATURE REVIEW

This chapter follows the reporting convention of presenting the theoretical orientation, methodology and methods in sequence, partly because they follow logically (Crotty 1998, Creswell 2014). This project has adopted the naturalistic approach of emergent design, which is reflexive and iterative rather than linear, so reporting in this order is not strictly authentic. Some theoretical discussion has been deferred to the method and results sections, so that decision-making is presented in context.

2.1 Theoretical overview

This thesis is oriented within a critical social constructionist framework, developed from the 'naturalistic inquiry' approach coined by Yvonna Lincoln and Egon Guba in their book of the same name. A slightly longer overview of the theoretical basis of critical constructionism is given here to provide the context for the focus group study as well as the literature review.

Lincoln and Guba frame naturalistic inquiry as a new paradigm emerging within social sciences (Lincoln & Guba 1985). The theoretical basis for naturalistic inquiry was heavily influenced by the work of Herbert Bloomer on adapting social research methods according to the principles of symbolic interactionism developed by George Herbert Mead (Lincoln & Guba 1985, Hammersley 1989). Deriving his position largely from earlier historicist and American pragmatist philosophers, Bloomer was loosely a realist, but argued that it was impossible to investigate reality without considering the social constructs which encompassed both researchers and research subjects (Hammersley 1989). Bloomer accepted Mead's evidence that the meaning of symbols was continuously changing through the process of social interaction. He understood that intellectual constructs such as axioms were also 'symbols', undermining the case for research which was designed and interpreted on the basis that such constructs were fixed. His response was to shift from grand theories based on high-level theoretical concepts towards a 'naturalistic' sociological method which "...approached the study of group activity through the eyes and experience of the people who have developed the activity." (Blumer 1956:689). Blumer's

contemporaries Peter Berger and Thomas Luckman were also heavily influenced by Mead's theories of symbolic interactionism, and are often credited alongside him as originators of social constructionism (Berger & Luckman 1966, Burr 2015). Their work aimed to develop a coherent sociology of knowledge, but unlike Bloomer expressly stopped short of examining its consequences for methodology. *Naturalistic Inquiry* picked up the threads of both sets of arguments, suspending judgement on the existence of objective reality and concluding that to the extent it was apprehendable, it was mutually shaped by participants and researchers (Lincoln & Guba 1985). Both authors have since backed away from their initial attempt to define naturalistic inquiry as a complete and internally coherent research paradigm and have subsequently embraced pluralism, locating their own work within a spectrum of broadly interpretivist research traditions (Guba 1993, Denzin & Lincoln 2011). The elements of the naturalistic model which have been retained in this project include the methodological approach of emergent design, the primary importance of the natural social context of the phenomena being investigated, and the principle that it is readers of research reports rather than authors who are best placed to make judgements about their for them.

Social constructionism has now developed into a broad theoretical field encompassing many methodological approaches in a wide range of social science disciplines (Burr 2015). Crotty (1998) describes a bifurcation in attitudes towards social structure within constructionism, leading to two broad ranges of theoretical perspectives which he describes as 'interpretivist' and 'critical'. Whereas interpretivists are ideologically neutral towards social context, critical theorists are more concerned with social inequality. The originators of critical theory are associated with the 'Frankfurt School' emerging from the Institute for Social Research at the University of Frankfurt. Scholars retained a central interest in Marx, and were methodologically and theoretically concerned with the processes by which some social groups came to perpetuate their own dominance through processes of social reproduction (Rothe & Ronge 2016). In the 1960s, the term 'critical' began to be applied to a diverse range of theoretical positions that explicitly inquired into or challenged the *status quo* (Gibson 2007). Many critical approaches emerged, some based around the theories of particular researchers (such as Jürgen Habermas or Paulo Freire) while others focussing on the interests of oppressed groups such as women and people

from black or minority ethnic communities (Crotty 1998, Gibson 2007). An important effect in the field of social research methods has been to highlight the potential for the research process itself to reproduce wider patterns of dominance and suppression. In the discipline of critical disability studies there is a long-standing concern with research that advances the careers of academics whilst doing “...little, if anything, to confront the social oppression and isolation experienced by disabled people or initiate policies which have made a significant improvement in the quality of their lives.” (Oliver 1992, Barnes & Mercer 1997:1). The main impact of critical theory within the current project has been the reflexive engagement with power, particularly in the contexts of the social missions of PNs, the empowerment and disempowerment of personal budgets users, and participants’ experiences of the research process.

2.2 Methodology and ethical considerations

The critical constructionist theoretical framework has had two major sets of consequences in terms of methodology. From a critical perspective it was necessary to take an inclusive approach to literature reflecting the perspectives of disabled people and other groups of personal budget users. However from a constructionist perspective, the inclusion of a large number of studies increased the risk of ‘context-stripping’, in which data are considered as if separate from the contexts in which they arose. This section gives a justification for the decisions taken, and locates them within a broader discussion of methodological approaches to aggregating and interpreting qualitative data. Following the naturalistic approach to emergent design (Lincoln & Guba 1985, Erlandson et al 1993), decisions about data analysis were deferred until after the search had been completed.

2.2.1 *Inclusion and exclusion criteria*

The search aimed to find all research about the activity of PNs in the UK from the implementation of Direct Payments on the first of April 1997. The search excluded publications relating to personal budgets held by parents of disabled children and research from outside the UK, and focussed on identifying research reports from 1997 onwards. The

search was originally conducted in the spring of 2014, and refreshed in the spring of 2016 (immediately prior to analysis).

Research relating only to the support of disabled children was excluded because of the separate and different histories of the networks providing support, and the different range of organisations included in support plans. The focus was on users of personal budgets funded by adult social care services and the English NHS. This is because the collective effects of policy changes in relation to these groups have been to incrementally increase access to wider populations, a process which was paralleled by a diversification of support provision (see Chapter 1). This continuity means creating a later cut-off point would be arbitrary and unnecessarily exclude relevant information.

There was no attempt to limit the search to peer-reviewed research. Glasby and Beresford (2006) have argued that what is counted as research evidence often privileges medical and academic perspectives, whilst eclipsing the perspectives of practitioners and service users. SCIE guidelines for systematic reviews and the manual for developing NICE guidelines both recommend including grey literature, partly to ensure that service user perspectives are adequately considered (Rutter et al. 2010, NICE 2016).

2.2.2 Approach to aggregation and interpretation

Data from within the UK were treated as an entity. While there were significant variations between the different parts of the UK, there have also been significant variations *within* different countries (Riddell et al. 2006). For example, all four territories have rural populations at risk of exclusion from health and social carer services (Baird & Wright 2006). Some of the best evidence for the operation of PNs in rural areas came from Wales and Scotland (e.g. Stainton & Boyce 2004, Ridley et al. 2012) but this is consistent with research conducted in rural England (Dawson 2000, Doheny & Milbourne 2013). The original Direct Payment legislation was specific to UK adult social care services, and was very similar in its effect in all four jurisdictions (Her Majesty's Government 1997a, 1997b, 1997c, 1997d). Many of the umbrella organisations involved in setting up direct payment schemes, such as the British Council of Organisations of Disabled People, operated across the UK, and the

principles underpinning the approach to independent living in the different countries and province were consistent (Glasby & Littlechild 2009, Morgan et al. 2001).

Any literature review using a constructionist framework will encounter the problem of a loss of context. The originators of naturalistic inquiry took a strong position on this issue, arguing that the different social contexts of different studies made aggregation of data impossible (Lincoln & Guba 1985). Instead of producing results which were generalisable across different contexts, the aim was to provide enough description to allow the reader to decide whether the results might be applicable in a different setting, and a description of the methods that were sufficient to establish 'trustworthiness'. The concept has been adapted here (see Table 2:1).

The problem of aggregating data from different ethnographic studies prompted the development of a method for 'meta-ethnography' (Noblit & Hare 1988). This provides the basic blueprint for the methods used here, although they have been adapted. Meta-ethnography differentiates between data aggregation (where the findings of different studies are simply categorised) and synthesis (where they are combined to produce some new understanding). These respectively provide the basis for the aggregative description presented in 2.4.1 and the thematic synthesis in 2.4.2 below. According to Schutz, fidelity to the original social phenomenon is lost when one progresses from the research participant's perspective (a first order construct) to that of the researcher (a second order construct) (Schutz & Natanson 1972). Aggregation operates at the level of second order constructs, whereas synthesis inevitably adds another layer of separation (Britten et al. 2002). Interpretative synthesis is characterised by 'synthesising arguments' that are concerned with developing original constructs that have a high explanatory value (Dixon-Woods et al. 2006). Aggregation of findings from earlier studies is a suitable method for mapping the activities of PNs and describing their reported benefits for personal budget users, whilst some degree of synthesis was necessary to begin to answer the more fundamental

Table 2:1 Establishing trustworthiness: possible correlates in literature review

Criterion	Conventional Term	Naturalistic term	In empirical research	In the context of a literature review	In the present review
Truth value	Internal validity	Credibility	• Prolonged engagement • Persistent observation • Triangulation • Referential adequacy • Peer debriefing • Member checks • Reflexive journal	• Extent of reviewer's engagement with literature • Degree of agreement/disagreement between sources • Recognition by stakeholders • Audit trail/account of process	• Appraisal of literature • Disagreements noted in aggregative description and considered in thematic analysis • Feedback from supervisors & advisory group • Use of computer-aided qualitative data analysis software (CAQDAS) to create audit trail
Applicability	External validity	Transferability	• Thick description • Purposive sampling • Reflexive journal	• Rich description of sources • Search strategy and inclusion/exclusion criteria • Audit trail/account of process	• Description of policy context and grouping into periods • Use of CAQDAS to create audit trail, reporting/publication
Consistency	Reliability	Dependability	• Dependability audit • Reflexive journal	• Audit trail/account of process	• Use of CAQDAS to create audit trail • Separate aggregative description from synthesis • Reporting/publication
Neutrality	Objectivity	Confirmability	• Confirmability audit • Reflexive journal	• As above	• As above

Extended from table 7.1 in Erlandson et al. 1993:133

questions about how this was achieved. The relationship between aggregation and synthesis and has been extensively discussed. Sandelowski and Barroso (2003) put reviews on a continuum between exploratory, through descriptive to explanatory, as the extent of original interpretation increases. Hammersley (2008) proposes a trifold division which subdivides aggregative approaches into those that accumulate evidence of a phenomenon, and those that consider the extent to which these data reinforce one another. Thomas and Harden's (2008) method for 'thematic synthesis' differentiates between descriptive themes (which are effectively aggregations), and interpretative themes. Major and Savin-Baden (2011) argue that aggregation is a necessary precursor to interpretation, and propose that instead of a continuum it is more helpful to classify approaches according to how far they have travelled towards theory building, resulting in a staged model of analysis, synthesis, interpretation and construction. None of these and a host of other methods is widely accepted as philosophically superior (Aveyard et al. 2016), leaving the way open for the researcher to make individual judgements. In the present review, the analysis has followed an original approach, divided into two stages. The first is an aggregative description based on categories that were judged to be "...secure and well specified." (Dixon-Woods et al. 2006:36), and the second is more interpretative synthesis of findings using a method based on Braun and Clarke's (2006, 2013) approach to thematic analysis.

2.3 Methods

2.3.1 Search

The search strategy consisted primarily of searching electronic databases, and subsequently conducting a 'chain, 'cascade' or 'snowball' search, by looking at the reference lists of publications matching the inclusion criteria (Patton 2002, Greenhalgh & Peacock 2005). Some publications were already known, or were recommended by colleagues.

The first stage of the search was conducted using electronic databases. Three were identified as being likely to hold publications relating to the topic (see Table 2:2).

Table 2:2 Databases searched

Social Care Online

"Social Care Online is the UK's largest online database of information on all aspects of social work and social care. It includes legislation, government documents, practice and guidance, systematic reviews, research briefings, UK grey (informally-published) literature, books, text books and journal articles. The database is updated daily and contains around 155,000 records from the 1980s onwards."

<http://www.scie-socialcareonline.org.uk/About/About>

Accessed 6/4/2016

CINAHL

"CINAHL Database provides indexing of the top nursing and allied health literature available including nursing journals and publications from the National League for Nursing and the American Nurses Association. Literature covers a wide range of topics including nursing, biomedicine, health sciences librarianship, alternative/complementary medicine, consumer health and 17 allied health disciplines."

Accessed 7/4/2016

<https://health.ebsco.com/products/the-cinahl-database>

Campbell Collaboration

"Campbell Systematic Reviews is the peer-reviewed online monograph series of systematic reviews prepared under the editorial control of the Campbell Collaboration. Campbell systematic reviews follow structured guidelines and standards for summarizing the international research evidence on the effects of interventions in crime and justice, education, international development, and social welfare."

http://www.campbellcollaboration.org/lib/?go=monograph&search=direct+payments&search_criteria=all_text

Accessed 7/4/2016

ASSIA

"ASSIA: Applied Social Sciences Index and Abstracts is an indexing and abstracting tool covering health, social services, psychology, sociology, economics, politics, race relations and education. Updated monthly, ASSIA provides a comprehensive source of social science and health information for the practical and academic professional. It contains records from over 500 journals published in 16 different countries, including the UK and US."

"Subject coverage: Education, Family, Gerontology, Health services, Housing, Mental health services, Nursing, Social work, Substance abuse."

Accessed 7/4/2016

<http://search.proquest.com/assia/productfulldescdetail?accountid=13041>

Although the focus of the current review is empirical research, the Campbell and Cochrane Collaboration databases were also searched to establish whether a similar inquiry had already been carried out or was planned in the near future.

For all three databases a similar approach to searching was adopted. Firstly, the database (or the separate list or thesaurus of search terms) was searched to identify terms relevant to two domains relevant to the inquiry:

- Terms related to 'personal budgets'.
- Terms related to 'PNs'

Secondly, alternative search free text terms were constructed. Search terms were tested for specificity in different combinations and optimised. Thirdly where possible database options were set to exclude duplicates and literature outside the scope of the search.

Fourthly, titles and abstracts were used to exclude publications obviously falling outside the scope of the review. Finally, publications were obtained and read to see if they were in fact empirical studies, and whether they contained findings pertinent to the research question.

Database searches for qualitative research are often problematic (Thomas & Harden 2008), sometimes because of the poor specificity of database terms (Dixon-Woods et al. 2006).

The best searches developed for ASSIA and CINAHL were significantly over-inclusive. The UK focus of Social Care Online meant that terms were often given the same meaning as in the present study, which may explain the larger number of publications identified with these tools. To try and ensure that relevant literature was not missed, searches erred on the side of being over-inclusive (Greenhalgh et al. 2005a). The cascade search was time-consuming but productive. As well as simply scanning the reference lists of included papers for other possible candidates, the references of research reports that had carried out searches were all retrieved and examined individually. The relatively high proportion of duplicates within the cascade search shows that research teams were often known to one another, and provides partial evidence of a coherent body of research.

In addition to the exclusion criteria mentioned above, literature that gave no account of the method was rejected (although this criterion was interpreted inclusively). The decision to exclude individual testimony and reportage was made in the light of arguments that

‘stories’ had been used to legitimate the ‘personalisation’ policy (Ferguson 2007, Needham 2014) which may have contributed to a distorted picture of its success (Slasberg et al. 2014, Mladenov et al. 2015). Research reviews and review articles were searched to ensure that the present review was not duplicating a similar study, and to aid the cascade search, but were not included themselves. The results are summarised in Table 2:3.

Table 2:3 Search results

Adapted from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher et al. 2009)

	Identified	Duplicates Removed	Excluded on Abstract	Not Found	Excluded on Full Text	Excluded on Appraisal	Final Included
Social Care Online	215	19	114	1	61	0	20
ASSIA	70	2	54	1	11	0	2
CINAHL	149	4	132	0	12	0	1
Cascade search	486	62	315	6	86	0	17
Recommendations and wider reading							5

2.3.2 Appraisal

The principal aims of the appraisal were to support the ‘trustworthiness’ of the findings, and to inform the selection of an appropriate method for extracting and analysing evidence from publications (Lincoln & Guba 1985, Erlandson et al. 1993, see Table 2:1). Appraisal can contribute to trustworthiness in several ways. Firstly, an in-depth appraisal of the literature can help to establish ‘credibility’ by providing evidence of the reviewer’s engagement with the source material. Providing a clear background and complete list of sources meets the criterion of ‘referential adequacy’. Within the context of trustworthiness, ‘thick description’ provides additional context that compensates to some extent for the loss of context. In empirical research reports, the audit trail “...provides for a thick description of both the inquiry context and the inquiry process.” (Erlandson et al. 1993:149). For this secondary analysis, these objectives have been pursued respectively by grouping and

appraising literature according to the according to the focus of the original researchers (2.3.2.2) and by the methods they used (2.3.2.1).

2.3.2.1 *Appraisal using review tools*

Interpretivist researchers often eschew numeric descriptions, for example arguing that reducing data to numbers isolates them from their original context (Erlandson et al. 1993). However, others question whether describing data using numbers is fundamentally different to using qualitative terms such as 'more' or 'less' (Braun & Clarke 2006), and argue that numbers can facilitate pattern recognition (Sandelowski et al. 2009). The numbers and calculations presented in this section aim to provide an overview of the quality of the research included in the review, to inform the reader's assessment of trustworthiness. They have not been used in the process of analysis itself.

Of the 45 publications included in the present review, only 11 were assessed as having any kind of explicit commitment to a theoretical position. In 5 cases this was assessed as 'weak' or partial. This precluded a full application of many of the techniques derived from meta-ethnography, which either require an explicit commitment to interpretivism (Barnett-Page & Thomas 2009) or which separate studies by 'research tradition' prior to reciprocal translation (Greenhalgh et al. 2005b). 35 of the publications studies with one or more element that was loosely qualitative (for example containing using interviews, discussion groups or similar) but typically without any reference to epistemology, ontology or 'claim to truth'. To gain some sense of quality, these were appraised using the consolidated criteria for reporting qualitative research (COREQ, Tong et al 2007). Results are shown in Figure 2 below, with full details in Appendix 1 Table A1:3. The second most common method used was surveys. To appraise these, an appraisal tool developed for a systematic review of healthcare interventions was adapted (Greenhalgh et al. 2005b). Table 2:4 shows the results. Three publications contained both survey and qualitative data, and five could not be appraised using either of these tools. *Making the choice: early insights from up2us* was an evaluation of several pilot sites using a variety of methods which were not described in detail (Slay 2011). Two publications could be loosely described as 'co-produced' because of the way they involved service users in a loose emergent design process (Witcher 2013,

Mackay et al. 2013), and the remaining two involved numeric methods, although without any explicit commitment to a positivist or similar paradigm (Jolly & Priestley 2004, Stainton et al. 2009).

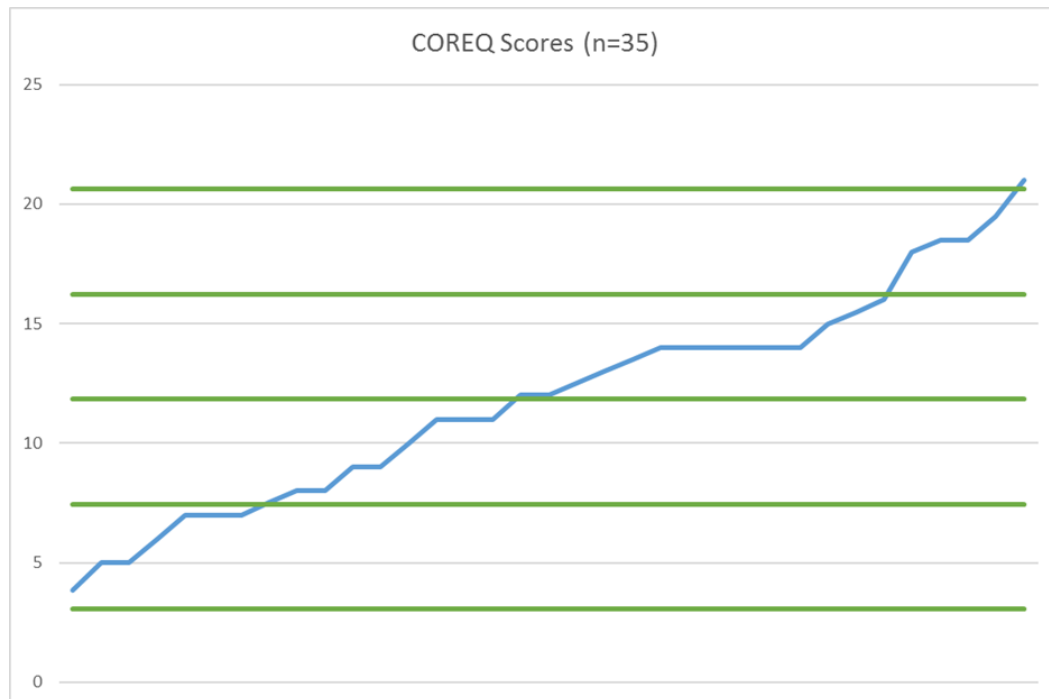


Figure 2: COREQ Scores (out of 32) for publications reporting qualitative elements
Standard deviations from the mean shown as green lines

Reporting of qualitative studies was generally of a low quality, and scores were close to being normally distributed. COREQ is divided into three domains (see Table A1:4 in Appendix 1), reflecting the capabilities of the research team and reflexivity of their approach, the study design, and their analysis and findings. Scores in the third domain were higher than in the first two. It may be significant that COREQ was designed as a quality checklist for reporting academic studies (Tong et al. 2007), while many of the publications included here were probably intended for a wider readership.

Surveys were appraised using a checklist designed for a systematic review of healthcare interventions (Greenhalgh et al. 2005b) (see Table 2:4). Like the COREQ scores, the totals here are also close to being normally distributed.

Table 2:4 Survey appraisal scores (out of 13) for publications containing survey elements*A4: Quality checklist for questionnaire surveys, Greenhalgh et al. 2005b:237*

Study Number (See Tbl. A1:1, Appendix 1)

	76	77	133	152	178	197	205	N006
1. Research question and design								
Was there a clear research question, and was this important and sensible?	1	0	0	0	1	1	1	1
Was a questionnaire the most appropriate research design for this question?	1	1	1	1	1	1	1	0.5
2. Sampling								
What was the sampling frame and was it sufficiently large and representative?	0.5	1	0	1	1	1	1	0.5
Did all participants in the sample understand what was required of them, and did they attribute the same meaning to the terms in the questionnaire?	0	0	0	0	0	0	0	0
3. Instrument								
What claims for reliability and validity have been made, and are these justified?	0	0	0	0	1	0	1	0
Did the questions cover all relevant aspects of the problem in a non-threatening and non-directive way?	0	0	0	1	0	1	1	1
Were open-ended (qualitative) and closed-ended (quantitative) questions used appropriately?	0	0	0	1	0	1	1	1
Was a pilot version administered to participants representative of those in the sampling frame, and the instrument modified accordingly?	0	0	0	1	1	1	1	0
4. Response								
What was the response rate and have non-responders been accounted for?	0.5	0	0	1	1	1	1	0.5
5. Coding and analysis								
Was the analysis appropriate (e.g. statistical analysis for quantitative answers, qualitative analysis for open-ended questions) and were the correct techniques used?	0	1	0	1	1	1	1	1
Were adequate measures in place to maintain accuracy of data?	0	0	0	0	0	0	0	0
6. Presentation of results								
Have all relevant results ('significant' and 'non-significant') been reported?	1	0	0	1	1	1	1	1
Is there any evidence of 'data dredging' (i.e. analyses that were not 'hypothesis driven')?	0	1	0	1	1	1	1	1

<i>Total Score</i>	4	4	1	9	9	10	11	7.5
<i>Total percentage</i>	31%	31%	8%	69%	69%	77%	85%	58%

Scores of 0.5 were given where the criterion had two components and 1 was met (e.g. the sample was representative but not large).

From a critical perspective, it is important to consider the groups whose perspectives are often privileged within conventions about what counts as ‘high quality’ research, and those (like disabled people) whose perspectives are excluded from it (Glasby & Beresford 2006). Similarly, Cheek (2007) cites her own research showing that:

“...supposedly objective metrics such as citation rates and journal impact factors are influenced by assumptions both philosophical and technical that are not necessarily related to the scientific quality...”

(Cheek 2007:1053)

An example in this case is the way that COREQ assesses publications on both the basis of authors paid roles and of their academic qualifications (Tong et al. 2007), when disabled people and other groups of personal budget users are systematically disadvantaged both in terms of educational and employment opportunities (Beckwith 2015). To guard against this type of bias, publications were also appraised in terms of authors’ relationship with the groups of people whose experiences were the focus of the research. Some level of interpretation and further research was required, as publications did not always provide full details of affiliation. Results are shown in Table 2:5.

Table 2:5 Involvement of peer network members in research

Orientation towards user group	Publications
Research team included user group organisations. Collaborative approach from the outset.	20
Research team employed user group members as researchers, or collaborated with local user groups during data collection.	8
No mention of relationship with user group.	17

COREQ scores for publications were divided between 'high' and 'low' depending on which side of the mean they fell. A simple Chi Squared test showed that in fact high quality reporting was positively correlated with association with user group organisations with a probability of $p < 0.01$ (with 8 of the 10 highest quality reports stemming from research including disabled people's organisations, compared with only 3 of the lowest quality). This would appear to indicate that it would have been possible to exclude the weaker reports without marginalising the voices of personal budget users and other stakeholders. However, there are also questions about the general validity of quality measures. For example, Crowe and Sheppard (2011) reviewed 44 common critical appraisal tools, and found that they had often been used inappropriately outside of their original philosophical and methodological contexts. Seale has argued more generally against the validity of using checklists to assess quality of interpretivist research, stating that "...the belief in multiple realities is inconsistent with attempts to judge the adequacy of singular versions." (Seale 2002:108). While some approaches to synthesising qualitative research advocate excluding publications based on quality criteria, others highlight the risks of excluding potentially relevant data and consequently advise against it (Dixon-Woods et al. 2006, Sandelowski & Barosso 2007). In this phase of the project the aim was to find what the research was saying rather than to weigh up competing claims, a common reason for excluding poor quality studies in systematic reviews (Barnett-Page & Thomas 2009). For all of these reasons, publications were not excluded on the basis of the perceived quality of the research methods.

2.3.2.2 *Salience to research question and description of research context*

The aims of the research reviewed are described graphically in Figure 3. The six publications that were specifically interested in both personal budgets and peer networks derive from two studies. The first was led by the late Professor David Brandon, Lana Morris and Rea Maglajlic under the auspices of the SHIELD Office at Anglia Polytechnic University, and was an exploration of the implementation of direct payments in the London Borough of Tower Hamlets (Maglajlic et al. 1998, Brandon & Majlajlic 2000, Magajlic et al. 2000). The second was led by Professor Val Williams of the Norah Fry Research Centre as part of a collaboration with the government Office for Disability Issues (ODI) and the National

Development Team for Inclusion. Known as the *Support Planning and Brokerage* study, this looked at the implementation of personal budgets in Essex, Richmond and Southampton (N Campbell et al. 2011, Williams & Porter 2011, Williams et al. 2014).

Within the literature included, there was little by way of sustained interest in the role that PNs had played in providing support for personal budget users; most of the studies were concerned with the way in which support could be provided for personal budget users, with the potentially helpful role of PNs emerging only as a finding.

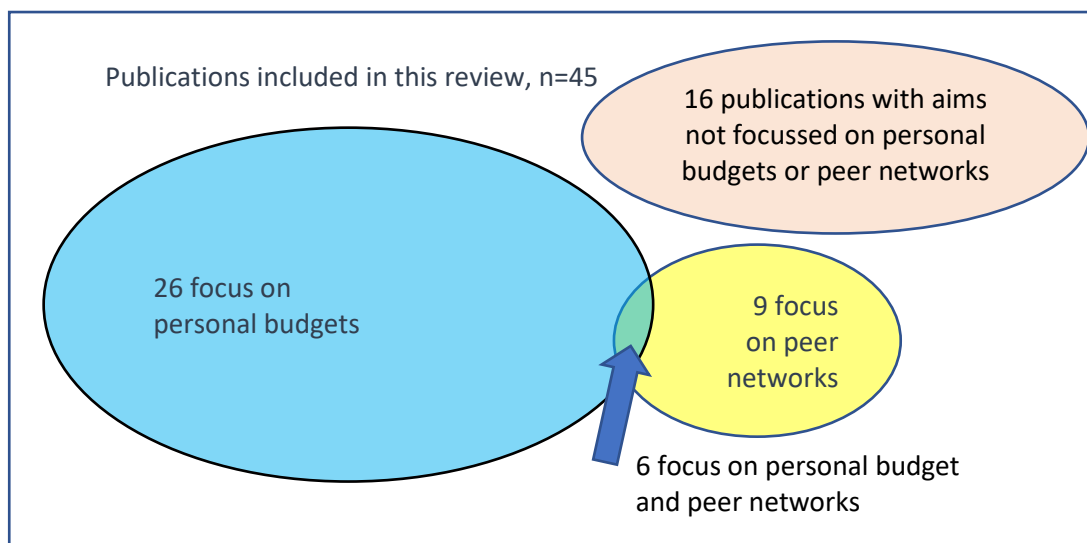


Figure 3: Venn diagram illustrating the focus of research questions for publications included in this review

The aims of the studies nearly always reflected wider concerns with the process of obtaining or managing a personal budget. These correlate strongly with historical developments in social policy described in section 1.2-1.5 (p.18). For convenience, these have been grouped into the three periods shown in Table 2:6, with the geographical coverage summarised in Table 2:7. The three periods relate to the dates of data collection (where given by the original authors) rather than the dates of publication.

Table 2:6 Focus of studies, and periods in which research was conducted.

	Publications included	Focus on Personal Budgets	Focus on Peer Networks	Other Focus
First period: (1997-2003)*	11	10	3	1
Second period: (2003-2008)	15	11	2	2
Third period: 2008-present	19	6	4	12

** Because the availability of personal budgets was extended incrementally and at slightly different rates in different parts of the UK, some degree of researcher judgement was necessary.*

Table 2:7 Geography of study sites.

See Table A1:2 Appendix 1 for a full list.

	England	Wales	Scotland	Northern Ireland
First period: (1997-2003)	6	3	3	1
Second period: (2003-2008)	15	6	4	4
Third period: 2008-present	15	3	4	1

The first period relates to the initial implementation of Direct Payments in adult social care from 1997 and the extension of their availability to older adults from 2000. Policy and practice guidelines issued in 1997 advised local authorities to assess people's capacity to manage a direct payment (Department of Health 1997). One focus of research in this period was the barriers that such processes created for people with intellectual impairments (Gardner 1999, Gramlich et al. 2002) or with needs relating to mental health (Ridley & Jones 2002). Most of the research from this first period looked at direct payment users in general, rather than focussing on people in specific 'client groups'. However, the combined effect of regulations restricting access and assessments of the ability to manage a direct payment meant that their use during this period was largely restricted to people with

physical and sensory impairments (Riddell et al. 2006), meaning that their experiences were strongly reflected in research findings from this period. Another important focus for researchers in this period was the uptake of direct payments, and the effectiveness of support services and local arrangements (Dawson 2000, Witcher et al. 2000, Sainton & Boyce 2004, Stainton et al. 2009).

The three publications from this period that focussed explicitly on PNs all derived from the SHIELD Tower Hamlets study (Maglajlic et al. 1998, Brandon & Majlajlic 2000, Magajlic et al. 2000). Tower Hamlets Coalition of Disabled People were a full partner in the research, and had been involved with the development of personal budgets since the 'third party' (indirect payment) schemes that predated the 1996 legislation. They were involved as support providers, and most of the relevant findings concerned ways in which support could be provided. This was typical of developments across England, in which disabled people's organisations had played a major part (Evans 2002, Pridmore 2006). Centres for Independent Living also played an important role in Scotland, but were less central to developments in Wales and Northern Ireland (Witcher 2000, Priestley et al. 2007).

From 2003 new regulations removed some of the bureaucratic barriers facing direct payment users with learning disabilities and using mental health services were dismantled (Her Majesty's Government 2003, 2004a, 2004b, Scottish Executive 2003a). This was followed by a significant increase in direct payment use amongst these groups (see Figure 1 for increase in users by impairment type in England). The English and Scottish executives made grant funding available to support implementation (Community Care 2003, Scottish Executive 2003b). Research during this period was again concerned with the extent and rate of take-up (Riddell et al. 2006), reviewing the support available for direct payment users (Davey et al. 2007, Hurstfield et al. 2007) and developing new systems and processes that would enable a growth in use, particularly amongst the groups targeted by the legal changes (Clark et al. 2004, Spandler & Vick 2004, Luckhurst 2005, Newbigging & Lowe 2005, Poll et al. 2006).

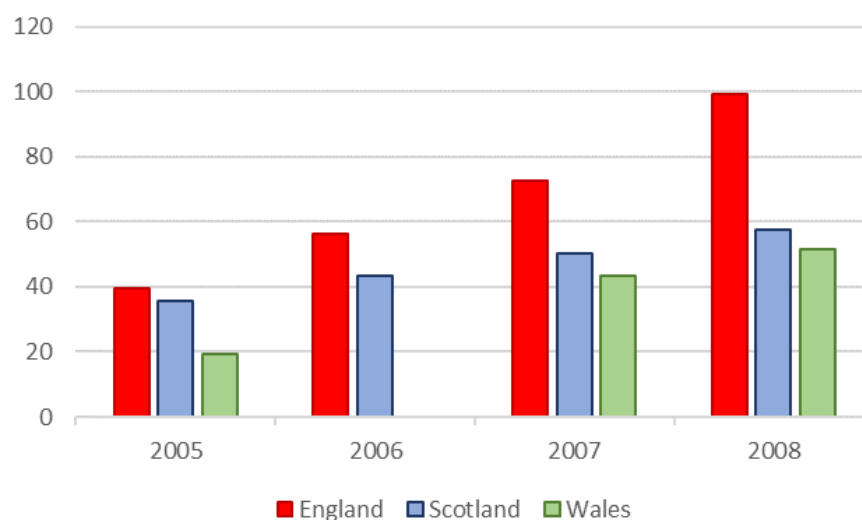


Figure 4: Numbers of Direct Payments per 100,000 population at year ends (31/3) in England, Scotland and Wales: 2005-2008

Data sources: England - Community Care Statistics, Referrals, Assessments and Packages of Care (RAP) Returns, Scotland - Self-Directed Support Survey 2005-2008, Wales – Direct Payment Survey Report 2008.

In 2005, the English 2005 Department of Health announcement that:

“By 2010, each locality (defined as that area covered by a Council with social services responsibilities) should have a user-led organisation modelled on existing CILs.”

(Department of Health 2005:91)

An additional £1.65 million user-led organisation or ‘ULO Development Fund’ was made available to support this objective in 2007. In Scotland, new regulations were also accompanied by guidance that local authorities establish “... a local support service which, where possible, should be independent and user-led.” (Scottish Executive 2007, Para:15). The concern with increasing uptake amongst ‘new’ groups of direct payment users is reflected in the type of peer network described in the research literature from this period. Of the 15 publications included from this period, 11 continued to describe PNs as providers of Direct Payment Schemes, Direct Payment Support Services or similar. However, an overlapping group of 10 publications record the growing involvement of other

organisations, particularly impairment-specific groups and charities. This supports the picture of increasing diversity amongst providers of support reported by two studies from this period (Davey et al. 2007, Maynard-Campbell et al. 2007).

During this second period, the English Department of Health had already begun to look for a single administrative process that could be used to devolve financial control to people in all 'client groups', and possibly incorporate government expenditure on support from other sources such as the Independent Living Fund and Supporting People (Department of Health 2005, 2006). Pilot tests were conducted in 13 English local authorities and simultaneously independently evaluated between 2006 and 2008 (Glendinning et al. 2008). The report itself meets the inclusion criteria for the present study, as PNs are mentioned in several places as examples of how support for individual budget users could be provided. The report cites the *Report on In Control's First Phase 2003–5*, which is significant here because it describes the evolution of a new 'brokerage' or 'support planning' function that was later provided through PNs (Poll et al. 2006). The essence of the idea was to separate the eligibility and needs assessment from the support planning process. While the former could still be carried out by a social worker or other officer of the local authority, the latter could be performed independently by the personal budget user, often with the assistance of informal carers or disability organisations. Departmental guidelines envisaged that user-led organisations would have an important role as providers of brokerage (Department of Health 2007).

In the third phase, the use of personal budgets in both England and Scotland was extended to allow a wider range of organisations and groups to manage them on other people's behalves (Department of Health 2009b). In England the new mechanism for costing and funding care consisted of allocating a 'personal budget' for everyone eligible for adult social care, and from this point the term becomes ubiquitous in the policy and research literature. If a personal budget user was unable or unwilling to manage direct payment, it could instead be managed by the local authority, by a 'suitable person' such a care home or an informal carer (even where they did not have a power of attorney or similar powers approved by the Court of Protection) or in some sort of combination of the above (Department of Health 2008, 2009a). In 2010, the Scottish Government began

implementing a 10-year national plan for self-directed support, bringing policy on personal budgets broadly into alignment with England (Scottish Government 2010, Ridley et al. 2012). Later these developments were consolidated by the Social Care (Self-directed Support) (Scotland) Act 2013, Section 4 of which created three new options for people eligible for social care to have direct payments managed on their behalves.

The research from this period frequently focussed on the wider 'personalisation' policy. Personalisation has been described as an overarching goal of the UK government's social care policy during this period, with the use of personal budgets and the process of 'self-directed support' representing core components of the model (Needham 2011, Slasberg et al. 2013). Studies from this third period included in the present review were frequently looking at personalisation (Manthorpe & Stevens 2010, Sowerby 2010, Slay 2011, Darling et al. 2012, Tew et al. 2015), self-directed support (Witcher 2013, Mackay et al. 2014), or person-centred care (Beresford et al. 2011). Researchers were also concerned with some of the specific issues associated with obtaining and managing personal budgets such as self-assessment (Darling et al. 2012), the employment of personal assistants (Patel & Pridmore 2010, The Fed CIL 2012) and managing risk (Mackay et al. 2014).

Perhaps because the aim of *Transforming Adult Social Care* was to develop a single mechanism that worked for everyone, only a minority of the studies included in the present review with data gathered after 2008 focus on specific 'client groups' (Manthorpe & Stevens 2010, Sowerby 2010, Newbrunner et al. 2011, Doheny & Milbourne 2013, Tew et al. 2015). However, researchers often sought to explore the experiences of these groups as one variable, or to purposively select participants with a view to being able to comment on differences (Pridmore 2010, N Campbell et al. 2011, Williams & Porter 2011, Darling et al. 2012, Patel & Williams et al. 2014). Brokerage was the most common focus of research into the activities of PNs during this period. Particularly significant in this context is the *Support Planning and Brokerage* study, which generated the material for three papers included here (N Campbell et al. 2011, Williams & Porter 2011, Williams et al. 2014). This was financed through the ULO Development Fund as an action research project, with the implementation of brokerage services proceeding alongside data collection. Eight other papers mentioned brokerage, either as their main focus or as an example of how PNs could

support personal budget users (NHS Confederation 2009, Manthorpe & Stevens 2010, Sowerby 2010, Beresford et al. 2011, Newbrunner et al. 2011, Darling et al. 2012, Doheny & Milbourne 2013, Tew et al. 2015).

In a development specific to England, The Health Act 2009 empowered the NHS to make 'personal health budgets' available to users of NHS services on a pilot basis (Schedule 1). The original regulations limited availability to people who were entitled to receive after-care from a Primary Care Trust, who met the criteria for the pilot scheme, and who agreed to have one (Her Majesty's Government 2010). In practice this meant people from the NHS 'continuing care' needs group, which included people with a wide range of life-limiting impairments who were assessed as being eligible for fully funded NHS care following hospital discharge (Department of Health 2009c). Personal health budgets were the exclusive focus of only one study included here (NHS Confederation 2009), although others commented on their potential (N Campbell et al. 2011, Newbrunner et al. 2011, Tew et al. 2015). This might relate to the much smaller numbers of personal health budget users. For example, figures from the last quarter of 2014-15 estimate that 62,535 were adults entitled to continuing care in England, compared to 889,520 long-term users of adult social care services, more than half of whom were using a personal budget by 2015 (Health and Social care Information Service 2015a, 2015b).

To summarise, research from the twenty-year period of the present review usually focussed on personal budgets, with a smaller number of publications investigating the activities of PNs or other topics. Perhaps for this reason, the research often reported on themes that reflected the issues of concern to policy-makers. These included the rate of uptake, barriers to implementation, and the strengths and weaknesses of different support schemes. Early on most of the PNs reported on were CILs, independent living schemes or similar projects under the control of disabled people. Typically support was provided to people with physical or sensory impairments. As the proportion of personal budget users with other illnesses or impairments increased, so did the proportion of reports describing other types of peer network. The majority of the research relates to England, which has a larger population than the other territories of the UK and which had a higher proportion of personal budget users throughout the study period. Research from Scotland and Wales

reports on similar issues to research in England. The review did not identify any research focusing exclusively on Northern Ireland.

2.2.3 Data extraction

To support the process of analysis, publications were imported into nVIVO 11 qualitative data analysis software (QSR International 2015). Where publications could not be acquired in a suitable electronic format, they were usually scanned, corrected and imported. Where this was not possible (e.g. because of poor quality scanned originals, or because of length in the case of the one book included) the publications were read and all relevant sections were typed manually and imported. The software made it possible to preserve extracts in their original context, and the automatic logging process created an audit trail that could be viewed by others. Most data were extracted from the results sections of the publications. Because the present review has a social constructionist orientation, data were viewed as being generated by the interaction between the original research team and research participants (Birks & Mills 2015). Consequently authors' interpretations of their data were also considered data for the purposes of this review. Similarly with respect to quantitative studies and quantitative elements of mixed methods evaluations, the authors' interpretations of data were extracted. This integrated approach to mixed method synthesis is considered appropriate where "...studies designated as qualitative or quantitative are not necessarily distinguishable from each other..." (Sandelowski et al. 2006:8).

2.2.4 Aggregation

Arksey and Baxter (2012) highlight a temporal dimension to direct payments, using data from a longitudinal study to show how people's experiences depended on the stage of their 'journeys' into, through and out of using direct payments. This corresponded strongly with the data extracted from the publications here. While different bureaucratic processes were used to allocate personal budgets, they all involved assessment and planning before supports could be put in place and maintained. This enabled the inductive development of the categories shown in Figure 5. Data which could not be coded at the bottom level were

coded at the next level up. All data extracted from the literature could be located within this model.

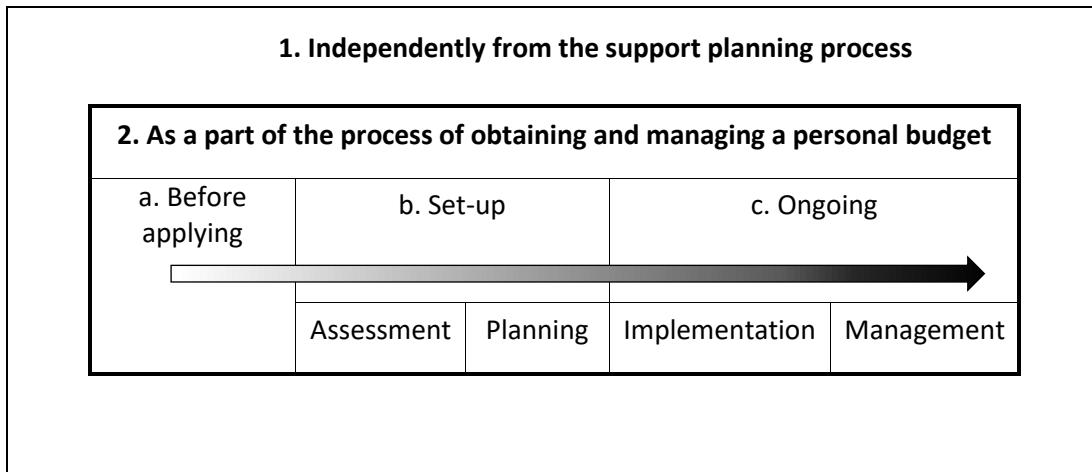


Figure 5: Coding scheme for aggregative/semantic description of the ways in which peer networks help people to obtain and manage personal budgets

2.2.5 Synthesis

Meta-ethnography proposes three methods for synthesising research: looking for similar lines of argument, conducting a refutational synthesis based on conclusions that do not agree with one another, and a reciprocal translational analysis, in which the results of each included study are translated into one another (Noblit & Hare 1988). The approach taken here was to develop lines of argument, giving contrary examples where they occurred, but reciprocal translation was not attempted.

While reciprocal translational analysis is a viable technique for synthesising qualitative studies (R Campbell et al. 2011), it was developed for small numbers of studies. In studies such as the present review that attempt to assemble data from a large number of reports, this can be impractical (Dixon-Woods et al. 2006). The process of establishing common lines of argument was carried out simultaneously with the consideration of contrary cases. The process for establishing lines of argument has been described as “...constantly comparing...” themes and attempting to establish relationships between them (Dixon-Woods et al. 2006:33). This approach, apparently derived from Glaser and Straus’ 1967 constant

comparative method, is common to a wide range of qualitative methods, including Braun and Clarke's (2006) approach to thematic analysis. This sets out a six-phase process, described in Table 2:8 (see section 3.7, below, for a fuller discussion of this method). Within this model, the first two stages can be thought of as aggregative, whilst the last four progressively move towards interpretation.

Table 2:8 Phases of thematic analysis

Reproduced from Braun & Clarke 2006:87

1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

2.4 Findings

The findings of the literature review are sub-divided into those resulting from the process of aggregation described in 2.2.4, and from the thematic analysis elucidated in 2.2.5.

2.4.1 *Aggregative description*

This section contains an aggregative description of support at the different stages of obtaining and managing a personal budget. Headings and subheadings follow those shown in Figure 5 (p.51).

1) Independently from the support planning process

Whilst most of the activities of PNs emerging from the research literature relate to supporting individual personal budget users, they have also played a pivotal role in developing and maintaining the infrastructure through which personal budgets are made available.

a) *Partnering in the local implementation of personal budgets*

PNs had often worked collaboratively with local partners during the development and implementation of personal budgets (Witcher et al. 2000, Wilson 2003). An early study of 4 local authorities in Scotland found that all 4 had involved PNs during the development of their PB programmes, and in three cases these organisations continued to be involved in steering groups (Witcher et al. 2000).

“Policy developments were strongest where there were shared goals and direct relationships between members of the disability community and local champions within purchasing authorities.”

(Riddell et al. 2006:12)

Senior statutory sector managers agreed that PNs had been important collaborators in the implementation of personal budgets in social care. They agreed that many of the solutions to barriers to implementation:

“...have come from the third sector. Local voluntary and user-led groups can add significant value to personal budgets schemes, and in areas such as brokerage, staff training and direct service provision they can often offer something unique, frequently at a lower cost.”

(NHS Confederation 2009:18-19)

Gramlich and others (2002) found that PNs had provided important expertise for local steering groups when personal budgets were implemented for people with learning disabilities. Peer support groups could be a useful source of feedback for planners (Clark et al. 2004) and local PNs were a source of support when direct payment support schemes lacked skills and capacity:

“In the absence of direct payments support agencies’ willingness, ability or resources to offer additional support relevant to mental health clients, some local mental health groups, advocacy projects, black and minority ethnic projects, user involvement projects and workers stepped in to provide additional support to clients.”

(Spandler & Vick 2004:56)

The independence of PNs from statutory control was highlighted as being particularly valuable (Beresford et al. 2011). After the launch of personal budgets, PNs played an important part in keeping them on the local agenda when interest within local authorities had waned (Witcher 2000). A pilot project funded by the housing action charity HACT operated in 6 English counties. The evaluation found:

“The voices and involvement of people who are affected by services is also integral to developing collaborative and collective approaches, but is under developed and has been undervalued in almost all the sites.”

(Slay 2011:17)

b) *Developing local capacity amongst peer networks*

Perhaps as a result of the emerging evidence of the importance of PNs in supporting the implementation of personal budgets, there was a perceived need to foster their development. This was apparent in the 2005 government’s planned expansion of Centres for independent Living announced in *Supporting the Life Chances of Disabled People* (Prime Minister’s Strategy Unit et al. 2005). Larger and more established PNs had a critical role in helping newer, smaller groups and organisations to get started.

“Groups can be supported by ULOs [user-led organisations] in terms of resources for meetings, doing newsletters, and so on. Building capacity in smaller self-organised groups is a key to user involvement in all aspects of independent living. Without support these groups are short lived, and not surprisingly, disabled people may disengage from being involved as a result.”

(Maynard-Campbell et al. 2007:11)

The *Wider Options* project looked at the creation of new organisations to support those groups who had previously been excluded from using personal budgets, and in some cases local PNs provided an essential role in guiding them through the early stages of their development (Luckhurst 2005).

There could be particular difficulties in developing PNs in more remote parts of the UK. Doheny and Milbourne (2013) describe a ‘community development’ aspect of the personalisation policy in which personal budgets sat in rural parts of England and Wales. Work in Wales seemed to require engagement with more generic charities such as the 50+

Network. This focussed more widely than personal budget support, also linking with preventing deterioration in people's health and wellbeing. In a follow-up to self-directed support test sites in Scotland, Ridley and others (2012) described how a nascent user network proved unsustainable. An alternative approach involved commissioning a service from a learning disability charity.

"What had been highly successful, however, was implementation of Community Connector posts across Highland in 8 areas. These were posts tasked with working with communities to promote SDS and to focus on developing community capacity."

(Ridley et al. 2012:19)

2) As a part of the process of obtaining and managing a personal budget

In a small qualitative longitudinal study carried out between 2007 and 2009, Arksey and Baxter (2012) illustrated the way in which people's support needs change over the duration of their use of direct payments. As well as the highly individual factors based on people's personal life journeys, many of the studies included in the present review depict specific support functions that are either only of use at one point in the process (for example around the initial assessment), or which tend to be of more use at one time than another.

a) Before applying for a personal budget

Before an individual can choose to use a personal budget, she or he must be aware of their existence, and have some knowledge of their purpose and functioning. PNs have often been involved in helping statutory agencies reach out to potential personal budget users, and Lewis (2005) provided examples of how this was achieved. Strategies included:

- appointing a development manager to produce materials.
- publicising personal budgets in the local media.
- operating 'surgeries', and providing briefings to planning forums, user groups and conferences.

Sometimes the process of raising awareness and providing information could be focussed on assisting statutory sector workers and sometimes on enabling other community groups and organisations to engage with personal budgets (Spandler & Vick 2004). Information could be provided by personal budget workers employed by PNs or service users themselves (Lewis 2005, Williams & Porter 2011).

It was often recognised that some people would require training to manage a personal budget. PNs often provided this, and sometimes also trained statutory sector workers (Witcher et al. 2000, Maynard-Campbell et al. 2007, N Campbell et al. 2011). Without support from a peer network, some statutory workers stated that they would not have pursued the option of a personal budget (Spandler & Vick 2004).

b) During the assessment and support-planning processes

To be eligible for a personal budget from public funds, people first needed to be assessed for eligibility. Early on in the implementation of personal budgets, guidance from the Policy Studies Institute had suggested that self-assessment might be more consistent with the 'independent living' approach (Hasler et al. 1999, cited in Ridley & Jones 2002). In some areas, PNs were involved with developing the bureaucratic systems to enable self-assessment. This extended to providing potential personal budget users with training and support to self-assess (Manthorpe & Stevens 2010, National Audit Office 2011, Darling et al. 2012).

PNs have often been commissioned to work alongside local authorities during the process of developing a support plan, often by providing 'brokerage' (see p.47 above). Within the literature included in the present review, the term 'brokerage' was first used by Dawson in 2000 and then subsequently in more than twenty other publications.

PNs had a spectrum of involvement in the planning process, from full integration (for example developing assessment tools and having access to the local authority's electronic record-keeping systems), to a clear separation of responsibilities (Poll et al. 2006, N

Campbell et al. 2011). Sometimes the relationship was problematic. The *Support Planning and Brokerage* study found that user-led organisations were often made to feel like the junior partner in the relationship, and that there could be practical barriers such as limited access to local authority electronic record-keeping systems (N Campbell et al. 2011).

Where PNs were supporting people with cognitive impairments, informal carers were nearly always involved (N Campbell et al. 2011). Carers played a particularly important role in helping people manage the bureaucracy associated with managing a personal budget:

"Of the 20 clients interviewed who were in receipt of and actually using direct payments, nearly all had had initial help from the direct payments support service in explaining what was needed in order to manage the payments. In terms of actually running the payments, a substantial proportion (8 people) had a close relative managing the paperwork for them."

(Spandler & Vick 2004:81)

In these situations, the peer network would often provide support to carers too. The involvement of an advocacy service enabled service users to express a clear and independent voice in the support planning process (N Campbell et al. 2011).

c) Implementation and ongoing maintenance of the support plan

Once the support plan has been agreed and the money released, it is necessary to purchase the supports and maintain them. The research gave many examples of how PNs were helpful.

One very common use of a personal budget is to pay for the time of personal care assistants, or personal assistants (Waters & Hatton 2014). A UK-wide survey of direct payment support schemes found that the majority offered help with recruiting and employing personal assistants (Riddell et al. 2006). This is echoed in a later survey of employers of personal assistants carried out for Skills for Care, which found that formal and

informal networks were both important routes for recruitment (Adams & Godwin 2008, see Figure 6 below). The same research also found that 17% of employers would have valued peer support in this context had it been available (Adams & Godwin 2008). The National Audit Office (2011) reported visiting one scheme where people with similar assessed needs shared their experience and knowledge of suitable providers. In their development project in six areas, the housing charity HACT found that connecting people with one another on the basis of shared ambitions (rather than for example membership of a 'client group' or use of the same residential project) was challenging for some providers. However, support groups eventually emerged which allowed people to link on the basis of other factors such as personal interests, geographical proximity and shared experiences (Slay 2011).

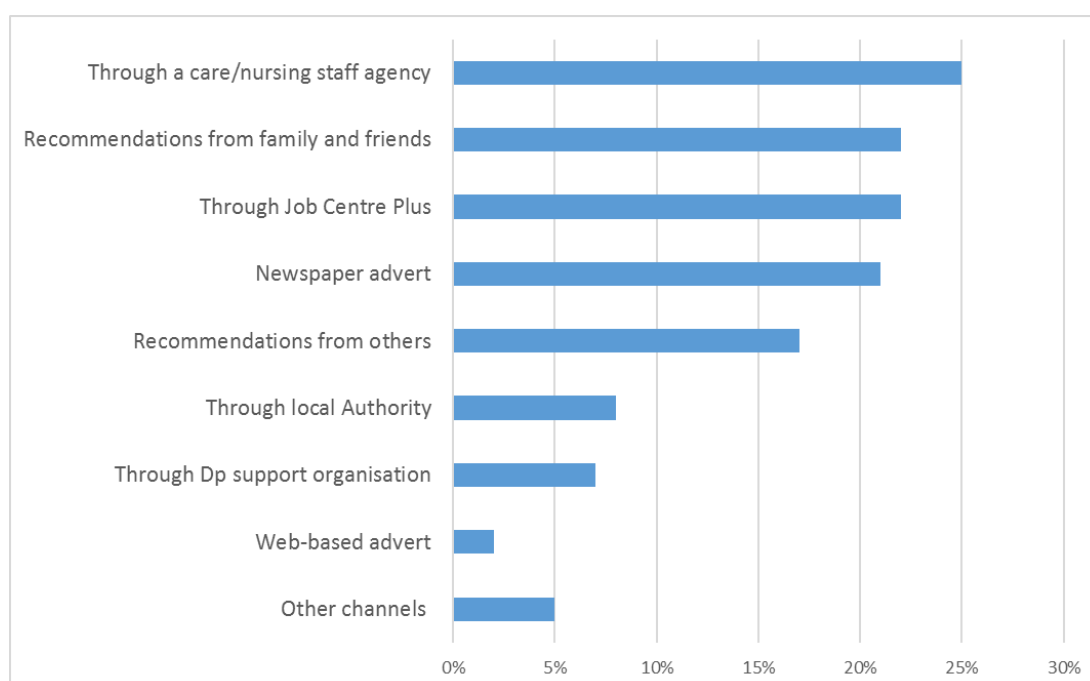


Figure 6: The proportion of employers using various recruitment channels when appointing their latest Personal Assistant under Direct Payments

Reproduced from Fig. 5.3 Adams & Godwin 2008:51

A number of pieces of research give good examples of the diversity of approaches taken by PNs in helping people to find and recruit personal assistants. One approach was maintained a register of personal assistants (Clark et al 2004, Swift 2007). One of the UK's first CILs ran a 'link-up' project to individual PB users and larger care providers to share best practice around employment (The Fed CIL 2012). The same research showed that once people had

employed a personal assistant, many still relied on PNs for support with employment. Figure 7 shows the different sources of support accessed by 48 personal budget users. Whilst the largest source of support probably reflects the process through which study participants were recruited, the other sources of support are diverse.

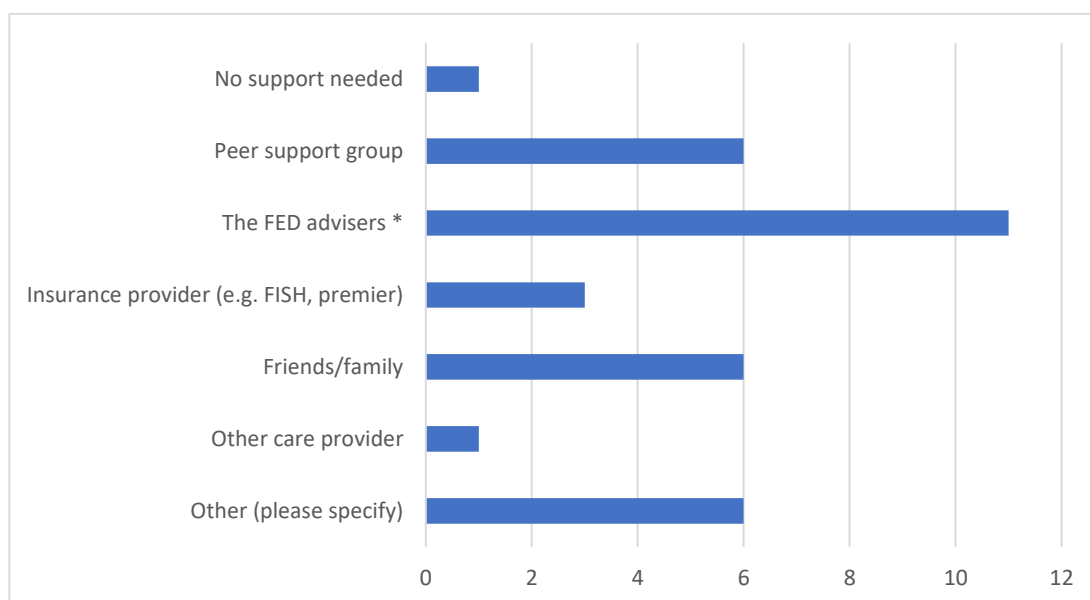


Figure 7: Where do you currently get support from when you have questions/problems with being an employer?

**Advisers employed by The Fed CIL. Reproduced from The Fed CIL 2012:17*

PNs were sometimes able to assist people to ‘pool’ their budgets to collectively purchase support, generating efficiencies. This apparently also improved confidence in direct payments, enhancing uptake (Newbigging & Lowe 2004, Swift 2007, N Campbell et al. 2011).

One type of peer network frequently used by parents of adults with learning disabilities is the Independent Living Trust (ILT), in which parents typically act as Trustees of a fund used to employ staff to support their children. This legal vehicle was also a useful way of co-ordinating the involvement of a wide range of different individuals and agencies in providing support to the Trust’s beneficiaries. There were also perceived advantages over individual caring relationships in terms of safeguarding and preventing abuse, simply because more people were involved in decisions (Luckhurst 2005).

Occasionally support plans will break down or need adjusting. In the research, ‘crisis management’ was sometimes performed by PNs rather than local authorities, saving money (Stainton et al. 2009).

2.4.2 Thematic synthesis

The previous section has described the activity of PNs in establishing the availability of PBs and in providing support to actual and potential PB users. This section will explore the characteristic approaches and qualities of PNs that the research indicated had helped them to perform these. Not all of these were present in every peer network, and many were also features of other organisations and groups involved in supporting PB users. The headings and subheadings follow those in Table 2:9.

Table 2:9 Themes, sub-themes and organising concepts

1)	Fostering collaboration Helping people by assisting organisations, groups and individuals to work collaboratively with one another. a) Peer Support b) Collaboration with other organisations, groups and individuals
2)	Enhancing communication Assisting communication between the personal budget user and other individuals, groups and organisations involved with the process of obtaining or managing a personal budget
3)	Confidence Increasing confidence amongst actual and potential personal budget users that they would be able to manage the process, and that having a personal budget would have benefits
4)	Specialist knowledge Specialist knowledge held by peer networks that informed the support provided to personal budget users.

1) *Fostering collaboration*

The research shows that collaborative working was characteristic of the way in which many PNs have supported actual and potential personal budget users. Collaboration can be divided into collaboration with 'peers' and collaboration with other groups, organisations and individuals.

a) *Peer Support*

'Peer support' is referred to in the overwhelming majority of the research literature, and is often asserted as an essential feature of CILs (Evans 2002, Gibbs 2005, Morris 2006, Department of Health 2007). 'Parity' was conceptualised in different ways. Peer support could operate between PB users (Witcher et al. 2000), people with mental health problems (Brandon & Maglajlic 2000) or those caring for someone with a learning disability (Swift 2007). Often no description of 'peer' was offered.

In their UK-wide survey of direct payment support schemes in 2004-5, Davey and others found that 75% offered some type of peer support. A survey carried out in 2003-4 found that 64% of 50 'Standard' Direct Payment Support Schemes offered some opportunity for peer support, a figure which at that time was regarded as surprisingly low (Luckhurst 2005). The focus on peer support for personal budget users within PNs was attested to by a national study commissioned by the Department of Health to map the capacity of user-led organisations. Of the CILs on a national database held by NCIL in 2006, 51-75% either provided or facilitated peer support (Maynard-Campbell et al. 2007).

Peer support was not the sole preserve of PNs: local authorities sometimes tried to establish peer support groups, though with limited success (Witcher et al. 2000, Glendinning et al. 2008). The majority of Direct Payment Support Schemes surveyed by Davey and others (2007) were provided by local and national charities, but a small minority were created by local authorities. Interestingly, these were much less likely to provide other related types of support, including peer support.

Many studies reported difficulties in establishing or sustaining peer support. An early direct payments project based in Norfolk found that whilst membership of peer support groups was high, attendance was low (Dawson 2000). The researchers thought that the rural geography of the county and difficulties with transportation might have been to blame. Manthorpe and Stevens (2010) found that confidentiality could also be a concern for people in small rural communities. Newbrunner and others (2011) reported that personal budget users with mental health problems generally did not attend peer support groups regularly. A pilot study of PB use among older adults in three local authority 'types' found that a peer support group established itself readily in a London Borough, but not in the other two locations (another city and a county council area), perhaps indicating that geography was not the only factor at work (Clark et al. 2004).

b) Collaboration with other organisations, groups and individuals

The research reports collaboration between PNs and statutory authorities (Witcher 2000, Lewis 2005, Poll et al. 2006, N Campbell et al. 2011, Williams & Porter 2011, Slay 2011, Wilson 2003), with informal carers (Luckhurst 2005, N Campbell et al. 2011), with local voluntary sector organisations and rights groups (Spandler & Vick 2004, Newbrunner et al. 2011) and with other agencies employing personal assistants (The Fed CIL 2012). However, PNs did not always have the resources to work collaboratively in this way (Witcher et al. 2013). Some PNs were worried that this could lead to them being perceived as disinterested or inward-facing, which might in turn lead to further funding cuts, creating a 'vicious circle' (Maynard-Campbell et al. 2007).

Contact with multiple networks made it much more likely that people would be able to manage both the support planning process, and the process of putting it into effect (Williams et al. 2014). In some areas and at some times, PNs were able to boost this 'network effect'. Ridley and Jones (2002) highlighted the importance of having a range of organisations for people to draw on for information and advice. People with dementia and their informal carers would often fall back on voluntary organisations for supplementary advice, even where receiving ongoing support from a user-led organisation or local authority (N Campbell et al. 2011). Personal budget users often relied on a number of

different networks both to identify potential employees, and to advise them about ongoing management issues (Adams & Godwin 2008, The Fed CIL 2012).

2) *Enhancing communication*

PNs often played a key role in communications about PBs, including by facilitating communication between the personal budget user and other individuals, groups and organisations involved with the process of obtaining or managing a personal budget. They were often able to provide “...direct and regular contact with the core constituency targeted by the DP scheme” (Stainton et al. 2009:170). Sowerby (2010) reported that a long-term relationship was necessary to communicate effectively with people with learning disabilities, and that doing so in the context of a peer network had particular advantages:

“To understand how to communicate with the person and how to support them to develop their own views will require enough time and contact to get to know each other well. There can be added benefit from meeting them in a group of their longstanding peers as individuals in the group can build on the contributions of others to get their points across.”

(Sowerby 2010:274)

User-led organisations which had a local geographical focus often had links with specific groups which might otherwise be ‘hard to reach’ (Maynard-Campbell et al. 2007). Newbrunner and others (2011) gave examples of PNs working to support outreach to people from transgender, lesbian, bisexual and gay communities, and people with HIV/AIDS.

Many studies reported that PNs had produced specialist communication aids, such as DVDs, videos, computer-based information, pictorial information for people who did not read, information leaflets and so forth (Maglajlic et al. 2000, Lewis 2005, Mackay et al. 2014, Williams & Porter 2014). Others found that “...user-led organisations saw themselves as having a wider and more experience-based information-giving role...” than their statutory sector partners (Newbrunner et al. 2011:25).

Several studies contrasted the ‘equality’ of communication within a peer network with the hierarchical communication personal budget users experienced with an ‘expert’ care professional (Spandler & Vick 2004, Williams et al. 2014, Tew et al. 2015). This linked with the ability to help people plan to meet their own aspirations rather than accept professional judgements about what was type of support might be most appropriate (Williams et al. 2014, Tew et al. 2015).

““With (ULO support planner), they would write down what you said, and then they would pull apart what you said, to get deeper into what you want, and what you’re thinking and what you’re saying. And they would pull out to know what you really do want, rather than a [local authority] care manager – this is what you say, and this is what they want.” ULO carer.”

(Williams & Porter 2011:46)

PNs were often engaged with the wider support systems of the personal budget user, including informal carers, family and friends. This meant that they could also be included in the support planning process (Williams et al. 2014).

3) *Building confidence among actual and potential personal budget users*

Many studies illustrated how PNs had helped actual and potential budget users to gain the confidence to take on a personal budget. The two features they had that seemed to make this possible were that they included people who were already using PBs successfully, and that they were viewed as trustworthy.

One large study compared support provided by local authorities with that given by impairment-specific charities and user-led organisations (Williams & Porter 2011). In two broadly comparable samples of about 40 people, 43% of those advised by Local Authority staff went on to manage a personal budget compared to 73% of the group advised by user-led organisations. While the charities were trusted and valued for their expert knowledge,

the best entry into the PB process was achieved by disabled people involved with user-led organisations that provided the opportunity for contact between existing and potential personal budget users. Many other studies highlighted the usefulness of putting actual and potential PB users in contact (Brandon & Maglajlic 1998, Brandon et al. 2000, Gramlich et al. 2002, Ridley & Jones 2002, Newbronner et al. 2011).

"If [service] users can talk to each other and see what the reactions are, they are more likely to see it as real for themselves, as well. And – from such meetings, there is a chance for 'word to get around'. (Staff)."

(Brandon & Maglajlic 1998:36)

"The preference was for a person with mental health problems to be involved who could confirm that "it worked for me and I've got the same problems as you." It was valuable to ask questions and discuss practical issues face to face with others, especially those with first hand experience of Direct Payment."

(Ridley & Jones 2002:52)

After a personal budget had been allocated, the ongoing involvement of a user-led organisation could be key to helping people feel that they were still in control (N Campbell et al. 2011). Several other studies emphasised the importance of the emotional as well as the practical roles of PNs in helping people to feel that they could meet the challenges of managing their own support (Newbigging & Lowe 2004, Luckhurst 2005, Hurstfield et al. 2007, Newbronner et al. 2011).

The research contained examples where PNs did not inspire confidence. Stainton and Boyce reported that some older adults did not want to get involved with the local coalition of disabled people because they were perceived as "too militant" (Stainton & Boyce 2004:447). People with learning disabilities were not necessarily impressed by the expertise within user-led organisations, and newly disabled people could also be dismissive

of the abilities of disabled advisers (Williams & Porter 2011). Not all people who met the statutory criteria for a PB saw themselves as 'disabled', or wanted to spend time with other disabled people (Beresford et al. 2011).

From the outset, PNs were seen as vital supports to personal budget users because of their independence from the direct control of statutory bodies (Maglajlic et al. 2000). In their independent evaluation of the national personal budget pilots, Glendinning and others (2008) found that PNs were valued as information providers because of the positive image they had amongst potential personal budget users, the closer position they had to service users and carers and their independence from statutory agencies. Three consequences of independence from local authority control were repeatedly linked with benefits for PB users:

- Not focussing on the PB primarily as a means of containing public expenditure (Glendinning et al. 2008, N Campbell et al. 2011, Williams & Porter 2011, Darling et al. 2012).
- Offering a real choice about taking a personal budget, rather than 'pushing' them on people (Patel & Pridmore 2010, Williams & Porter 2011). It is worth noting that Newbrunner and others (2011) found that some PB users believed that PNs were themselves required to promote PBs under the terms of their contracts.
- Taking a positive approach to risk. Two studies reported that statutory services often attempted to 'steer' the planning process in a particular direction, whereas support planners from PNs would start with people's ambitions for their own lives (Beresford et al. 2011, Williams & Porter 2011). Mackay and others found that by working with advocates, statutory sector workers were better able to appreciate service users' perspectives on risk and vice versa (Mackay et al. 2014).

4) *Specialist knowledge*

The earliest study included in this review begins with a short summary of the independent living movement and its relevance to the community care policy, citing the arguments of Oliver (1990) and Morris (1994) that discretionary 'care' assessed for and provided by agents of the local authority was different to and incompatible with the right to

independent living (Witcher 2000). In the contemporary pilot study evaluated by Dawson (2000), the local Council of Disabled People provided training for staff on the social model of disability. These illustrate the significance of the concepts underpinning PBs to people within the disabled people's movement. Although these models were not the sole preserve of PNs, they appeared to be more deeply embedded than in statutory organisations (Newbigging & Lowe 2004, Maynard-N Campbell et al. 2007).

Most of the studies included in the present review make passing references to concepts such as independent living, the social model of disability, person-centred care and the recovery model. Comparatively few investigated how the models worked in practice. The survey reported by Wilson found that providers who reported working with the social model were more likely to be offering a choice of provision than those who did not (Wilson 2003). Personal budget services provided by CILs were more oriented towards helping people use their budgets to live independently than simply to purchase support (Davey et al. 2007). Similarly, time-and-task support plans were much less likely to offer choice than those developed using a person-centred process (The FED CIL 2012). Person-centred planning was usually framed in terms of offering personal budget users a choice, and considering how supports would fit in with people's lives rather than vice versa (e.g. Poll et al. 2006, Beresford et al. 2011).

“Crucially people see person-centred support as much more than a technique. They see it as an approach to support that is strongly value based and where the relationship between service user and worker is of central importance.”

(Beresford et al. 2011:62)

A similar picture emerges from the *Support Planning and Brokerage* study (N Campbell et al. 2011, Williams & Porter 2011). Services provided by user-led organisations had a different type of expertise about personal budgets reflecting the perspectives of the people using themselves. Support was particularly useful when coming from people with lived experience.

“...because of their real understanding of the ‘lived experiences’ of disabled people, ULOs are able to provide a range of services that are both shaped and delivered by disabled people.”

(N Campbell et al. 2011:25)

One study mapped the activities of CILs in England 2006 (Maynard-Campbell et al. 2007) shortly after another conducted a similar study looking at all support providers (Davey et al. 2007). A rough comparison shows that advocacy, support with the direct payments process (including through peer support), financial advice and support (including on welfare benefits) and some campaigning work were common to both. However, CILs frequently provided a range of additional supports that other schemes did not. These included transport services, information about leisure activities, housing advice, and information about assistive technology. This slightly broader array arguably reflects the focus on ‘independent living’ and the supports necessary to achieve it, in comparison to the narrower range of supports necessary simply to enable people to use PBs.

The expertise of user-led organisations included knowledge about accessible environments, diversity issues, and self-help techniques for disabled people, was again often derived from lived experience:

“Users have more vision and more experience (in their condition, coping, support, self help). They have shared knowledge and experiences that unite them – “understanding the small and big things that make a difference to my life”.”

(Maynard-Campbell et al. 2007: 68)

An interesting point to consider is how this expertise is held within the peer network, and then communicated to the people who needed it. Several reports mentioned the expertise held directly by personal budget users, and shared through peer support groups or public meetings (Clark et al. 2004, Newbigging & Lowe 2004, Slay 2011, Williams et al. 2014). An advantage of this approach was that when information was shared in this way people could

‘feed off each other’ without the need for an intermediary. Other potential explanations were PNs’ organisational mission and culture (Maynard-Campbell et al. 2007) and the lived experience of peer supporters with impairments (Williams & Porter 2011). Several of the other reports also made passing references to the expert knowledge held by PNs (Maglajilic et al. 2000, Witcher et al. 2000, Clarke et al. 2004, Newbigging and Lowe 2004, Newbronner et al. 2011, Slay 2011, The Fed CIL 2012, Mackay et al. 2013).

There were forms of specialist knowledge which PNs did not have, but which were possessed by statutory agencies. This included knowledge about complicated safeguarding issues, and where the personal budget holder’s impairments might need specialist medical interventions (N Campbell et al. 2011).

2.4.3 Discussion of findings

2.4.3.1 *Reflection on methods and limitations of the study*

Though the initial aim had been to locate all research reporting on the topic within the limits specified, this was unlikely to have been achieved. The large proportion of literature identified through the cascade search reflects the limited precision of database search terms, and that the primary interests of researchers reporting on this topic often lay elsewhere. However, the large number of duplicates identified through the cascade search points to a coherent body of literature, and the recurrence of many authors in different combinations across the study period indicates that groups of researchers were often known to each other. It therefore seems unlikely that any major study could have been overlooked.

The picture of the widespread and significant contribution of PNs in the initial development and increasing use of PBs is widely acknowledged in national policy (Prime Minister’s Strategy Unit et al. 2005), by statutory sector leaders (NHS Confederation 2009), and within the disabled people’s movement (Morris 2006, 2014, Pearson & Trevisan 2015). In view of the broad agreement between most of the sources included here with one another and with this wider literature, the picture of the involvement of PNs depicted in aggregative

description is credible, even though the sources were dispersed geographically and chronologically.

The long period from which the evidence is drawn and the wide variety of geographical and policy contexts also weakens the claim that the themes are stable. Thematic synthesis is inherently further from the data than the aggregative description because it involves ‘third order’ synthesising constructs (Britten et al. 2002). Nevertheless, the themes developed here proved stable during the supplementary coding of more than a dozen additional reports identified through the cascade, arguably meeting the criterion of ‘conceptual saturation’ put forward by Thomas and Harden (2008) as analogous to the ‘theoretical saturation’ commonly applied to theory development in naturalistic inquiry and grounded theory approaches (Lincoln & Guba 1985, Stern 2007, Birks & Mills 2015). It is therefore reasonable to conclude that they reflect the data.

2.4.3.2 Conclusions and implications for second phase

The analysis of the existing literature was able to partially answer the research question, and to highlight issues for further investigation during the second stage of the study.

All the objectives for the present study are predicated on the idea that PNs have a characteristic approach, and that it is therefore possible to investigate it. The literature did indicate a characteristic approach which could be seen at each stage of the process of obtaining and managing a personal budget, and in the wider strategic activities aimed at supporting the policy. This characteristic approach could be described thematically in terms of collaboration both within and across networks, and an ability to communicate with personal budget users and inspire their confidence. The approach was supported by specialist knowledge, often stemming from lived experience but sometimes also formulated into explicit theories, methods and models of support. However, there are a number of caveats to these conclusions. There was considerable variation in the types of peer network providing support and in the support which individual networks provided, and the geographical and historical policy contexts in which they operated varied widely. Some of the studies included were conducted nearly two decades ago, raising questions about

whether their findings would reflect the present situation. This question applies specifically to the first three objectives of the study described in section 1.6 (p.27), which relate to the range of PNs, the contexts in which they operate, and the perceived benefits and drawbacks of the support provided. To confirm the findings from the literature review, the next phase of the study would need to revisit these questions using contemporary data.

The thematic synthesis also has implications for the second phase. These apply to the fourth and fifth objectives of the study, which relate to the operation of peer identity in the process of support provision. Within the literature reviewed, concepts of peer identity were rarely explicit. Yet related constructs such as peer support, the central importance of lived experience and of user control were associated with all the themes described in the previous section. Many of the models, methods and theories described in the fourth theme make these ideas explicit. However there was little consensus about how these approaches achieved the affects claimed for them. Some studies attributed the distinctive qualities of PNs to values-based concepts underpinning 'personalisation' and 'person-centred' practices (Maynard-Campbell et al. 2007, Beresford et al. 2011, Williams & Porter 2011). If this is true then it is perhaps surprising, given the widespread diffusion of these models and practices beyond PNs. For example the social model of disability is now commonly taught to social work students (Morgan 2012), and person-centred planning is built into the Care and Support Statutory Guidance (Department of Health and Social Care 2018). Another explanation, and one which relates more closely to the objectives of the present study, is that benefits are related to the inculcation of peer identity. For example Williams and Porter (2011) concluded that, while support delivered by a CIL wasn't by itself sufficient to have a significant transformative effect:

"... coupled with ongoing contacts, membership and active contributions, individuals did experience greater control and an opening up of their lives through becoming part of a larger collective of disabled people with a mission for change."

(Williams & Porter 2011:64)

Other studies also talked about this process of identity formation. Stainton and Boyce (2004) found that PB users regarded some staff at a local Independent Living Scheme as being 'role models' for what could be achieved by disabled people. In a peer support model in mental health, contact with the 'recovery' model was found to inculcate a 'recovery mindset' (Tew et al. 2015). However, Roulstone and Morgan (2009) have urged caution when speculating about the transformational impact CILs and other 'collectivities of identity', pointing out that the vast majority of people eligible for PBs will have little contact with them. While changes to people's self-concept and identity clear did occur, it could not have happened on a scale large enough to account for the reported benefits of support provided through PNs.

An alternative theory is that the development of peer identity could be impacting in personal budget users indirectly, through the people providing support. It seems credible that the types of changes described in the quotation on the previous page could be at least as common in peer supporters working within PNs as in personal budget users. If these changes were associated with the development of skill in providing peer support, then this might represent a plausible mechanism through which the characteristic approaches of PNs could operate. Consequently, the next phase of the study would focus specifically on peer supporters.

2.4.3.3 *Summary*

Taken as a whole, the research evidence showed a characteristic approach to providing support at each stage of the process of obtaining and managing a personal budget, and in the wider strategic support for the implementation of personal budgets. Generally personal budget users benefitted from this approach, which was often favourably compared to the support provided by other organisations. However, this approach varied between studies, and evolved over the course of the 20-year period for which personal budgets have been available. A goal for the second phase of the study is therefore to determine whether current provision fits with this model, to find out if similar benefits for personal budget users are reported, and to explore the effects of contemporary contexts on the support provided.

The ways in which PNs provided support could be described in terms of four themes, each describing a characteristic of their approaches. While no one of these characteristics is exclusive to PNs, collectively they described an approach that is fundamentally different to that of statutory services. Concepts of peer identity are central to these differences, but the mechanisms by which peer identity operates remain opaque. Peer supporters working in PNs are at the interface between the organisations providing support and personal budget users. In the second, empirical phase of the study, they will be the group most likely to be able to throw light on how peer identity impacts on the provision of support.

CHAPTER 3: METHODS

This chapter describes methods chosen for an empirical study to follow from the literature review. It provides an introduction to the focus group method, explaining how it could help answer the questions left unanswered by the first phase of the research. The theoretical orientation described in section 2.1 (p.28) is revisited and its methodological consequences for this phase of the study are set out. Detailed sections describe and justify the approach to sampling, recruitment, the composition of the schedule, the approach to moderation and the mechanics of data recording. The approach to analysis is explained and located within the family of methods for qualitative data analysis. Finally, the methods used are reviewed in terms of their rigour and ethics using Lincoln and Guba's framework for trustworthiness (Lincoln & Guba 1985, Guba & Lincoln 1989).

3.1 Introduction

Focus groups are commonly thought to have originated with the focussed interviews of groups developed by Robert K Merton in the 1940s and 1950s (Merton 1987, Lunt & Livingstone 1996). They became a popular method amongst market researchers and subsequently qualitative researchers in the 1980s and 1990s, when methodological guides began to emerge (e.g. Kreuger 1988, Morgan 1990). Morgan (1997) argues that the features which distinguish focus groups from participant observation and individual interviews are the focus, which is created by the active role of the group facilitator, and the interaction between group members. This creates the opportunity to generate large quantities of data focussed accurately on the research question in a short period of time, making it a good choice pragmatically. It was decided to host a series of groups in a short period of time and include participants from a diverse range of PNs. This would generate a contemporary data set which could be used to revisit the findings of the literature review in relation to the range of organisations and groups providing support, the contexts in which they operate, and the perceived benefits and drawbacks of this type of support for personal budget users.

Focus groups are useful in surfacing shared, tacit beliefs through the process of interaction (Macnaughten & Mayers 2004). Objectives four and five of the present study are concerned with the role of peer identity in providing support to PB users, at both an organisational and individual level. Chapter 2 concluded that the most likely site at which these factors might operate was the interface between the peer supporter and the person being supported. Focus groups consisting of peer supporters were seen as a suitable method for accessing peer supporters' surface-level knowledge and experience as well as their deeper cultural orientations to providing support.

3.2 Theoretical perspective

It has been suggested that from epistemological and related methodological perspectives, focus group research falls into two broad orientations (Ryan et al. 2014). In the first and original formulation, participants' contributions are said to emanate from more-or-less stable pre-formed views and opinions. This is a psychological orientation based within a positivist paradigm. In the second orientation, data are conceptualised as being co-constructed by participants and the facilitator, and this is consistent with the critical constructionist position of the present study. Viewing focus group data in this way also allows for a critical interpretation, in the sense of allowing "...the entanglement of fact and value to become visible, by showing up ... the way in which tacit valuations are present in all apparently purely factual description..." (Jarvis 1998:48). The aim of this section is to describe the basis for the interpretation and analysis of focus groups data from a critical constructionist perspective.

The terms 'constructivist' and 'constructionist' are not always consistently applied (Burr 2015). This thesis follows Young & Collin's (2004) scheme, in which the former refers to the way in which social factors determine individual psychological characteristics, and the latter to the way that knowledge itself is socially produced. In the present study, knowledge can be seen as being constructed at different levels. Firstly and principally it is constructed through the practices of providing peer support, in the organisational contexts of the PNs represented and in the individual contexts of the lives of those concerned. At a secondary

level it can be seen as the product of the social interactions between group participants and the facilitator during the group. Focus groups therefore provide an opportunity to apprehend the practices of peer support reflected through a conversation between peer supporters from different agencies. However, from a constructionist perspective the relationship between the data and the phenomenon under investigation is not straightforward. From the processes of recruitment and facilitation through to the subsequent labelling, aggregation and interpretation of the data, the researcher's impact is ubiquitous. From a constructionist perspective it is not possible to 'bracket off' this impact, which is pervasive. Consequently the following account of the methods aims to provide sufficient detail for the reader to assess their possible impact and consequently the trustworthiness of the findings (Lincoln & Guba 1985, 1986, Erlandson et al 1993).

In qualitative research, critical methodologies exist on a spectrum between those that aim to directly address power imbalances between the researcher and participants, and those that merely seek to surface and describe them (Gibson 2007, Denzin & Lincoln 2008). The literature review identified that independence from professional and bureaucratic (health and social care system) hierarchies was an important feature of the support provided through PNs, so positional identities within the support planning process were within the scope of the study. Addressing inequality directly was not an aim, but this study and its report aim to contribute to the theory of independent living, which is fundamentally an emancipatory endeavour (Evans 2002). The researcher was aware of his own agency and relatively powerful position, both as the focus group moderator and as the person interpreting the data. Methodologically steps were taken to minimise power differential between the researcher and participants, and these are reported below.

3.3 Sampling

In naturalistic inquiry, the sample is determined principally by the purpose of the inquiry rather than the desire to generalise from the results (Lincoln & Guba 1985). Purposeful or purposive sampling "...increases the range of data exposed [sic] and maximises the researcher's ability to identify emerging themes that take adequate account of contextual

conditions and cultural norms.” (Erlandson et al. 1993:82). Organisational and individual peer-identity were an explicit focus of the research (see objective 4), and the literature review indicated that cultural factors might have an important impact. The terms acculturation and enculturation both refer to processes of cultural transmission, with the former often being characterised as a process of socialisation occurring when individuals from different cultures interact (e.g. Gibson 2001) and the latter placing more emphasis on the agentic choice to assimilate elements of a culture (Weinreich 2009). The entry of peer supporters into a peer network was identified as a potentially important site at which acculturation or enculturation might occur. Consequently recruitment focussed on peer supporters who were deeply immersed in the cultures of their own networks.

Some of the PNs identified in the literature review consisted of facilitated or unfacilitated meetings between personal budget users who had no training or supervision, and no close relationship with one another or with the organisation hosting the group. There was no reason to suppose people simply attending these groups would have significant experience of providing support, have a rationale for providing support in a particular way, or an understanding of the role of the host organisation in contextualising that support. Consequently recruitment focussed solely on peer supporters in paid or organisationally defined volunteer roles.

Patton (2002) notes that there are no hard-and-fast rules about sample size in qualitative research. Morgan (1997) cites a widely applied ‘rule of thumb’ that focus group research typically consists of three to five groups, each consisting of six to ten members. Braun and Clarke (2013) suggest that when considering size, researchers should balance the desire to maximise the diversity of the participants with the potential difficulties of moderating a larger group, and pragmatically consider the demands of transcribing and coding data. In the present study, the principal aim was to recruit sufficient numbers to allow for a wide range of perspectives and experiences to emerge, and to collect enough information about participants to provide context and potentially to support interpretation based on participants’ organisational and demographic characteristics.

Morgan (1997) highlights a range of factors for consideration when deciding on whether to separate different types of participant into separate groups. Segmentation might be desirable where hierarchies or prevailing social attitudes make it difficult for those in less powerful positions to make their voices heard. This was considered in the context of different types of PNs, but the advantages of heterogeneous groups were thought to outweigh the risks. Morgan (1997) argues that participants must have enough in common to feel comfortable enough to be able to speak to one another. Bryman (2016) discusses the potential drawbacks and benefits of recruiting participants who are actually known to one another, and suggests that it may sometimes be appropriate to select on this basis. To offset the risks of intimidation and marginalisation, potential participants in the present study were encouraged to bring a colleague for ‘moral support’ if they wanted to (see A2.3 *Participant information Sheet* in Appendix 2). Having two or more participants from the same peer network could also help generate data relating to the internal dynamics of organisations (Holbrook & Jackson 1996), and provide examples of variation within organisational ‘cases’ as well as between them.

There was no attempt to recruit a representative sample of any particular population, but participants were asked to complete a short background questionnaire to describe the organisation they worked with and their role, as well as demographic information such as age, gender, health and disability (see Appendix A2.2). The demographic information used the same questions and categories as the 2011 census (NOMIS 2012), so that participants could be described in relation to the wider population. These data were gathered to provide context and inform readers’ decisions about transferability (Lincoln & Guba 1985, Erlandson et al. 1993), rather than to support any kind of statistical analysis.

3.4 Recruitment

Initially the aim had been to host four focus groups, each with six to twelve participants. It was anticipated that some participants would have impairments that affected their ability to attend, so accessible venues with good transport links were chosen. The initial sites were Universities in the Greater London area, and in a smaller city in the south midlands.

Peek and Fothergill (2009) describe three different approaches to recruitment; researcher-driven, key informant and spontaneous. The approach applied here began as the first of these, in which the researcher sought to make information about the groups accessible to as wide a population as possible within the study area. A database initially of around two hundred PNs and associated umbrella groups, representative bodies, related research projects and so forth was compiled from publicly available data over the summer of 2015. After obtaining ethical permission from the University Research Ethics Committee (Ref: 150925, see A2.1 Appendix 2), articles describing the research were posted on the world wide web and on social media. Organisations and networks were proactively approached and asked to circulate information internally and externally. Those that responded were also asked about other ways in which information could be circulated. The responses from disabled people's organisations, professional groups and umbrella bodies were often very positive. Many had their own internal and outward-facing media channels, which they used to disseminate information. Sometimes short articles about the research were composed and linked electronically to the researcher's contact details and further information about the project. This process passed through several iterations before communication was funnelled towards recruitment for specific focus groups in different parts of the country.

Individuals expressing an interest were sent further information, a consent form and a background information questionnaire, and encouraged to contact the researcher if they had any further questions (see A2.3 Appendix 2). For paid staff, permission was sought from employers for people to attend in work time and receive reimbursement for any travel expenses. Where there was no employer, or employers were not able to pay travel costs, participants were reimbursed.

Sufficient numbers of participants were recruited for two of the original focus groups to proceed, one at each of the sites. Some potential participants from the north and south west of the country were unable to travel those distances, and alternative options were explored. Two potential participants were attending a scheduled meeting of a disabled people's network in the north of England, and the convenors offered to host a focus group immediately after the meeting. This third group combined elements of spontaneous and

researcher-driven approaches (Peek & Fothergill 2009), with those participating including network members, people recruited by the researcher, and employees of the organisation hosting the meeting. Four participants attended the first group, three the second and nine the third. The groups were held between September and November of 2015. The organisation of groups was affected by a range of pragmatic factors. Delays in obtaining ethical approval pushed the timing of groups into the academic year, constraining the availability of potential observers. In all three groups participants dropped out of the study on the day the groups were due to take place.

3.5 The schedule

The schedule (see Appendix A2.4) followed Kreuger and Casey's (2000) formula of opening, introductory, transitional and key question areas. The draft schedule was discussed with the project advisory group and amended in the light of feedback. Each focus group began with participants being asked to introduce themselves in the context of their organisation's work with personal budgets. As well as allowing participants to 'break the ice' and begin to speak, this began the process of helping people orientate their own roles and organisations with those of other participants, and provided additional data about the PNs and people's individual roles that could be combined with that gathered through the background information sheets. The schedule contained four key question areas, linking to each of the chronological stages of obtaining and managing a personal budget identified during the literature review. Questions were pre-prepared under each heading, but the aim was to rely on the organic nature of the group and encourage interactions between group members to focus the groups' discussion within each heading (Braun and Clarke 2013, Claverling & McLaughlin 2007). An ending question was prepared, but in practice all three groups were still running strongly when the set time elapsed. Finally, the moderator thanked the group and explained that participants would be provided with a short summary within a week, at which point they could make further written comments if they wished.

3.6 Moderation

Other than moving the discussion forward through the schedule, moderation consisted of four key tasks; checking for consensus, asking for examples, supporting participation and focusing the discussion. All of these tasks pre-form the data to some extent, and all require the moderator to make judgements in real time. The moderator's role also included collection of consent forms and background information sheets where they had not been sent in advance, and the operation of the audio recording equipment.

3.6.1 *Checking for Consensus*

When a participant reported an issue, checking whether others had experienced anything similar. In the same way, when a participant offered an interpretation, checking whether other participants shared the same view. This would be important in establishing regularities or patterns within the data, which is fundamental to naturalistic inquiry (Lincoln & Guba 1985, Hammersley 1989). It is also a useful strategy in encouraging interaction, which is important for exposing tacit as well as overt views (Macnaughten & Mayers 2004).

3.6.2 *Asking for examples*

Asking participants to give specific examples or instances of the phenomena they were describing, or to explain what experiences had led them to the conclusions they had drawn. This serves both to stimulate further discussion (Kandola 2012) and to establish the link between experience and interpretation, necessary for 'thick description' (Geertz 1973, Ponterotto 2006).

3.6.3 *Supporting participation*

This took a variety of forms, for example going back to a previous place in the discussion where a participant was attempting to contribute, or overtly valuing a particular contribution from a reticent participant. While such interventions risk being understood by participants as supporting a particular view (Bryman 2016), they are arguably necessary to

surface views that might be controversial and as a consequence of which participants might be reticent (Braun 2000, Kamberelis & Dimitriadis 2011).

3.6.4 *Focusing the discussion*

This involved making an initial assessment of whether the emerging discussions were relevant to the research question, and if not, refocussing on the topic. Following this, it was also necessary to decide whether to structure a systematic exploration of an emerging issue, or allow participants to structure it themselves. Madriz (2000) has argued that participants' questions to one another represent an important counterpoint to the researcher's power in determining both the 'research question' and controlling data collection, which can allow the emergence of participants own hierarchies of importance. However, against this possibility one must set the potential for unusable data, and consequent the ethical implications of having taken people's time with an agreed aim that was not subsequently achieved.

Each group ended by asking participants if they had anything they wanted to add to their previous comments, either by way of clarification or addition. Before closing, the researcher explained what would happen with the data and offered to send summaries of the group's content back to participants to check.

3.6.5 *Data recording*

Data were collected both in the focus group and a via a participant information questionnaire (see A2.2 Appendix 2), which aimed to capture a range of demographic and organisational information. The questions about age, ethnicity, sex, health and disability status were taken from the 2011 population census for England and Wales (Office for National Statistics, 2014). The organisational data asked people about the type of organisation they worked in, their role, the tasks they most commonly undertook, and their relationships with PB users.

Electronic devices were used to make two audio recordings of each focus group. In addition, the moderator took simultaneous notes. Two of the three focus groups were observed by non-participant academics, one from the project's advisory group and the other from a research team also interested in peer support. Observers assisted the facilitator to reflect and debrief, and also assisted with practical tasks such as seating and ventilation. Within a week of each group, the moderator's notes and the recordings were used to produce a short summary of who said what. The summary was then shared with participants, who were invited to comment on whether the researcher had misinterpreted anything they'd said, and to make additional comments if they wished. This was a precaution against misunderstanding, but also an opportunity to collect additional data. One clarification was received.

3.7 Approach to analysis

The approach to the analysis presented in Chapter 4 broadly follows Braun and Clarke's (2006, 2013) development of Boyatzis' (1998) method of thematic analysis. This is informed by other interpretivist methods of qualitative data analysis where they are consistent with the social constructionist and critical theoretical framework in which the present study sits. The purpose of this section is to describe the methods used for analysing and interpreting the focus groups, the results of which are reported in Chapter 4. A theoretical discussion of these results in relation to the research question is presented in Chapter 5.

Boyatzis (1998) traces thematic analysis as a method to the many approaches to qualitative data analysis that had been developed during the flowering of qualitative methods in the social sciences during the 1980s and early 1990s. Many of the approaches cited by Boyatzis were themselves directly or indirectly influenced by Glaser and Strauss' (1967) constant comparative method, and could be broadly characterised as attempts to systematise and extend it (e.g. Miles and Huberman 1984, Silverman 1993). The constant comparative method itself began as an attempt to structure the process of interpreting qualitative data "... by using explicit coding and analytic procedures." (Glaser & Strauss 1967:102). Much of the debate about qualitative methods over the subsequent fifty years has related to the fit between different methods and their epistemological and ontological positions (Denzin &

Lincoln 2017). Boyatzis (1998) presented thematic analysis as largely theory-independent, in the sense that the responsibility for the fit between method and methodology sat with the researcher rather than being an inherent property of the method, a point accepted by Braun and Clarke (2006, 2013).

Thematic analysis is a process of moving from description towards interpretation of data (Boyatzis 1998, Braun and Clarke 2006, 2013). Different authors often break these down into different stages, and sometimes use specific nomenclature which can obscure the similarities between approaches. Because of its shared origins, thematic analysis is procedurally similar to many approaches within the grounded theory family of methods (Bryant & Charmaz 2007). These usually also involve a staged progression from the raw data, for example by moving from labels to codes and categories (Charmaz 2006, Birks & Mills 2015). Braun and Clarke (2013) have described the process of data analysis as familiarisation and coding, followed by identifying, analysing and interpreting patterns across data, and this is the nomenclature applied here.

Over the past decade some researchers have debated the role of interaction in groups, and the extent to which this should form a focus for analysis (Farnsworth & Boon 2010, Morgan 2010, Belzile and Öberg 2012). On one level, this debate relates to early discussions about context-stripping in qualitative studies (e.g. Lincoln & Guba 1985, Erlandson et al. 1993) and the extent to which it is acceptable to analyse text separately from the group context from which it emerges during the process of coding and analysis. At perhaps a more fundamental level, Hollander (2004) questions whether the social context of the group can prevent certain discourses from emerging, or to put it more directly, whether participants will feel able to air potentially embarrassing, frightening or humiliating topics. The steps taken to support participants have already been reported in section 3.6, above. Morgan (2010) argues that whilst interaction may produce data, this does not necessarily mean that the interaction *is* the data, or at least the data most relevant to the research question. In the present study the main focus of the investigation was the practice of providing support, as described by participants. However interactions between participants were often apparent and have sometimes been interpreted. The diversity of opinion within each emerging theme is reported within the limits of the space available.

3.7.1. Familiarisation

The researcher transcribed the groups using nVIVO 11 software (QSR 2015), which served to re-familiarise him with what had been said. Using software can help make management of large data sets more manageable and also more transparent, by creating an audit trail and allowing others to see the analysis alongside the recordings and transcripts (Sinkovics & Alfoldi 2012). The three focus groups produced transcripts of approximately 10,000 words in total. Each of the five sections of Chapter 4 reports the results of a separate process of inquiry, based on a distinct orientation towards the data based on the research question and the subordinate objectives. In reality these were often conducted concurrently and iteratively, but for convenience they are reported sequentially.

3.7.2 Coding

Boyatzis' (1998) criteria for codes are that they should be conceptually meaningful in relation to the phenomenon being investigated, be clear and concise, and remain close to the data. Thematic analysis differentiates between semantic codes, which "...mirror participants' language and concepts..." and latent codes, which "...invoke the researcher's conceptual and theoretical framework to identify *implicit* meanings within the data." (Braun & Clarke 2013:207, original italics). Most of the codes applied during the analysis stemmed directly from the research question or its objectives, and fall largely within the semantic category.

Coding can be complete (i.e. everything everyone says is coded) or selective. In this case, coding was selective. The literature review for the present project had aggregated findings using a scheme based on the different stages individuals went through to obtain and subsequently manage a personal budget (see Fig. 5 p.51). The first stage of the analysis involved coding all descriptions of the activities of PNs using this scheme. This created the initial a data-set that formed the basis of later analyses. At various stages throughout the analysis, the transcripts were re-read, and a small number of additional extracts matching emergent themes were coded.

3.7.3 Interpretation and analysis

Braun and Clarke note that at its most basic level “...a pattern-based analysis allows you to identify and report the salient features of the data.” (2013:223) Sections 4.2, 4.3 and 4.4 broadly fit with this description. Where interpretation stopped at this level, the principal approach was to describe the relationship between codes, and then summarise the data within them, reporting common traits, exceptions and the degree of convergence and divergence.

The next stage of the process is looking for patterns or regularities across the data set. In Braun and Clarke’s (2013) model, this involves looking for ‘candidate themes’. These are then reviewed, and if accepted can be refined before being promoted to themes. A similar process exists with the grounded theory method, where labels can be promoted to codes, codes to categories and so forth (Birks & Mills 2015). Candidate themes are distinguished from other regularities (known as ‘features’) by the presence of a ‘central organising concept’. An example of a feature can be seen in section 4.4 of the following chapter. This looks at the forums at which support was provided, which are divided into individual or group settings. The distinction between the two does not meet the criterion of having a central organising concept, and simply clusters and describes data according to whether support was provided individually or in groups. This can be contrasted with section 4.5 (peer support and its impact), which also looks at peer support in group and individual settings. However, on this occasion there is a central organising concept, which is the relationship between peer identity and peer support.

Decisions about promoting candidate themes can be made on a number of different grounds. Unlike Boyatzis (1998), who argues that the significance of themes can be determined by counting the occurrences of data items within them, Braun and Clarke (2006, 2013) argue that salience to the research question is at least as important. In their model, a good theme still needs to work across a proportion of the data, but the size of the proportion is a matter for the researcher’s judgement. Where relevant, the present report

mentions whether there were examples in each focus group, and whether there were multiple examples in each group.

Braun and Clarke (2013) are clear that the process of analysis continues from coding into the write-up. The aim of the report is to tell the story of each theme, and describe the relationships between them. In the current study the number of items within each theme was often quite small, making it possible to cluster linked examples and make bullet point lists of the important features. These have been retained as a part of the audit trail.

‘Thick description’ aims to preserve the conceptual language of research participants in the process of reportage and analysis of ethnographic research (Geertz 1973). It is often described as a key feature in reporting qualitative research, and is regarded as an important means of establishing transferability (Lincoln & Guba 1985, Erlandson et al, 1993). Ponterotto (2006) argues that the key significance of thick description is that it provides sufficient context to allow the researcher (and where reported, the reader) to attribute intentionality to the actor. In the context of the current thesis, thick description is principally in the form of elongated quotations, where necessary with additional discussion of the ways in which key terms (such as ‘peer’) were used. Braun and Clarke (2013) recommend that quotations are used illustratively when themes are semantic, and interpreted where they are latent, and this advice has largely been followed here.

3.8 Trustworthiness

Trustworthiness has been defined as a property of the research report that helps the reader to determine whether “...the findings of an enquiry are worth paying attention to ...” (Lincoln & Guba 1985:290). Within the word limit of the current thesis, the researcher can only present a summary of the data and an overview of the process of interpretation and analysis to assist the reader in making that judgement. This collates and summarises the relevant information, supplementing it with a fuller discussion where necessary.

In describing the likely characteristics of research within the 'new paradigm' of naturalistic inquiry, Lincoln and Guba (1985) rationalised that the positivist criteria of reliability, validity and objectivity could not be applied. Instead they noted that researchers were likely develop "...new (but analogous) criteria..." (1985:43) and included a suggested taxonomy. This consisted of credibility (posited as equivalent to internal validity), transferability (external validity and hence generalisability), dependability (reliability) and confirmability (objectivity) (Lincoln & Guba 1985, 1986), to which a fifth criterion of authenticity was subsequently added (Guba & Lincoln 1989). This scheme is still cited in generic social science text books (e.g. Bryman 2016) and has been adapted for many specific methods, including focus groups (e.g. Plummer 2017). The scheme has also been heavily criticised, particularly in respect of the concept of confirmability which sits uncomfortably within a social constructionist epistemology (Holt 1991, Sandelowski 1993, Seale 2002). Nevertheless, if qualitative research is to pull "...back from the relativist abyss." (Seale 2002:106) then arguably some attempt at quality assurance is necessary (Horsburgh 2003).

Rolfe (2006) identified three broad positions in relation to quality criteria for qualitative research: those who wanted to apply positivist criteria, those who wanted to develop separate criteria for qualitative research, and those who believed that no predetermined criteria would be appropriate in all cases. The present study has adopted the third position, partly because criteria reflect the authors' value systems and philosophical approaches in ways that may not be transparent (Cheek 2007, Santiago-Delefosse et al. 2015). The approach taken here is to report the measures that have been taken to establish trustworthiness within Lincoln & Guba's (1985) framework, primarily as a means of organising the information in a pattern with which many readers will be familiar. Further criticisms of the 1985 framework are considered in the relevant sections. Authenticity has been reported alongside other ethical considerations for convenience.

3.8.1 Credibility

The main techniques used to establish credibility have been described as prolonged engagement, persistent observation, triangulation, referential adequacy, peer debriefing, member checks and the keeping of a reflexive journal (Erlandson et al. 1993). Engagement

with the topic took place over a twenty-year period, both in terms of the researcher's personal and professional life (see Appendix 3) and the time over which research literature was aggregated (see literature review, above). The purpose of the focus groups was to provide a contemporary cross-section of current perspectives. Persistence can relate to the time spent with the data as well with focus group participants. The process of analysis began in earnest in August 2017 and is arguably continuing up to the time of writing. In the context of focus groups, triangulation can be conceptualised as enabling comparisons between participants, and between the groups themselves. The degree of consensus and disagreement is reported in the relevant sections of the following chapter.

Member-checking is strongly advocated by Guba and Lincoln (1989) but rejected by Sandalowski (2003) on the basis that if realities are multiple and co-constructed, there is no reason why the researcher's reality could not depart significantly from those of the participants. Member checking of focus group data therefore took place at the point of data collection (what was said), rather than interpretation (what it means).

The primary source material for the focus groups consisted of the audio recordings, contemporary notes and participant background questionnaires. Colleagues observed two of the three groups without participating, and were able to provide some comments and observations. Throughout the process of data collection and analysis, the researcher also kept a journal. This was not a single document, but a series of notes in different formats. For example a reflective note was produced after each individual focus group, and a log of potentially important or significant ideas was kept during transcription of the focus groups and throughout the process of coding and analysis. The capacity of the computer-aided qualitative data analysis software to link specific insights directly with the data was also occasionally useful. As well as assisting the researcher with the iterative and reflective process of moving between different coding schemes and different interpretations, the record forms part of an audit trail, and also provides some evidence of reflexivity in terms of the researcher's critical awareness of his own active involvement in the production of meaning from the data.

3.8.2 *Transferability*

Within Lincoln and Guba's (1985) framework, transferability is supposed to replace the criterion of generalisability, as it is the reader that makes the decision about whether research from one context might have implications for another (Noblit & Hare 1988, Erlandson et al. 1993). Techniques to inform transferability include thick description, purposive sampling, and the use of a reflexive journal. The following chapter gives a description of focus group participants and uses quotations to illustrate the relationship between participants' statements and their imputed meaning (see 3.7.3 for a fuller explanation). The approach to sampling was purposive, and a full account has been given in sections 3.3 and 3.4.

The relevance of the reflexive journal to transferability is primarily to address issues that would correlate to bias in a positivist paradigm, particularly in the context of recruitment and moderation. The relationship between the researcher and potential participants (and of participants to one another) is likely to have had an effect on recruitment, and will also impact on the co-construction of data. In the focus groups there was no attempt to restrict participation of people who were known to each other or to the researcher. In two cases, the relationships between participants from the same networks were very close, reflecting long-term collaborations developing personal budgets and other supports for disabled people within their localities. Most participants were known to the researcher to some extent, typically through the recruitment process but also for example as attendees at the same conference about personal budgets. In one case, the researcher had worked with a participant as employees of the same network providing peer support to personal budget users, although not closely and more than five years previously. Some researchers view these intersections cautiously and in terms of data contamination (Bryman 2016). However, the idea of uncontaminated data can be seen as an aspiration toward objectivity which is not consistent with the constructionist paradigm (Farnsworth & Boon 2010). Whilst acknowledging the potential down-sides, Braun and Clarke (2013) note that 'interactional familiarity' between participants can make it easier for people to talk. Dixon-Swift and others (2007) argue that all qualitative researchers will need to build a rapport with participants that will allow researchers to access their stories. Although reported separately

here, the process of recruitment and moderation can be viewed as a developing relationship, in which all parties make decisions about how far to commit. In the present study, these decisions are likely to have been informed by political as well as personal considerations, particularly in terms of the overt aims of the independent living movement and the related objective of disability rights. Though the researcher attempted to be circumspect, giving only brief and factual accounts of his previous research and professional experience, this was redundant where he was already known to potential participants directly or indirectly through his previous professional and academic work. For example, summaries of researcher's professional history have been published many times, and would have been readily available to potential participants through the internet. Appendix 3 provides a reflexive biography which summarises this and other relevant background.

3.8.3 *Dependability and confirmability*

As well as the ubiquitous reflexive journal, the main mechanism suggested for achieving both of these criteria is an audit trail (Lincoln & Guba 1985, Erlandson et al. 1993). Most of the documents relating to the audit trail have already been described, but to them should probably be added the numerous application forms, reports, supervision records and so forth required by the University's regulations, as well as the less frequent reports to the project's advisory group. Lincoln and Guba's original (1985) vision of dependability suggested a 'step-wise replication' of the process of analysis and a review of the research documents from the perspective of process and product. Neither of these approaches appear to have been tried by the original authors, and certainly in the current project there would not have been sufficient resources. However, the records mentioned above provide partial evidence that the methods were thought to be appropriate by more experienced researchers, and plausibly applied. The confirmability element of the audit is more contentious. The idea that different researchers would be likely to come up with the same result by applying the same method contradicts the essentially pluralistic idea of multiple, simultaneously existing co-constructed realities inherent in a social constructionist world view (Sandelowski 1993, Seale 2002, Rolfe 2004). Erlandson and others (1993) put forward a rather more realistic proposal, that the audit trail should enable an auditor to follow the decision-making process; that is the aspiration here.

3.9.4 Ethics and authenticity

The University has a code of practice for research involving human participants which is based on the Economic and Social Research Council 's Framework for Research Ethics (Economic and Research Council 2015, Oxford Brookes University 2016). This is based on the following six principles:

- “Research participants should take part voluntarily, free from any coercion or undue influence, and their rights, dignity and (when possible) autonomy should be respected and appropriately protected.
- Research should be worthwhile and provide value that outweighs any risk or harm.
- Researchers should aim to maximise the benefit of the research and minimise potential risk of harm to participants and researchers. All potential risk and harm should be mitigated by robust precautions.
- Research staff and participants should be given appropriate information about the purpose, methods and intended uses of the research, what their participation in the research entails and what risks and benefits, if any, are involved.
- Individual research participant and group preferences regarding anonymity should be respected and participant requirements concerning the confidential nature of information and personal data should be respected.
- Research should be designed, reviewed and undertaken to ensure recognised standards of integrity are met, and quality and transparency are assured.
- The independence of research should be clear, and any conflicts of interest or partiality should be explicit.”

(Oxford Brookes University 2016)

The University's procedures required a project proposal consistent with these principles and data protection legislation in force at the time, which was designed to meet the fifth criterion. The approval letter is reproduced in Appendix A2.1. The approach to recruitment has been detailed in section 3.4, and participants were provided with detailed information

including by means of the participant information sheet included in Appendix A2.3. Risks to participants were judged to be minimal, but mitigation was put in place where appropriate, for example by liaising with employers to ensure that participants could attend in work time, by reimbursing people for travel expenses and by ensuring that venues were accessible. As Braun and Clarke (2013) note, anonymity cannot be achieved within a group and confidentiality cannot be guaranteed. However the expectation of confidentiality was agreed by all participants, and data that could help identify participants has been removed from the quotations in the following chapter [using square brackets to denote missing data]. For the same reason full tables of data collected from background information sheets are not reported.

Within a critical constructionist paradigm, the co-creation of data raises questions about who 'owns' the research data and who benefits from it. Guba and Lincoln's criteria for authenticity were added to their other criteria for trustworthiness in 1989 with these concerns in mind. Authenticity involves recognising a range of possible alternative interpretations of the data, sharing the 'expert' power with participants and other key stakeholders, thereby enabling political or social action that reflects interests other than those of the researcher (Guba & Lincoln 1989, Seale 2002). The focus group process itself partially fulfils these criteria. Firstly, the approach to moderation was to explicitly value different contributions from different participants. Madriz (2000) argues that focus groups are potentially more empowering than individual interviews. This is because of the potential to minimise power imbalances between individual participants, and also between the researcher and the group. Similarly, Kamberelis and Dimitriadis (2011) have drawn parallels between focus groups and Freire's 'study circles', which were designed to raise the consciousness of oppressed groups (Freire 1970). Given their explicit commitment to disability rights, it is likely that many focus group participants already regarded themselves as being involved in emancipatory activism and viewed their participation in this context.

The background section has given an account of the origins of direct payments within the UK independent living movement, and there have been many attempts to develop specific methodologies within the wider context of disability activism (Turner & Beresford 2005). An early but still relevant example was Oliver's (1996) emancipatory disability research. Oliver

noted that truly emancipatory research can only really be assessed retrospectively on the basis of its impact. It is sincerely hoped that the present research will make a small but positive contribution to the theory of independent living that will be useful to people with impairments and their allies, and the present report itself represents an important step towards this objective.

3.9 Summary

The second phase of the study used data gathered from three focus groups within an overarching critical constructionist theoretical framework. Focus groups were chosen pragmatically because they enabled the collection of a large amount of data in a short period of time (Morgan 1997), and theoretically because of the potential to surface tacit as well as explicit beliefs about the process of providing peer support for personal budget users (Macnaughten & Mayers 2004). Three focus groups with a total of sixteen participants were hosted during the autumn of 2015, and supplementary demographic and organisational data were collected to provide additional context during analysis.

Participants' tacit and explicit beliefs were conceptualised as socially constructed, but through different processes. People's explicit beliefs were viewed as being generated primarily through the process of providing peer support, in the individual contexts of people's life circumstances and the organisational contexts of PNs. Sampling and facilitation both aimed to access this level. People's tacit beliefs were also apparent in the focus group process, in terms of what was said but also of the interactions between participants and the facilitator. Thus the primary data set was the 'content' of the focus groups, with the 'process' forming a supplementary secondary layer. Data were coded using computer-assisted qualitative data analysis software, and thematic analysis (Braun and Clarke 2006, 2013) was used to generate semantic and latent themes, and to describe other regularities within the data.

Because the data were co-constructed by the researcher and the participants, the impacts of power relationships and the privileged status of the researcher were considered during

design of the study and throughout the analysis. These were unlikely to have been eliminated, and the report aims to provide enough information for the reader to assess the trustworthiness of the findings (Lincoln & Guba 1985).

CHAPTER 4: FINDINGS

Data were gathered from three focus groups. Approximately four and a half hours of discussions were recorded, producing transcripts totalling roughly ten thousand words. Fourteen of the sixteen participants also completed background information sheets, giving information about themselves, the PNs they represented and the roles they fulfilled within them. Some supplementary information about some PNs was also collected from organisations' web sites.

The analysis is reported in seven sections, which can be roughly divided into three parts according to the aspects of the research question to which they correspond;

- Sections 4.1 to 4.4 relate primarily to the first three objectives (see 1.6, p.27), and describe the PNs, the contexts in which they operate, and the helpful and unhelpful features of the support provided in individual and group settings.
- Section 4.5 focuses on the issue of peer identity, which is central to the fourth objective.
- Sections 4.6 and 4.7 look in detail at the roles PNs play in supporting people to manage personal budgets, and to mediate in their relationships with statutory agencies. These final sections reflect the research question holistically.

The fifth objective, which relates to developing an adequate theoretical account, is pursued in Chapter 5.

4.1 Description of participants and peer networks

Information about participants and the PNs they represented was collected for all but two of the sixteen participants, although in some cases parts of the form were left blank. Data is summarised here to provide context. There was no attempt to recruit a statistically representative sample according to any characteristic.

4.1.1 *Peer network and organisational affiliation*

It was possible to supplement the information about PNs provided by participants with information in the public domain (typically on the internet). This was useful because two of the sixteen participants did not complete background questionnaires, and also because many participants had multiple roles in other organisations and groups that were revealed in the groups themselves. Even with the additional supplementary data, the following analysis can only provide a superficial description of what for many participants was clearly a long-term and profound engagement with disabled people's organisations and health and social care services.

The sixteen participants identified themselves as working primarily in eleven different PNs, and described secondary affiliations with eleven more. Nine were primarily working with user-led or disabled people's organisations, and one with a Community Interest Company, Co-operative or Social Business (researcher-defined categories chosen by participants). The remaining organisation was an NHS Trust, where the participant had been tasked with setting up and providing support to a peer network. Because there was no systematic attempt to collect data about secondary affiliations through the questionnaire, most of the information came from the focus groups and subsequent internet research. Of the eleven additional organisations described, three were interpreted by the researcher as falling into the category of 'disabled people's user-led organisation', two were charities, and one was a 'Community Interest Company, Co-operative or Social Business'. The remaining three were a local authority, a formal partnership between statutory bodies and disabled people's organisations, and an informal local group. This phenomenon of participation in multiple networks reflects the findings of many earlier studies (e.g. Adams & Godwin 2008, Williams & Porter 2011, The Fed CIL 2012).

4.1.2 *Roles and tasks*

Thirteen participants were in paid roles and three were volunteers. Of the eleven who chose a category describing their roles, eight stated that support for PB users was the main focus, whilst three said it formed part of a larger role. Most people's roles involved

supporting personal budget users on an ongoing basis. This contrasts with support provided by local authorities, which can fall away after a support plan is put into place (Arksey & Baxter 2012).

4.1.3 *Personal characteristics of participants*

Fourteen of the sixteen participants completed the sections of the background questionnaire relating to personal characteristics. This is not an attempt to establish the representativeness of participants. While some comparator data is provided for context, calculations of significance are not presented.

Of the fourteen participants completing the forms, five identified as male and nine as female. This compares to a population average of 51% female and 49% male adults in England and Wales in 2011 (NOMIS 2012). The approximate average age of participants was 48. One focus group participant identified as Irish, one as Caribbean, with twelve of the fourteen other participants describing themselves as coming from an English/Welsh/Scottish/Northern Irish/British background.

The 2011 census included questions on both health and disability (Office for National Statistics 2013). The principal factor associated with both these variables in the general population is age, which is positively associated with a decrease in 'good health' and an increase in the impacts of disability. Tables 4:1 and 4:2 compare focus group participants with the general population of England and Wales for people of the same median age category. The majority of the focus group participants considered themselves to have an impairment that impacted significantly on their lives in some way. Five of the six whose impairments affected their day-to-day activities a lot were in paid roles, as were three of the four who had impairments limiting them a little. Clearly many participants had significant experience of living with ill-health or impairments.

Table 4:1 Day-to-day activities of participants

Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? (Please include problems related to old age). Compared to population of England and Wales Aged 45-49. Data Source: NOMIS (2012) 2011 Census data, table DC3302EW - Long-term health problem or disability by general health by sex by age, retrieved 30/5/2018

	Population, England & Wales	Focus Group participants
Sample size	4,100,526	14
Day-to-day activities not limited	85%	29%
Day-to-day activities limited a little	8%	29%
Day-to-day activities limited a lot	7%	42%

Table 4:2 Self-reported health of participants

How is your health in general? Compared to population of England and Wales Aged 45-49. Data Source: NOMIS (2012) 2011 Census data, table DC3302EW - Long-term health problem or disability by general health by sex by age, retrieved 30/5/2018

	Population, England & Wales	Focus Group participants
Sample size	4,100,526	14
Very good/Good health	82%	50%
Fair health	13%	36%
Bad/ Very bad health	6%	14%

4.2 Activities of Peer Networks

Chapter 2 analysed research conducted with personal budget users in the United Kingdom, and collated the evidence of the features of peer support which users had found helpful or unhelpful. The scheme used to collate the data was based on the different stages individuals went through to obtain and subsequently manage a personal budget (see Fig. 5, p.51). One aim of the empirical study was to see if the scheme developed from earlier research was compatible with contemporary data. The first stage of the analysis was therefore to code all descriptions of the activities of PNs in relation to personal budget users the scheme developed for the literature review. The division of activity relating to peer support from other activity was straight-forward. Because the classification scheme for activity used a three-layer nested hierarchy, data which did not fit easily with categories at the base layer were coded at the parent level.

4.2.1 *Activity independent from the support planning process*

As well as providing direct support to personal budget users, many PNs were engaged with wider systemic issues. Engagement existed on a spectrum between confrontation of and collaboration with statutory planners. All three focus groups contained multiple examples of this type of activity. At the collaborative end of the spectrum, many participants described involvement in partnerships with the local authority, local NHS bodies or other organisations. One was Chair of a direct payments user group, which led to her being invited to Co-chair a formal partnership between local statutory and voluntary sectors and disability groups. Another was invited to join a project evaluating decisions about how personal health budgets were allocated. At the confrontational end of the spectrum, PNs would challenge statutory bodies about individual decisions and contest local working arrangements.

Many of the support groups hosted by PNs aimed to feed back information to planners about what was working well and what was not. Two groups appeared to have been initially set up for this purpose, and subsequently developed a wider remit. Sometimes providing feedback was an explicit requirement of groups that were commissioned or

financially supported by statutory bodies, and in other situations feedback was viewed as a useful by-product of groups that would have taken place anyway. Some networks were formed with the purpose of influencing the way statutory systems worked by challenging ineffective design and reporting examples of poor practice.

Another activity not directly related to individual service users was the provision of training. Several PNs had trained statutory sector workers, whilst others offered them surgeries on personal budgets, provided placement opportunities for social work students, or hosted visits from new employees as a part of their inductions.

Part of the role of some PNs was to lobby or raise awareness of issues that were not directly linked to the personal budget process. For example, one network made a film of the issues facing disabled children, and another supported a school event providing information for families about disabled children's transition into adulthood. PNs also hosted social events, for example to celebrate the International Day of Persons with Disabilities.

4.2.2 Activity as a part of the process of obtaining and managing a personal budget

The overwhelming majority of data relate to the process of obtaining and managing a personal budget, which reflects the recruitment criteria for participants and the topic guide for focus group discussions; most of the questions were specific to the different stages of the process described in Fig. 5 (p.51). It is consequently interesting that more than a third of the quotations coded related to the process as a whole, rather than to any specific stage. This could reflect the different methods, in the sense that focus group participants were able to move backwards and forwards in their discussions where research reports tended to group information into categories. However, it may also reflect a holistic vision of people's experiences of obtaining and managing a personal budget, even where the support provider was not involved for the whole process. Several participants expressed frustration that they were only commissioned to provide support at specific stages of the process, or had no way of gaining access to potential personal budget users before they were assessed. Three participants in one group talked at length about the difficulty of

providing information to people in ways and at times when it would be useful to them. This was thought to require persistence, an ability to anticipate people's future needs, and an appreciation of their emotional states, for example in terms of their reactions to life-changing injuries or illnesses.

4.2.2.1 Before applying for a personal budget

PNs represented in all three focus groups provided support to people who had not yet taken the first step towards obtaining a personal budget. Sometimes they were already involved with people in other contexts, for example by providing other types of support, or let people know about the possibility of a personal budget while responding to a generic enquiry. One participant reported proactively contacting users of social care budgets whom he thought might have been eligible for personal health budgets and explaining how they could get an assessment.

Once people were aware of what a personal budget was, PNs used a range of strategies to support them to decide whether they wanted one. This involved giving them the information they would need to make decisions in an unpressured environment. Peer supporters often did this in group settings, where group members would be able to meet others who were already using personal budgets and ask them about their experiences. One participant described having 'lent' her personal assistant to a friend, so she could find out what it was like.

The majority of specific examples of the types of information given were about the bureaucratic process and how it worked, the resources that might be available to support people, and their potential responsibilities as personal budget holders and as employers. However, some of the information was much more nuanced. One participant argued that it was no use providing people with information about personal budgets while they were still too emotionally or physically fragile to make use of it, and also gave a contrasting example of a man who could possibly have kept his job if he had known about the availability of personal assistants at an earlier stage.

4.2.2.2 *During the assessment and support-planning processes*

Once people had decided that they wanted to apply for a personal budget, PNs were able to help them take the next step. Two of the three focus groups had representatives of organisations that were able to support people during the initial assessment of need and eligibility. Three of the examples of this type of support involved challenging the decisions of statutory bodies to try and increase the financial value of the personal budget. Some PNs provided specialist approaches to assessment, for example using person-centred tools, or assisting people to complete self-assessments.

Support during the planning stage was often described in the context of the roles of local authorities. In all three focus groups there seemed to be a consensus that local authorities were providing less help with support planning than they once had, creating opportunities for PNs but also placing additional demands on them. Some of the support provided by PNs was directed at resisting 'top-down' planning, sometimes conducted without the active involvement of clients.

"Social services do admit that they'll give people, they do the resource allocation and everything, they give people 'My Life, My Way' [A support planning tool], which is our support plan, to fill in. They get back a couple of weeks later, and if the person hasn't filled it in, the social worker fills it in. I mean that's really bad practice, but that's what's happening."

Male participant in paid role

The support provided by PNs was often contrasted with that provided by statutory bodies in terms of encouraging people to pursue their life goals, rather than meeting their basic needs. Participants provided many examples, such as a young woman being encouraged to use her personal budget to develop the skills necessary to run her own business, and a man being supported to use his respite budget to pay his son to take him to watch a Rugby tournament rather than to go into a care home temporarily. Participants described their expertise in re-formatting these aspirations in terms that would improve users' chances of

getting support plans approved by local authorities or the NHS. PNs also contributed other types of specialist knowledge, for example about disability aids, where personal assistants could be found and how to employ them, knowledge about local service providers and other people's experience of using them, additional sources of funding, and how budgets could be pooled and who with.

Those PNs that provided support in groups rather than in individual sessions gave people the opportunity to talk to one another before putting a support plan in place, to build up a detailed picture of how other people had used their budgets.

"...often my clients will put in a significant amount of work, and talk to other people about various different ways that they're spending their money."

Female participant in paid role.

This could also be problematic, as local authorities could approve certain types of support for some people but not for others, leading to confusion and annoyance.

4.2.2.3 *Implementation and ongoing maintenance of the support plan*

The major focus at this stage was helping people to access and maintain their working relationships with paid personal assistants, occasionally extending to 'letting them go' and finding replacements. Usually networks were commissioned to provide support to PB users, but some would also work with 'self-funders' who did not have any financial support from statutory agencies. Most of the focus group discussions about support with PAs related to direct employment, but PNs also provided support to people accessing PAs through care agencies. PNs could provide advice about what kinds of care different agencies could provide, and whether they were reliable. Participants in one group commented that peer support was the only medium through which personal budget users could get this type of information, because formal organisations were worried about being challenged legally if they did so.

Support with recruiting, employing and managing PAs was a significant part of the role played by many of the participants. People gave many illustrations of the advantages of direct employment, including the lower cost and the additional flexibility, particularly with the timing of the support and what could be done with it. This additional flexibility could come at the cost of additional bureaucracy, for example in keeping track of hours and payments made, and making reports back to the local authority, and several of the organisations represented offered help with this type of administration. As at the assessment stage, people's relationships with statutory funders was often strained, and the support role sometimes extended into advocacy helping people to challenge decisions or work through difficult bureaucratic processes.

One network hosted a peer support group specifically for employers of PAs, and also provided a surgery for people to get information and advice. There seemed to be a consensus in all three focus groups that employment law was an area where the unwary PB user could encounter problems, and advice and support in this area was commonly offered. This could be formal and informal. Some of the advice offered by PNs was very expert, relating for example to insurance, pension schemes, criminal records of employees, systems of accounting, and access to funding for training PAs to carry out specialist tasks. More informally, members of one direct payments user group would support one another to experiment, and not worry too much about running foul of legal or bureaucratic requirements.

Part of the function of PNs was to provide emotional support as well as practical help. Such help was frequently informal, particularly where support was provided through groups rather than in one-to-one settings, but was sometimes explicitly framed as an additional service provided by the agency, for example as a support group or a befriending service.

4.3 The contexts in which peer networks operate

An aim of the research was to explore the contexts in which PNs provided support. These were clearly important in relation to both sets of roles described above. These changing contexts can be thought of in terms of the knowledge PNs needed to fulfil their roles, and the other resources including money that increased their capacity to provide help.

PNs required a detailed knowledge of how personal budgets can be used, and of the specific needs of PB users in a range of different situations. Although this clearly often derived from the lived experience of network members, it could also come from liaison with local statutory and voluntary sector bodies, with other PNs, and through providing a service to personal budget users. PNs seemed to have multiple relationships with other similar networks, sometimes mediated by people who had roles in multiple networks. Relationships with the individual PB users supported were also critical. Each instance of support also presented PNs with an opportunity to learn.

While knowledge was important, so were other resources. Participants often described financial contracts to provide services that PNs had with local statutory bodies, or as subcontractors to other agencies. Sometimes statutory bodies provided support in other forms, for example by tasking paid staff to provide administrative help, or by allowing PNs to use meeting rooms. Less commonly PNs were able to share resources with one another, for example by hosting joint events. Some participants even used their own money or staff to provide support to other people.

Figure 8 summarises the main relationships which participants described as having an impact on their provision of support to actual and potential personal budget users, conceptualised in terms of inputs and outputs. The figure divides agencies into two broad types (large statutory NHS and local authority bodies and other PNs) although some organisations had part of the character of both (for example large charities). The left-hand side of the diagram represents the inputs that enable PNs to be able to carry out the activities necessary to support PB users, which are characterised as outputs and summarised on the right-hand side. Although the analysis was not focussed on the direct

(unmediated) relationships that often exist between local statutory bodies and PB users, they are shown in the figure for context. PNs have been conceptually placed in the centre of the diagram with other organisations and individuals around them. This reflects the orientation towards the research question.

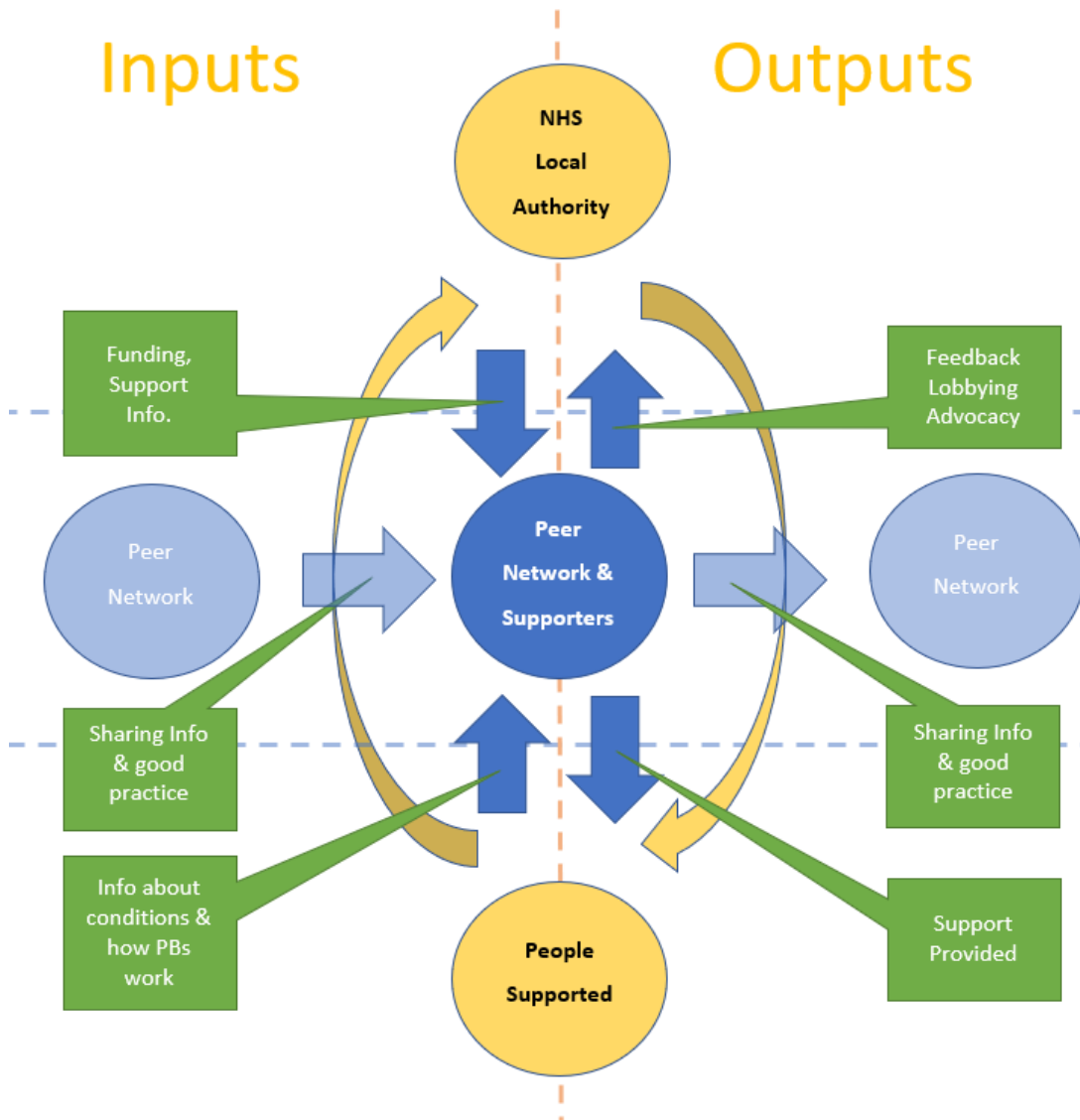


Figure 8: Schematic of the context in which peer networks operate

4.3.1 Local statutory bodies

Inputs from local NHS and social care bodies included money, information about personal budgets and how the associated bureaucracies worked, and feedback from lobbying and campaigning.

All the PNs providing support to personal budget users were either receiving direct or indirect financial support from the local authority or NHS bodies, or had received it in the past. The general experience of participants seemed to be that funding had decreased over time, whilst expectations of what PNs could achieve with it had increased. This emerged in all three focus groups. The decrease in funding for PNs was also frequently accompanied by a reduction in the support for PB users commissioned from other sources.

“You know there's more and more encouragement for people to do it themselves ... but sometimes people still need that handholding along the way. It sometimes feels that a lot of this is kind of passed over to the peer support group, and sometimes we've felt like we're a bit of a substitute for the formal support that should be out there.”

Female participant in defined volunteer role

Another important input from the local statutory bodies was expert information about how the personal budget system worked. Participants in all three focus groups described a reduced expertise amongst statutory sector workers.

"I think a good point that we haven't mentioned is that we probably spend a good third of our time supporting social workers who don't understand their own procedures, which is a bit bizarre when you think how small we are in relation to the social work department and they'll ring us, and say 'Well, what do I do?'. Well, ask your manager, you know?"

Male participant in paid role

In one area, the local authority had decommissioned support for social care budget users, and one participant expressed concern about the viability of the local peer network without access to expert support. Another participant made a related point about the information that local statutory bodies gave to the peer network that she was involved with.

"You see, peer support networks do not, cannot work without support. I mean all of the people, by definition, who use direct payments or personal health budgets are not well in some way or another, have limited amounts of energy, and have almost no access to new information, and therefore if it's just 'go on, off you go' it would be go on off you go and stop."

Female participant in defined volunteer role.

Feedback from local statutory bodies could also be viewed as a resource. As discussed in the section describing roles, being able to provide evidence of the impact of lobbying, consultations and collaborations was perceived to be essential to motivating PB users to participate in some types of group. Similarly, PNs provided a great deal of information to local statutory bodies, both as a result of advocacy and lobbying, and as a part of collaborations and agreements. Participants described how this was sometimes actively sought by local statutory bodies, and sometimes regarded as an incidental by-product.

4.3.2 Other peer networks

Participants frequently wore multiple 'hats', having roles in many PNs.

"I'm a volunteer for [Area] Association on Disability, and the last project I was a volunteer for was [Advocacy Project], and that was training people to give peer support to others, from the assessment stage through to the support planning. I was the key worker for three families whose adult children were wanting to move to supported living. I'm also a Trustee of an Independent Living Trust and a volunteer for a community cafe and for [name], which is an art project, where people do the Direct Payments to pay for the support."

Female participant in defined volunteer role

When they were not themselves at the node linking different networks with one another, they frequently described the relationship. This was often in the context of exchanging information. Coincidentally, it emerged that one of the PNs in one focus group had modelled itself on a direct payments support group which another member from another part of the country had been involved in facilitating.

"When that closed down was when we were starting up. And I was searching like mad around the country, you know on the internet for any other groups that were independent of direct payments providers, and I think I came across that."

Female participant in defined volunteer role.

This illustrates the way the internet and other communications technologies were used to share models of practice and other information. However, face-to-face contact still appeared to be common.

"I think also for social events, which is another way that we do a lot of peer support, for kind of social gatherings, network events, different events that we've done. That works well collectively and bringing everyone together, and over the past two years when we've done international day for disabled people, it's been really good to see how people network with themselves, so nothing to do with us, we invite them, they come. And that's a good thing to see, so people from all ages, ethnicities and disability groups and that's very positive."

Female participant in paid role

4.3.3 Personal budget users

Participants frequently demonstrated a deep knowledge not only of the personal budget process, but also of the life circumstances of personal budget users and their emotional needs. The understanding was often linked with lived experience of disability, sometimes directly in the case of peer supporters who had impairments themselves, and sometimes indirectly through the understanding held within the network. PNs were able to update, deepen and extend this understanding through their ongoing contact with personal budget users through the support that they provided.

The larger PNs were often employers, and focus group participants who represented them were frequently in paid roles. They were often able to give clear examples of where they had gleaned important information through providing a service. There were examples of this in all three focus groups.

"What's disappointing, I don't know whether it's a trend, but support planning is being taken back in house? So, there's less opportunity for people to write their own support plans and get support from family members or whatever because the social workers are doing it themselves, and sometimes they're just writing it themselves without the individual knowing it's been done or seeing it, and the same thing is

happening with the whole five CCGs [NHS Clinical Commissioning Groups] in the [local area], there's one nurse who works for the CSUs [Commissioning Support Units] who's writing all the support [plans], 'Oh, it's much quicker if I do it' [group laughs]."

Female participant in paid role

Participants from smaller networks, were usually in defined roles such as Chair or Co-ordinator. Often people had come into these roles either because they had formed the networks themselves, or because they had taken on a leadership role in the early stages.

"So the one person who has adult boys with learning disabilities says 'Oh go on [Participant name] you've done it before, you can chair it'."

Female participant in defined volunteer role

In these cases, and where participants in paid roles had impairments themselves, it often was not possible to identify the sources of their knowledge. There were examples of where it had come from their own lived experience, from the lived experience of other network members, and where it had been gained through providing support.

Though financial transactions between PNs and personal budget users were not frequently mentioned, there were examples. In one focus group a participant described how the peer network had taken the decision to fund people to attend support groups, as individuals' personal budgets had been cut to the point where they were not able to pay themselves. One peer network, an Independent Living Trust for adults with learning disabilities, used their personal budgets to pay for a range of activities and supports provided by paid staff employed by the Trust. However, the Trustees were not paid for their time. In all three focus groups, focus group participants gave examples of where people had used their own resources to supplement those of the network.

4.4 Group and one-to-one support

Another way of looking at the support provided is to divide it according to the forum through which it was provided. The term 'forum' is used to differentiate from the medium of communication (i.e. face-to-face contact, telephone, email etc.). All the actions relating to support described in the previous section could be coded as taking place at an individual or a group level. One-to-one work could be carried out face-to-face, in real time over the telephone or via the internet, or be conducted through sequential exchanges of messages. Group work was primarily carried out face-to-face, although some groups had experimented with Facebook and other social media as a supplementary means of communication.

Often organisations and groups used both approaches in various combinations, or hybrids where one-to-one work fed into groupwork or vice versa. One large peer network provided a range of individual supports as specified by local authority and NHS commissioners, but also hosted less structured support groups.

4.4.1 Individual support

PNs provided support on a one-to-one basis through all of the stages of obtaining and managing a personal budget. Many of the focus group participants in paid roles were constrained in the support that they could offer by the nature of the contract their network had with local statutory commissioners. Their involvement was sometimes limited to specific parts of the process; the two most common were setting up the support plan and maintaining it on an ongoing basis.

At the set-up stage, the principal task was support planning. In all three focus groups, participants described a trend of shrinking resources at this stage, both in terms of the support provided by PNs themselves and the support provided by local statutory bodies (or commissioned by them from other types of organisation). In all three focus groups there were discussions about the impact that this had on PNs, particularly the rising expectations which they were not always able to meet. Many PNs had at one point been commissioned

to help people develop support plans, but this appeared to be in decline. Where PNs were still involved, this seemed to be exceptional and for specific groups of people. Examples included people with learning disabilities, those paying for their own care and support, and individuals with NHS personal health budgets. Most of the commissioned support provided to existing users of PBs related to finding, employing and managing personal assistants.

Participants often contrasted the type of the support they gave with that provided in the statutory sector, even where the task was superficially similar. One focus group discussed self-assessment, with a participant providing a detailed account of how it was superior to an assessment carried out by a statutory care co-ordinator. Two participants described the way they helped PB users to use resources to meet their needs more effectively, for example by attending a sporting event instead of using a care home for respite, or having driving lessons instead of using taxis. One participant contrasted the realistic assessment of risk provided by PNs with the risk-averse approach of social workers. Another said that in a survey of their clients, people felt more respected.

One-to-one support at a distance was mentioned, but rarely. Examples included an information and advice line and a 'network navigator' service which helped people to orientate themselves within the often-confusing world of health and social care services, both of which were provided over the telephone.

Where people were not in paid roles, they appeared to have a greater degree of flexibility about the type of support they could provide. Even where they were no longer paid to do so, PNs seemed to be prepared to provide some help for people trying to find out about how PBs worked. Focus group participants working as volunteers seemed to have more discretion to provide individual support as and when needed. Perhaps because of this, support could be more *ad hoc*, and tailored to the individual circumstances facing people. Examples included the 'loan' of a PA to another disabled person, and other similar examples where focus group participants simply helped people to do things that they were finding difficult, such as completing financial returns to the local authority, or budgeting for services.

Some specific types of individual volunteer work were co-ordinated by PNs. Examples included a 'buddy' scheme, where a new PB user is paired with a more experienced person, a befriending scheme, and peer advocacy, where volunteer PB users supported one another in meetings with the funding body.

4.4.2 Group support

Participants from all three focus groups gave examples of structured support groups, which were usually planned in advance and aimed at particular types of PB user. However, there were also examples of other types of group which seemed to be unplanned, with a spontaneous agenda. Participants described their work as facilitators and/or convenors of the different types of group. Perhaps because of this, the type of support they provided did not always map as easily onto the process of obtaining and managing a personal budget. While there were examples of groups providing support at all stages of the process, and also working to improve the PB process more widely, this was typically because the group had taken on the task in response to an issue arising in the group.

Some people used groups to find out about personal budgets before deciding to pursue one. This allowed members to explore PBs from multiple perspectives. There was a good example of this in one of the focus groups organised for this project, where people made the best of the opportunity to talk to the experts around the table about their own circumstances. Participants frequently reported that people used groups for networking, both by making connections with other group members and by getting information about other contacts they could follow up later. Gaining other perspectives could be valuable even for experienced PB users. The emotional support function of groups could also be valued by experienced personal budget users.

Groups organised for a specified purpose included advocacy groups, where people were supported to advance particular issues, typically with local authorities or the NHS, and wider campaigning groups. Some of the specific groups mentioned were for people with particular types of impairment, or their informal carers. In one area, the local authority worked in partnership with a peer network to provide training for actual and potential

personal budget users. In two focus groups, participants discussed the way support groups were now having to substitute for the support that would once have been provided by local authorities.

Some support groups provided a means for people to pool personal budgets. The Independent Living Trust was the most complex of these, providing a structure that encompasses housing, daytime activities (including businesses), and a string of other services and supports. PNs also provided support for people to pool budgets for day care, transport and accommodation.

Participants described a range of strategies to use electronic media for supporting people in between meetings. These included using web sites and Facebook pages to post information. One participant reported trying to use Skype, although the technology was unsuitable for some PB users whilst others lacked key equipment. Another reported having attempted to host an online forum, but again cited problems with the technology and the time necessary for moderation as reasons for discontinuation.

Participants had problems starting and sustaining support groups. Travel and access were obvious difficulties, particularly for groups with a wide geographical catchment area. Finding a time when everybody could attend was also problematic. Maintaining an adequate regular attendance, or at least a small core group, was also difficult. Participants described the stressful lives personal budget users often led. Their relationships with local statutory organisations frequently seemed to cause anger or despair, and the very severe levels of impairment with which some people were living often made attendance difficult or impossible. These difficulties were linked by one participant with a persistently pessimistic attitude in the support group, which had led to the temporary suspension of the group. Another possible difficulty mentioned by two participants was the perceived hierarchy between some disabled people's organisations, which meant some groups were perceived as exclusive or elitist.

4.4.3 The relationship between individual and group support

Individual support and support in groups were linked to one another in many ways, both between and within networks. This relationship worked in both directions. Several participants in two different focus groups described how they would be able to carry issues arising in groups forwards by providing individuals with one-to-one support. Similarly, one-to-one work often involved making people aware of the group support where it existed.

In all three focus groups, there were examples of PNs providing information and advice or similar roles, which could route individuals to appropriate support groups whether provided by that organisation or by someone else. One participant provided individual support to two PB users with learning disabilities to enable them to attend a forum. Two organisations hosted advocacy groups, where group members would help one another take up individual issues with statutory bodies. Participants gave many examples of where they or other group members had provided follow-up support outside of the group when people had asked for help. In some cases this was a formal part of the service provided by the organisation, but in others it was an *ad hoc* arrangement between individual group members. One organisation used a closed Facebook group for people to post inquiries in between groups, which sometimes led to individual support. One participant described supporting a PB user individually because she or he was unable to attend the group.

One participant described a support group, now no longer running, which combined group support and individual support, for example by inviting the payroll manager from the managed account service to the group, both to be held to account for the level of service provided and to provide 'on the spot' help where people were having difficulties.

4.5 Peer support and its impact

The literature review showed a broad range of understandings of peer support that were sometimes explicit but more commonly implied. In all three focus groups, participants were asked directly about their understandings of peer support, but the answers were usually

quite brief. However, the wider discussions both following direct questions and at other times allowed participants to surface their individual and organisational understandings of peer support in relation to the use of personal budgets. People described peer support in the contexts of group and individual support. There were also discussions about the relationship between support and organisational structure.

4.5.1 Peer identity in groups

Participants described a very wide range of different meanings of 'peer' operating at this level. The concept could sometimes relate to the activity of the group (for example using a personal budget, or lobbying local statutory health and social care organisations), or the impairments or health conditions of members. Sometimes this was quite specific, for example one group existed purely for people qualifying for NHS Continuing Health Care using personal health budgets. At other times, the definition appeared to be much more inclusive. Generally, participants seemed to take a permissive approach to defining 'peer' in the context of group support.

"People with shared experiences supporting each other, whether that be disabled people or people representing their loved ones, people that they care about in an informal way."

Female participant in paid role.

In one focus group discussion, participants seemed to agree that it was important for group members themselves to define whatever 'peer' meant to them, rather than for convenors or facilitators to decide it for them.

For many of the smaller groups represented, the organisational structure and group structure were identical; the group was the organisation. Two of the longest-lasting and apparently most stable groups were focussed on personal budgets and run by and for personal budget users, but interestingly they had both initially been set up by other agencies (in one case by the local authority, and in another by a local direct payment support organisation). This type of evolving relationship between parent organisation and group seemed fairly common, and was described by several participants.

"Yeah, it was housed inside within [peer network] for a while, but then actually moved out and was completely independent."

Male participant in paid role

Participants also gave examples of where a larger organisation had developed from a peer support group, for example for parents of disabled children. The larger organisations seemed to regularly start groups either where they were commissioned to do so, or where there was a perceived need. Similarly groups were frequently suspended or wound up for a variety of reasons, including low attendance. Groups and services often seemed to change their membership or their primary function, or both. Sometimes groups needed to change their purpose to fill the gaps left by reductions in support provided by other agencies, and sometimes to focus more directly on challenging the practices of local statutory organisations.

"...people in our group talk about let's extend the remit, one, it could be that it's an independent living group so that it doesn't just deal with direct payments, and another is let's just make it completely just disability self-help group, so that we can talk about anything."

Female participant in defined volunteer role

Having the particular characteristic associated with peer identity was usually associated with access to particular types of group; they were usually 'for' personal budget users, parents of people with disabilities and so forth. Peer identity was also linked with the benefits of group membership, particularly in terms of access to relevant information, being understood and experiencing empathy.

"It's also the fact that you're not feeling like you're being judged. If you're a peer-to-peer, your peer's not going to judge you."

Female participant in defined volunteer role

Participants reported that group members would often benefit from participating in different groups. This could be linked with getting help or advice with different aspects of the process of obtaining and managing a personal budget, but also seemed to be linked with seeing things from different perspectives. The following quote comes from a section describing what happened when members of an established peer network of carers attended a new group for personal budget users.

“And so there's a really clear support system, and they know each other and everything. And I think that for them to come out of that, into a place where they're seen not as a parent of people, whatever, but as themselves managing a direct payment on behalf of someone else, it's quite a different to look at it, and it means that it is they who are the centre and not the adult child, and that's why it kind of works quite well, and kind of supports them in a slightly different way...”

Female participant in defined volunteer role

4.5.2 Peer identity in individuals

“So there's all sorts of definitions of peer support is, peer advocacy and peer mentoring [group laughs] and I think it's a bit of a challenge. I see it as a little bit of all of that. It's whatever people want it to be.”

Female participant in defined volunteer role.

Being a family member or informal carer was sometimes classed as a ‘peer’ relationship, and in other settings carers were included as peers within groups defined by impairment type or the use of personal budgets.

"Any family member who's caring can equally come along within that, and we class that within the peer support element, because somebody's going through that whole experience."

Male participant in a paid role

Some focus group participants identified themselves as users of personal budgets and also as disabled people, but did not explicitly link this with their defined paid or volunteer roles as 'peer supporters'. While it was sometimes apparent that participants' lived experience had a relationship with the peer support they provided, this was always implied rather than stated.

In all three groups, participants gave examples linking discretionary provision of support with a shared identity, for example:

"... we've had 70-80 year-olds ring us up, and I know, if I just say, 'ring social services' they're not going to do that. So in that case, even though it's taking more work on for me than technically I wouldn't have to do, I will always do that. I'll always do referrals to social services to make sure at least the referral gets through the door. And that's just something I do because I'm a human being, I care about disabled people."

Male participant, paid role

As with group support, the boundary around what constituted peer identity was interpreted broadly. Sometimes it related to the qualities of individuals, and sometimes to the nature of the peer network. Peer identity in individuals was often linked with access to supports, and the beneficial aspects of support. Trust, empathy and expert knowledge were all qualities that participants linked with support provided by 'peers'.

4.5.3 Peer identity and organisational structure

Peer support groups were sometimes facilitated by people who were not 'peers' in the sense used by the group, and individual peer support was often provided by employees or volunteers who did not have experience of poor health or impairments themselves. It could be inferred that in these cases, the dimension of parity within 'peer' support was conferred by organisational characteristics which were reflected in the nature of the support provided.

All of the participants in paid roles represented PNs that were legally constituted organisations, many of which seemed to have a constitution that partly defined the peer relationship. In one focus group, two participants described their organisations as being user-led. One of these explained how being a user-led organisation had initially led to all employees being disabled:

"When we set that up originally it was like to work for [organisation] you had to be disabled, according to the definition of disability or whatever, but now we've changed that, because we recognise that there are times when we need a mixture of staff ..."

Male participant, paid role

The same participant explained that the organisation's service users had explicitly valued this element of the service provided when surveyed. A second participant commented that their organisation was also user-led, and that a lot of their Independent Living Advisers had disabilities themselves:

"... it does make a difference when we go out and we see the people who we're supporting. Quite often they've not had a very good experience of social services, and you know, they're reluctant to see people, but once they understand that we're independent from social services, although we're commissioned to do the support, you can see that they begin to relax."

Female participant, paid role

In this second quote, the participant seems to conflate the independence of the organisation, the fact that it is user-led, and the disabilities of many (but not all) of the workers. A similar discussion emerged in a different focus group, when the facilitator queried a participant's distinction between groups where workers had peer experience, and those that were peer-led.

"That's purely because the people who are working for us don't have an impairment and therefore can't be classed as. As a whole, the whole Directors have a self-declared impairment, and I think about fifty percent of the workforce does. But it just depends on jobs and job titles as to whether people do or not. I mean I could say our [senior organisational member] has a husband who's [describes impairment]. So she understands it from ground level, and the differences, and so do several of the other people who're working within the team. They all have great understanding of disability and of personalisation and so forth. But you can't actually put it forth as a user-led thing in that case ... it is still sort of peer support, but if you differentiate between it, you could say that it couldn't be."

Male participant, paid role

The participant is clear that in his view 'pure' peer support can only be provided by people with disabilities, but an organisation that is led by disabled people and staffed by people with a range of other experiences of impairment can provide support that is nearly indistinguishable. There were several other instances where participants alluded to the

beneficial relationship between the structure of the peer network and the nature of the support provided, without being specific about what it was.

Overall, the relationship between peer identity, the support provided and the impact it had on personal budget users was nuanced and complex. There were many meanings of 'peer' in use, and no participants were insistent that their interpretations were correct. At a group level peer identity helped to determine the purpose and focus of meetings (although these could change over time), enabled people to make requests of each other, and provided links to forums for individual peer support. Individuals sometimes linked their own lived experience with that of other people, and often cited this as a source of additional insight. In these cases they were sometimes prepared to make great efforts that went beyond the basic expectations of people in their roles. Individual and group understandings of 'peer' were both linked to organisational structures which required the involvement of a majority of people with illnesses or impairments in the workforce or on the governing body. However, there were clearly a range of interpretations of the term 'user-led organisation'. Participants identified many qualities of peer support that were helpful to personal budget users. With both individual and group support, it was apparent that these qualities could be present in 'peer support' offered by employees and volunteers who were not themselves 'peers'.

4.6 Providing information and organising support

A lot of the activities of peer supporters consisted of providing information to personal budget users, but characterising their activity in this way would obscure the sophisticated interpersonal skills in use. The information-giving role can be thought of as existing along a continuum of support. At one end, the peer network is more-or-less passive, and may not even be aware that information has been imparted (for example if it is downloaded for a web site). At the other end, many of the networks provided additional support so that people would be able to make sense of the information they were given, and subsequently to apply it in practice. This support could be characterised as educational, because it helped people to learn how to do things. Participants also described helping personal budget users who were experiencing distress to cope with their difficult feelings. This support could be

characterised as emotional. Focus group participants were involved in organising things on people's behalves, in two different contexts. Firstly, they were often involved with organising the peer network itself. Secondly when people were unable or did not want to manage their own support, participants organised this for them. This scheme is illustrated in Figure 9.

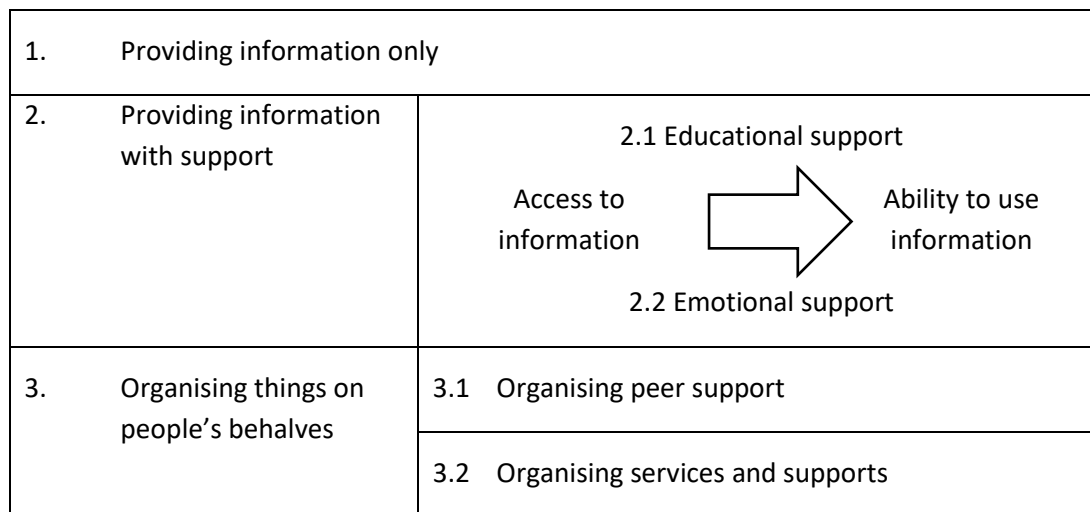


Figure 9: The continuum of support offered to help people make use of information

4.6.1 Providing information only

PNs provided information to actual and potential personal budget users, both about personal budgets and about the wider context in which they could be used. Where networks were unable to provide support to people directly, they also directed people to other organisations and agencies. Many networks represented in the focus groups maintained web sites, Facebook pages and used other media to provide information without people needing to make direct contact. This included information about other PNs, including those not explicitly aiming to provide support to PB users. There were frequent examples of this type of function, which was described in all three focus groups.

The most common way in which participants described the individual and group work was in terms of the provision or exchange of information. The types of information and its purposes have been described in 4.2 (p.102) and 4.3 (p.108).

4.6.2 Providing Information with educational and emotional support

In all three focus groups, participants described the type of help they gave people to make effective use of information. Sometimes the stated goal was to help people through a difficult stage of the process, but frequently there was also an aim of helping people to learn how to do things for themselves.

4.6.2.1 Educational Support

One peer network had input from a local authority learning and development worker, who organised a series of free training sessions aimed at helping people develop basic skills relating to personal budgets. These included training with bureaucratic tasks such as budgeting and carrying out criminal records checks, but extended to sessions on assertiveness and confidence-building:

“It's all of that that makes life easier, so when you finally have your direct payment set up and you've got all your insurance and you've got all these things, you're then OK and you're able to do the things you want to do...”

Female participant in a paid role

Some support groups would have a particular theme on a specific date, which could have been organised in advance or decided on the day.

“...we did some Care Act training, which was really useful, and we've done some safeguarding training, so that people understand what safeguarding is and what it looks like. You don't need to know what all

the processes are, but you do need to know what it is and what it looks like, so that they can protect themselves, but also so they're watching for other people as well ..."

Female participant in a defined volunteer role

Other support groups simply provided an opportunity for people to meet. Irrespective of the degree of central organisation by the facilitator, almost all groups seemed to enable PB users to talk to each other and find out how other people were doing things. The presence of people who were actually doing some of the things they'd heard about helped new and potential PB users to get a more realistic understanding of what was involved.

"I personally think that if you have something like that [pooled arrangements between PB users in a particular area] that you build people's confidence and they'll start to see they can actually do things. Because if you do things with people rather than for people then they learn ..."

Female participant in a defined volunteer role

The role of providing education and support was frequently focussed on employing personal assistants. It included things like advice about creating job descriptions and person specifications so that the recruitment process was lawful, help with budgeting and making financial reports to the funding body, using online tools for calculating income tax and other deductions for payroll purposes, learning how to apply for Disclosure and Barring Service (criminal records) checks, and generally dealing with the types of routine issues that arose when employing people.

Often the educational process required the supporter to be able to anticipate issues or problems, so that people would be ready when they arose.

"Most of the people I support do want to use direct payments to employ personal assistants, so the service that we provide is passing the

information to them, so they know what's entailed in taking on a personal assistant with regards to becoming an employer and acting lawfully.”

Female participant in paid role

In one focus group, there was a detailed discussion about anticipating the impact of progressive conditions.

“It isn't so much about being condition-specific, it's about being with other people who have had to work through how they're going to get support, and understanding that there are processes that, as people get worse, they can actually ask for more help and more support ... So if you've got something than means you can't use your hands in 3 years' time, then start planning now for how you're going to manage things. And if it means you're not going to be able to walk, think about what that means in terms of housing, and transport ...”

Female participant in a defined volunteer role.

4.6.2.2 *Emotional management*

Personal budget users could be distressed for a range of reasons, often linked either with the difficulties and stresses of living with their impairments, or specifically with the perceived inadequacy of the help they were offered by statutory services. Although some participants described providing emotional support to people for its own sake, it was usually associated with helping people with a particular task or process. Participants often showed that they often used considerable discretion about the duration, level and type of support necessary to help people learn.

“... I have a friend who ... was in a wheelchair angry as hell, everything was a crisis because the last place they wanted to be was in a wheelchair, they couldn't accept any of what was happening to them ...

and peer support kind of helped. And now, he's not angry as hell, he's not accepting ... but not everything is a crisis, and some things aren't even a drama, because his support systems are working in a way and he's coming to terms with it."

Female participant in defined volunteer role

"And it was done at the lady's own pace because she had quite a lot of anxiety, and so we had to do it over a series of several months ..."

Female participant in a paid role

Providing the help at a time when people were able to make use of it was perceived as critical, and participants from all three focus groups spoke about the work they did to support people emotionally, and the emotional cost to themselves.

Participants in all three groups explained the work they would do to help people who were finding it difficult to complete tasks associated with the PB process because of their emotional response to the help that was or was not forthcoming from statutory bodies. One participant explained how she had attempted to help someone get their needs reassessed, and the sense of defeat and futility that arose when she was informed that any reassessment would probably result in a reduction rather than an increase in the personal budget.

"... and the social worker has gone 'I can come out and see you, but you do need to understand that if I come out and see you I'll be cutting your budget by 30%. And of course they go 'Don't worry, then'."

Female participant in defined volunteer role

Another participant described how she had attempted to support a PB user in a similar situation. The quotation shows the link between the educational and the emotional aspect of the role performed.

“...and one of those [additional supports], as soon as it went in the support plan the social worker's manager has said 'I can't see the need for that', and she's had to go absolutely wild about and say 'It's the first time I've asked for anything, and I can't even get it', and it's now got to the point of that person having the meeting with the social worker's manager. She's saying 'I'm not even going to do this meeting if I'm not going to get anything out of it', and so it's persuading her that, if you don't do the meeting you probably won't get anything out of it but if you have the meeting, that person'll have a chance to meet you, and have a conversation.”

Female participant in a paid role.

Support was sometimes extended to people's families. The following exchange comes from a group where participants were discussing the importance of emotional support.

“I think it's hard to get peer support going for a personal health budgets. I think you [to following participant] mentioned it. People are so ill, if you qualify for CHC [NHS Continuing Healthcare] you are very ill, and maybe not very mobile and maybe there's something about the carers supporting each other?”

Female participant in paid role

“Oh yeah, that's still part of it. Any family member who's caring can equally come along within that, and we class that within the peer support element, because somebody's going through that whole experience. If someone's ill you pretty much live that with that friend or family member. So it goes all the way round. At last week's meeting the parents of a nineteen-year-old girl with a brain injury came along, it was very much they're hearing what's going on so they can look out for her future. And understanding all that's going on ...”

Male participant in paid role

There were similar examples of people linking emotional support with peer support in all three focus groups.

“And they're all supporting each other now. And it's quite nice to see that if someone needs someone to talk to there's someone there for them. But they're also arranging going out with the kids to parks and having picnics and stuff, and that's peer support if you like, and there's no money changing hand because it's just parents getting together, realising there's nothing out there for their children, and getting their kids some real help.”

Female participant in defined volunteer role

4.6.3 Organising support

The organising role could be divided into two overlapping functions. Firstly, participants described the many ways in which they were involved in running the PNs themselves. Secondly, where people did not want to take on organising their own personal budgets, or were unable to do so, it was common for PNs to take on some of these tasks.

4.6.3.1 Organising peer support

The first division encompassed the range the organisational activities one would expect for the ways in which peer support was delivered. For groups, it involved things like booking meetings, planning the agenda, notifying potential attendees, arranging for external speakers and so forth. For individual support, it could involve arranging initial contacts with people, organising meetings with them and subsequently planning the activities which followed.

4.6.3.2 Organising services and support

The second type of organising involved picking up the tasks that PB users were unable or unwilling to do for themselves. For some PNs this could be quite informal, with people tackling tasks such as returning financial information to statutory bodies because PB users were unable to do so for themselves.

"The support that comes from the [Independent Living] Trust, well, it's mainly from me, because I'm the one that has the most spare time ..."

Female participant, defined volunteer role.

In other cases, PNs were commissioned to provide specific supports at defined stages of the process, for example by purchasing specialist disability aids on people's behalves, helping to recruit personal assistants, or providing a pensions and payroll service:

"...we had, the payroll manager came in to meet some of the peers, and then actually talking about it and explaining where it's going to go, and [peer network] is equally going to work as their secondary - they all have to sign up because they're the genuine employer - but [peer network] is going to take the information on their behalf, so they still don't have to worry about that element of it, and that is being funded by each CCG [NHS Clinical Commissioning Group] which has paid in for the option to be there if somebody wants to run their personal health budget completely themselves."

Male participant in paid role

"If they have a direct payment, we've got, as a part of our service, we've got a PA database of about eight or nine hundred potential people, and if someone hasn't got a PA we'll sit down with them and draw up a person spec., that sort of thing, of what they're actually looking for. We post that to all the potential applicants on our PA database, post it on

the universal job match, with all the applicant details essentially. And then when we've got them all in, we'll distribute them to the disabled people, really with as much support as they feel they need. Most people do want full support with the whole thing."

Female participant in paid role

These quotations illustrate the intention of tapering support so that PB users could assume as much control as they wanted. This is consistent with the educational role, where people were provided with guidance and support until they were able to do things for themselves.

Each of the graduated roles described in this section implies a shared or very similar understanding of the reciprocal roles of supporters and personal budget users. The information-providing role shows that some PB users are understood as being able to comprehend the information they are given, and to make their own decisions about what to do as a consequence. The education and support and the organising roles both show an understanding that some PB users have varying abilities and capacities to manage their personal budgets. Some may be able to learn how to manage these tasks for themselves, with ancillary emotional and educational support. Others will want other people to organise things on their behalves, but may want to take control themselves at some point in the future. All three roles described above are consistent with an ideal that people should have support when it is wanted, but should be able to dispense with it when not.

4.7 Mediating between the personal budget user and the funder

PNs played an important role in mediating the relationships between personal budget users and the agencies that had statutory responsibility for assessing their needs, calculating the amount of money included in personal budgets, and agreeing the support arrangements. This could be broadly termed as advocacy, but 'mediation' is used here to avoid the confusion that often arises from conflicting service-based, legal and theoretical models of advocacy (Chapman et al. 2012). In this sense, mediation simply means that PNs were interposed between personal budget users and providers. Mediation could be thought of as

existing on a continuum between challenge and collaboration. At the former end, participants positioned themselves as activists working with PB users to contest individual decisions and to achieve wider changes in the way that health and social care systems operated. At the latter end, they perceived themselves as partnering with statutory bodies to try and meet the needs of PB users. Each focus group produced discussions about this type of relationship.

At least two of the PNs represented in the focus groups had been set up by statutory organisations, with a third being established initially by a direct payments support provider that was itself funded by the local authority. Feedback from PB users was clearly something which some statutory organisations valued and were prepared to invest in. Many PNs described collaborating with statutory agencies, for example to implement the 'Making It Real' (Think Local Act Personal 2012) standards in their area, or by hosting groups at which personal budget users could both receive briefings from statutory organisations and large voluntary providers, and 'hold them to account'.

Many PNs provided formal advocacy services, either in the form of advocacy groups or one-to-one advocacy, or both. Participants in all three focus groups gave examples of where they had successfully challenged local authority decisions which were presented as unjust and incorrect. One concerned the case of a PB user who had had both legs amputated and had been told that the threshold for providing care had not been reached. Another from a different focus group described a case where someone had been initially assessed as needing three hours of care a day, and as a result of assistance from the PN this had been increased to twenty-four hours. Two participants in the remaining focus group described the case of a long-term personal budget user funded by social care services, who had been told to sack her team of personal assistants when she reached the threshold for NHS Continuing Health Care. She received peer support through a lengthy legal process.

Another type of challenge related to persistent patterns of poor practice by local authorities, which were linked by participants to reductions in budgets and lower levels of knowledge among staff. These challenges were often pursued at an organisational level rather than on behalf of individual personal; budget users. In one focus group there was a

long exchange about the value of financial support from statutory organisations, and the problems that came with it. One PN had lost its local authority funding, but found it easier to provide advocacy as a result. Another had deliberately not sought to renew its local authority contract and had obtained funding from a large grant-making charity instead. This resulted in greater independence, but the participant reported that the local authority was less likely to pay attention to them once they were no longer contracted to provide support, limiting their effectiveness. A third participant reported taking a more cautious approach to challenging the local authority, again linked to their role as a commissioner:

“...you’re biting your lip a little bit because, you know it won’t work and particularly in these times it’s not overly wise.”

Male participant in a paid role

Many PNs hosted groups that were intended to inform the development of local services, and two were part of formal partnerships with this objective. There were frequent examples from all three focus groups of where, as a result of their influence, the system for supporting personal budget users had changed for the better. One participant described how the PN had negotiated an agreement to be able to directly refer people for a local authority assessment. Previously they had had to direct people to self-refer, probably meaning that many would have not obtained support.

Achieving this kind of change, and being able to tell members of PNs that it had happened, was perceived as pivotal in maintaining motivation amongst PN members.

“I think that the way you get peer support groups to continue, is that there’s some evidence that they’re making a difference. If you’re just slamming your head against a brick wall. There’s some people like me who are idiot enough to carry on, but there are lots of other people who just say: ‘You know we’ve been to five meetings about this and not a single obvious change has been made, I’m not going to any more’.”

Female participant in defined volunteer role

An interesting variant on this perspective was that it could actually be easier to establish a peer network where the statutory systems were not functioning well:

“I think that’s interesting, actually, because anecdotally in personal health budget world, the biggest peer networks, or most active peer networks have been those that have got some common cause, where something’s not working right for a huge number of people, and then a group have got together to bang on doors and things like that.”

Female participant in paid role

The mediating role seems to have a shifting dynamic, but within some fixed parameters. PNs’ capacities to meet the needs of individual PB users and sustain peer support groups is partly dependent on their ability to achieve change (and in the case of groups, to report it back to members). To be able to advocate effectively, the peer network needs to engage with PN users on an individual and/or collective level, both of which require resources. Obtaining money through a contract with the NHS or local authority provides some financial resource and some credibility and influence with statutory bodies, but may weaken independence and therefore the ability to challenge. PNs perceive that statutory bodies will pay them to provide support to PB users, and to report issues or work collaboratively on the development of personal budget systems, but show concerns that they may withdraw funding or block them in other ways if they are considered to be too antagonistic. To function effectively, PNs must navigate this intermediate role carefully to maintain sufficient resources to meet the needs of PB users, and sustain their credibility with both PB users and statutory partners.

4.8 Summary

Three focus groups with sixteen participants were held in the autumn of 2015. Fourteen completed background information sheets giving some details about themselves, the organisations they represented and their roles within them, and supplementary information about some networks was collected for additional context. Many participants had multiple roles in many different PNs. The majority of these could be categorised as disabled people's user-led organisations, but they included social enterprises, networks supported by statutory bodies, and informal groups. Providing support to personal budget users was the main activity for about half the participants, while for others it frequently formed part of a wider role. Most of the participants had a health condition or impairment that affected them significantly, meaning that they were often able to talk from their own lived experience as well as their knowledge of supporting others.

In order to address the study's principal aim, to inquire into how PNs support budget users, it was necessary to establish whether these types of organisation did in fact have a characteristic approach. The research data reported in Chapter 2 indicated that this was the case, but the data on which this conclusion was based had been collected from over a twenty-year period. The focus group data could be organised according to the same scheme (shown in Figure 5, p.51), and when this was done the descriptions of the support provided were very similar. This supports the conclusion that PNs do have characteristic approaches to supporting personal budget users.

The analysis of focus group data showed that PNs were dependent on a number of key relationships in order to continue to function. These provided them with the up-to-date expertise, and the financial and other material resources necessary to provide a service. Although other types of relationship were mentioned, the most important external relationships were with the statutory bodies that funded personal budgets (and often the support services that went with them), and other PNs. The most important internal relationships were with network members and personal budget users. Managing both sets of relationships effectively required skilful management of competing pressures. PNs' credibility with their own service users depended to some extent on their ability to achieve

change, which was in turn dependent on the resources needed to lobby, advocate or participate in joint initiatives with statutory organisations. Contracts from the same statutory bodies were a major source of funding for many of the PNs represented, and a hostile relationship could put these at jeopardy. PNs had all developed unique strategies for managing this tension, which ranged from opting out of local authority funding to focus on advocacy to partnering statutory bodies to co-produce the local personal budget system.

The analysis of focus group data found three main processes that could partially explain the consistency in the approach. All of the support described in the focus groups was consistent with the values that people should get as much help as they needed, and have as much control as they were willing and able to exercise. The majority of the organisations represented were user-led disabled people's organisations, and some focus group participants were very knowledgeable about the history of disabled people and the independent living movement. Similarly, most of the participants had lived experience of ill-health or disability, and most of the networks represented were (or had at some point been) constituted by others in the same circumstances. However, it was also apparent that PNs were constantly learning, from their experiences of providing support, and from their relationships with other organisations and groups. In this sense, the characteristic approach of PNs could be thought of as emerging dynamically from the process of providing support.

Another of the study's objectives (see section 1.6) was to explore the context in which PNs operated. Despite having a similar ideal of the type of support that should be available to people, the approaches of the organisations represented were quite distinct from one another. Some of the variation could be attributed to innovation, but PNs also seemed to be constrained by the funding that was available to them and their relationships with other organisations in the local patchwork of commissioned and voluntary supports. Participants painted a broadly consistent picture of recent changes within their local health and social care systems. The PNs represented were often experiencing some sort of combination of reduced funding and increasing expectations of what they were able to provide for it. Statutory workers were less well-informed about the process of obtaining and managing personal budgets than they had been, and frequently arranged support on people's behalves rather than engaging them in a collaborative process. Where one-to-one support

was still available, it was often restricted to certain groups of personal budget users or to part of the process, frequently helping people to find, employ and manage personal assistants.

The second and third objectives of the study related to the benefits and drawbacks of the support provided by PNs, and the features that people found helpful or unhelpful. The benefits and drawbacks of support were sometimes associated with the forum through which it was provided. The advantages of individual support usually corresponded to the specific tasks associated with obtaining and managing a personal budget. Individual support was often contrasted with statutory support in terms of its ability to help people develop support packages in ways that met their aspirations as people rather than just their needs for care. There were also sometimes disadvantages, for example the limits on support imposed by a lack of access or resources. Groups allowed people to expand their networks by meeting other people and finding out about other sources of support, and to check their understandings directly with other personal budget users, though this could sometimes cause confusion. The less organised character of some support groups gave them the flexibility to respond to issues as they arose, but sometimes meant they were not relevant to all members. Participants usually described groups as supportive, but sometimes the emotional distress and pessimism of those attending made participation difficult. Individual and group support were often combined with one another very effectively.

The fourth and fifth objectives of the study relate to the operation of peer identity in the process of support provision. Peer identity was found to operate differently at individual, group and organisational levels. The analysis found a range of different meanings for what it meant to be a 'peer'. Some participants put forward well-developed definitions, whereas others argued that it was important for groups and individuals to be able to have their own understandings. Definitions were sometimes based on personal characteristics, such as a specific type of impairment, or were derived from common activities such as managing a personal budget. While it was often necessary for personal budget users to have these characteristics to gain access to support, this was usually interpreted inclusively (for example in decisions about providing support to informal carers and family members). Peer identity could be defined by the characteristics of organisations as well as those of the

individuals who worked in them, so that 'peer support' could be provided or facilitated by staff and volunteers who did not themselves have the characteristic quality that defined peers in that context.

Peer identity was strongly associated with the positive qualities of support. At an organisational and an individual level, parity meant being independent from the statutory sector, and on the same side as the personal budget user. In a group context, having shared characteristics meant that the group was likely to have relevant information and expertise, helped members to empathise with each other, and allayed people's fears that they might be 'judged'. While not always necessary, support from people with lived experience had specific advantages, for example in the contexts of educational and emotional support. Educational support often consisted of talking to people who had experience of performing the same tasks and who could show them what to do. Emotional support often came from people who had had similar experiences of the loss and distress associated with illness and disability, and who were able to anticipate its impact.

CHAPTER 5: THEORETICAL DISCUSSION OF FINDINGS

In qualitative research, deep theorising is typically reserved until after data has been collected and analysed, irrespective of whether a grounded theory is developed or other mid-range theories are applied. In naturalistic research, this reflects questions about whether concepts developed in advance of the study can adequately reflect the reality of every set of social conditions, and the risk of forcing data to fit into the theoretical model (Blumer 1969, Lincoln & Guba 1985). Irrespective of the research tradition, the issue of 'fit' between the data and the theory is always a central concern. An adequate theoretical discussion should be able to identify the important features of the results in relation to the purpose of the study, and provide a coherent explanatory framework. In the present study, the fifth objective was specifically to develop a theoretical framework to link lived experience, peer identity and support for personal budget users. That is the principal purpose of this chapter. The overarching objective is to propose a theoretical model of peer support that is consistent with the findings reported in Chapter 2 and Chapter 4.

The first important finding is that there was a consistent approach to providing support across more than twenty years, shared by PNs using different criteria for what was denoted as a 'peer'. The possible sources of influence were diverse. They included people's knowledge of the independent living movement and other specialist theories, methods and models of support; the lived experience of illness and disability amongst peer supporters, often coupled with organisational control exercised by peers; and the dynamic processes of managing relationships with external bodies such as local authorities at the same time as engaging with network members and personal budget users. This raises the question of whether a single theoretical approach could draw these factors together in a unified model.

To survive and to be effective, PNs needed to balance their relationships with their members and service users, and with other organisations such as statutory commissioners and other PNs. Section 4.7 reports that this was achieved in quite different ways. For example some PNs were engaged in formal partnerships, while others were deliberately separating themselves so that they could challenge more strongly. Section 4.3 reports that in all three focus groups, participants reported the effects of financial cuts. Could a

theoretical model describe these complex interrelationships, and account for the impact of diminishing resources?

Section 4.6 reports that all the organisations represented by PNs operated an approach to peer support consistent with the value that people should have as much or as little support as they wanted. Support was described as having two principal dimensions; educational and emotional. In both cases, participants reported positive qualities of support associated with support provided by 'peers'. As sections 4.4 and 4.5 showed, peer identity operated differently at organisational, group and individual levels, although there were structural connections between them (for example in terms of having a majority of peers on the governing body, and referral routes between individual and group peer support). Section 4.2 reports that while the majority of peer supporters had relevant lived experience, some did not. This raises the question of how peer support provided by people who were not 'peers' could have the same or very similar effects.

The principal theoretical model used to answer these questions is Pierre Bourdieu's (1977) theory of practice. The first section of this chapter introduces the model and its basic theoretical components, and sketches out how these could apply to peer support and the use of personal budgets. The second section develops this model further by applying and refining a number of developments of practice theory by more recent scholars. The combined effect is an original theoretical model, which can be used to explain how PNs support people to obtain and manage a personal budget. This is then summarised in a final section.

5.1 Application of practice theory

Pierre Bourdieu's (1977) practice theory aimed to resolve widely debated theoretical problems in contemporary anthropology, such as the apparent dualism between social structure and human agency, and other similar dichotomies (Bourdieu 1977, 1990, Calhoun 1993). This was achieved by locating identity, conceived as a disposition to act in a particular way, in the context of social practices in intersecting social fields. The centrality

of practice from a theoretical and methodological perspective makes Bourdieu's model a good candidate for the present study, with its focus on the practice of supporting people with personal budgets. Bourdieu analyses practice in terms of three key concepts; social field, 'habitus' and different forms of capital. His theory has been described as a 'grand theory' (Walther 2014), in the sense that it could potentially be applied in any social situation. A feature of grand theories is that they lack sufficient specific detail to link with the low-level empirical studies such as the present inquiry, meaning that they need to be specifically reformulated in relation to issues and social conditions under investigation before they become useful (Merton 1949). This is consistent with the naturalistic perspective, in which the adequacy of concepts can only be judged in relation to the specific social conditions being inquired into (Blumer 1969, Hammersley 1989). Bourdieu himself makes a similar argument:

"Such notions as field, habitus and capital can be defined, but only in the within the theoretical system they constitute, not in isolation."

(Bourdieu & Wacquant 1992:96).

This section develops these concepts to provide a basic theoretical framework for the activities of PNs and peer supporters, and the contexts in which they operate. This framework is then developed and elaborated in section 5.3.

5.1.1 *Habitus*

Bourdieu's sociology aims to produce core concepts that are "...polymorphic, subtle and adaptable." (Bourdieu & Wacquant 1992:23) and which are therefore universally applicable. Rigid academic definitions are avoided, and key concepts are repeatedly reformulated and extended (Maton 2012). *Habitus* is described as:

"... systems of durable, transposable dispositions, structured structures predisposed to function as structuring structures, that is, as principles which generate and organize practices and representations that can be objectively adapted to their

outcomes without presupposing a conscious aiming at ends or an express mastery of the operations necessary in order to attain them.”

(Bourdieu 1990:53)

As the quote makes clear, *habitus* describes a tendency to behave in a particular way which may or may not be conscious, and which therefore does not require the imposition of a psychological framework to rationalise the relationship between the external world and the internal thought processes of the actor. Bourdieu rejects the idea that social institutions are experienced as external to the self, and thereby moves outside of earlier sociological frameworks which view society primarily in terms of the interaction between human agents and social structures (Bourdieu 1990, Grenfell 2012). *Habitus* incorporates the results of improvised action orientated towards achieving particular objectives, which eventually become relatively fixed. Once the disposition to act in a particular way is established, it becomes one of the factors which determine individuals’ experiences in the future.

For the purposes of the present study, it may be useful to differentiate between primary and secondary *habitus*. Primary *habitus*, acquired principally during early childhood through family relationships, is perceived as more durable and less flexible than secondary *habitus*, which is embedded during schooling (Bourdieu 1977, Walther 2014). The distinction between primary and secondary *habitus* is potentially useful in describing people’s abilities to adapt to serious illnesses or impairments. For example it has been argued that people born with impairments have a different capacity to respond to their social status as disabled people to those who acquire their impairments later in life (Oliver & Barnes 2012).

By the time that personal budgets were becoming a central focus of UK policy, people using health and social care systems were often thought of as having been inadvertently socialised into a state of dependency (e.g. Prime Minister’s Strategy Unit et al. 2005). This idea goes back to early deviance theorists such as Goffman (1961, 1963) and Lemert (1951), who were later credited with providing the kernel of the idea that people’s experiences of ‘disability’ could be shaped as much by internalised social attitudes as by the physical impact of their impairments (Oliver & Barnes 2012). Set against this was the mission of the Independent Living Movement, which advocated that people with experience of living

independently with their impairments were in the best position to support others to do the same (Evans 2002). The education and support role of PNs described in section 4.6.2 can be conceptualised in terms of supporting the emergence of a type of secondary *habitus* which encompassed the qualities necessary to manage one's own support.

5.1.2 Capital

For Bourdieu (1986) capital was always the product of labour, but this could manifest in cultural and social as well as economic forms. When reified or socially acknowledged any of these forms this could be described as symbolic capital, which produces higher social status (Bourdieu 1977, 1986). Bourdieu presents capital in a Marxian context, in the sense it cannot not be separated from or seen as 'real' other than as a part of a system of social relations. The primary theoretical purpose of capital is to describe the relational advantages and disadvantages of individuals and social groups within social systems, or 'capitalism' (Marx 1999). Bourdieu's (1977) empirical work on the French public school system concluded that the inter-generational dominance of the upper classes could not completely be accounted for by money (economic capital), and developed additional forms of capital to explain other types of advantage that were often hidden from view. This locates him within a wider group of human theory capitalists, whose main point of departure from Marx was that workers and communities could invest in developing their own attributes, trade them in the labour market, and gain a return on their investments (Lin 2001). In the present study, the development of skills allowing people to manage their own care and support can be seen as analogous to this. Disabled people have invested labour in developing the approaches such as independent living, which reduce dependence on institutional and other less favourable state supports.

Bourdieu (1896) proposes that labour can be invested in four principal types of capital. Firstly, there is cultural capital, which for the purposes of the present study can be thought of as resulting from the labour invested in developing approaches to managing personal budgets. Secondly, social capital derives from the work invested in developing and maintaining PNs, which allows individual personal budget users access to the knowledge and contacts of other network members. Economic capital in this context is mainly the

money required to sustain PNs and which allow them to provide people with support. Any of these types of capital could be referred to as symbolic when represented symbolically within a particular social field. The capacity to convert one form of capital into another is central to Bourdieu's scheme. For example investing economic capital in private schooling can produce the cultural capital that will enable the next generation to enjoy the same degree of privileged access to the highest paid jobs and their concordant social positions, allowing the social system to reproduce itself.

Cultural capital is described by Bourdieu (1986) as existing in three main forms:

institutional, objectified and embodied. Institutional capital is exemplified as the property rights of particular groups, which resonates with the legal right to a personal budget among those deemed eligible, or the right to access a peer support group where one possesses the characteristics that define 'peers' in that context. Objectified cultural capital is described as "...cultural goods (pictures, books, dictionaries, instruments, machines, etc.), which are the trace or realization of theories or critiques of these theories." (Bourdieu 1986). This could describe the web sites, Facebook pages, guides and support planning tools developed by PNs. Finally, cultural capital could be embodied in the form of *habitus*. The *habitus* of peer supporters encompassed both the knowledge and skills to live independently with a personal budget, and to help someone else to do the same. Because the concept of *habitus* spans conscious and unconscious dispositions, the cultural capital residing in PNs incorporates both the formal strategies and systems aimed at supporting personal budget users, and the wider but unformulated knowledge and experience of network members. It can incorporate dispositions gained through formal learning and improvisation, either in the context of managing one's own supports or helping someone else to do the same. The capacity to provide the support described in Chapter 4 is dependent on the cultural capital available within the peer network.

Bourdieu (1986) proposed the concept of social capital having noticed that people could gain very different advantages from the cultural and economic capital they possessed depending on the social networks available to them. Having impeccable manners and the money to pay for a private school education may be of significantly greater use if one plays golf with the Headmaster. In the present study, the benefits of PNs can be described in part

through the better access to other individuals and groups which they provide to their own members and service users. This can be seen particularly in the mediating role described in 4.7, where personal budget users were able to gain additional economic capital as the result of the cultural capital (knowledge about entitlement thresholds) available through the peer network.

“So I have a member who is very unwell, he spends the majority of time in bed, he was given three and a half hours support per day, and he needed more than that, so we had to support him to go to a lawyer, and now he has 24 hours plus waking nights...”

Female participant in paid role

5.1.3 Field

Social fields are social spaces within wider society differentiated from one another by varying social practices, and by different rules governing the way that *habitus* and capital interact. Bourdieu’s original (1977) concern was to explain how class-based interest groups continued to dominate different fields and perpetuate their own dominance (hegemony). Practice theory can consequently be thought of as a critical theory, as well as a theory of social reproduction (Calhoun 1993). Dominance is maintained partly because social processes such as the operation of capital are ‘misrecognised’ as value-free when they covertly promote the interests of dominant groups at the expense of others. In critical disability studies, the Bourdieusian concept of misrecognition has been developed to describe status injustices in which people with impairments are less valued, and the resulting maldistributive injustice in which they are deprived economically (Dodd 2016). PNs can be thought of as emerging social fields constituted around the common interests of members. These have formed partly to challenge injustice, operate with norms and values that prioritise lived experience above professional judgement, and promulgate empowering identities to replace the ‘disabling identities’ (Oliver & Barnes 2012) reproduced in mainstream society.

The existence of fields is tacit rather than explicit, and their boundaries and rules need to be established experimentally (Bourdieu & Wacquant 1992, Thomson 2012, Walther 2014). Collective and individual identities within social fields are hierarchical, and high status provides advantages by facilitating the exchanges of different forms of capital and legitimating social practices seen as the preserve of particular groups. Social care services prior to personal budgets have been described as operating a 'professional gift model' in which "...needy people are assessed by professionals to establish what kind of professional care is appropriate; this care is then provided by other professionals who are paid for by the first group." (Duffy 2012). The hierarchical field rules value the symbolic capital (job role, professional registration, qualifications etc.) of the care manager more than the lived experience (cultural capital) of the personal budget user. It is the different operation of capital that allows the dominant groups to maintain control. The absence of professional status and the explicit values of parity within user-led organisations can make the field rules of PNs different, although of course they do not preclude the existence of other forms of hierarchy. For example the focus groups revealed hierarchies between group facilitators and group members, between people with learning disabilities and physical impairments, and between people according to whether they'd been part of the original intake of the Independent Living Fund.

Within PNs, the lived experience (cultural capital) of peer supporters is often more highly valued than professional expertise, and the personal budget user retains formal control over economic capital (personal budget). Taking responsibility for managing a personal budget and working with a peer network to manage it can be thought of as moving capital from one social field into another, where it can be employed to greater advantage. Of course most personal budget users will continue to have ongoing contact with statutory health and social care services, and the management of this boundary is another important area in which PNs play an important role.

5.2 Developments of practice theory

Bourdieu's practice theory has been subject to numerous adaptations and extensions. This section gives an original elaboration and combination of five of these to account for the key findings of the study. Firstly, the incorporation of 'boundary objects' and 'boundary brokers' enables a more detailed depiction of the ways peer supporters operate across field boundaries (Eckert 1988, Wenger 1998, Kimble et al. 2010, Akkerman & Bakker 2011). This extends the theoretical basis for the mediating role reported in section 4.7. Secondly the division of social capital into bonding, bridging and linking functions enables a distinction between the various populations with which PNs interact (Gittel & Vidal 1998, Putnam et al. 1993, Putnam 2002, 2004, Szreter & Woolcock 2004). This provides for greater clarity about the different effects of peer identity when operating internally within a peer network, and between PNs and other organisations. Thirdly, Lavé and Wenger's (1991) application of the concept of 'scaffolding' can be used to highlight the relational aspects of the educational dimension of peer support. Similarly, the demarcation of emotional capital as a form of cultural capital (Nowotny 1981, Reay 2004, Cottingham 2016) can model the emotional dimension of peer support. Finally, Holland and others' (1998) socio-historical approach can be used to provide a more detailed account of cultural generation and reproduction of expertise in peer support and its relationship with identity formation.

5.2.1 Boundaries

Central to the notion of field is that people exist in multiple social fields (Bourdieu 1977, 1986). Peer supporters gave many examples of where they were able to operate effectively across PNs and statutory services, for example by framing people's support needs in such a way as to ensure their support plans were approved, or by helping statutory services design better systems. The concept of the 'boundary object' (Star & Greisemer 1989, Star 2010) was developed to describe artefacts that allow actors in overlapping fields to co-ordinate activity without consensus about its meaning or purpose. Boundary objects can be abstract, concrete or both, and have three key properties (Star & Greisemer 1989). Firstly, they must exist in at least two intersecting fields, and meet the informational needs of actors within both. Secondly to achieve this they may be weakly specified in a general sense, but more

strongly specified within specific fields. Finally, despite their different meanings in different social fields, they must have signifiers which make them recognisable across field boundaries. Many of the key documents in health and social care services might fulfil these criteria, but arguably the most important are the support plan and the personal budget, which sit the centre of the relationship between the state and the personal budget user.

In her work in American schools, Eckert (1988) highlighted the roles of particular students within a larger group of sport-oriented male students – ‘Jocks’ – who were able to operate simultaneously within their own social field and that of the school hierarchy:

“The Jock career aims at prominence in a hierarchy based on control of crucial school resources. These resources - space, information, freedoms, visibility, the right and the materials to organize a variety of social events - are ultimately controlled by school personnel and are distributed to the student body through student brokers. These brokers are Jocks who are sufficiently successful at dealing with adults to gain the confidence and cooperation of school personnel and who at the same time command a significant student network within which to trade these resources.”

(Eckert 1988:191)

Wenger (1998) integrated the idea of brokers (whom I shall term ‘boundary brokers’ to distinguish them from support brokers) into his thinking about boundary objects. Where boundary objects act as a focus around which actors in different fields can negotiate connections, the boundary brokers assist in the diffusion of practices across field boundaries. This requires a hierarchical identity in both fields of sufficient status to gain the attention of actors and address the conflicting priorities of both groups. In the present study, this relates to the mediating role played by peer supporters described in section 4.7. To operate effectively in the different fields of the peer network and health and social care systems, peer supporters did need sufficient status in both systems. Arguably they needed the credibility derived from their contact with personal budget users to have an influence

with the statutory sector, and their status as employees or volunteers within the network to have credibility with personal budget users.

Wenger (1988) stresses the ‘participative connection’ between the different social worlds and its capacity to generate innovation, an idea that has subsequently entered the mainstream of educational and organisational theory (Akkerman & Bakker 2011, Kimble et al. 2017). Some of the activities of peer support described by participants were statutory sector practices that peer supporters have ported into the field of PNs and reinterpreted, for example using driving lessons in place of a transport service. The focus groups also provided illustrations of practices moving in the other direction, for example when PNs provided training to social workers and students or developed support planning tools that were subsequently used by social workers.

5.2.2 Social capital

A commonly recognised problem with social capital theory is the wide disparity between scholars in the ways they define and apply the concept (Lin 2001, Szreter & Woolcock 2004). Putnam (2004) points to the near exponential growth in the number of academic studies using social capital as a framework, and links this to inevitable variations in terminology. Szreter and Woolcock (2004) argue that social capital belongs to a class of ‘essentially contested concepts’ which - like gender, social class and race - are too important for groups with different political and theoretical positions to concede to one another. This section will develop the concept of social capital in a way which is relevant to the present study, and which responds to some of the more common criticisms of the ways that others have applied it.

To be useful experimentally, Lin (2001) argues that social capital as social structure must be distinguished from social capital as resources accessible through that structure. Putnam (2004) makes a similar point, arguing for a theoretical separation between the norms of reciprocity – the main focus of his own analysis – and their consequences. Szreter and Woolcock (2004) use the metaphor of wires connecting different individuals and groups, and the electricity passing through them. Within the present study the resources passing

between and within PNs can be adequately conceptualised using economic or cultural capital, freeing up the concept of social capital to describe the norms and values of PNs, and the conditions for reciprocity between them and the other groups. This theoretical separation resolves another related conceptual problem, initially identified by Putnam (2002). If social capital is regarded as the labour invested in and accessible through a social network, how is it possible to differentiate between the investment and the immediate return ('consumption value') experienced as the improvement in wellbeing that often results from any social contact (Putnam 2002, Courtin & Knapp 2017, Duke 2017)? This can be resolved by conceptualising the emotional benefit of supportive social contact in terms of emotional capital, a type of cultural capital (see 5.3.3 below).

Putnam (2002) describes (rather than defines) social capital as "...social networks and the associated norms of reciprocity...". Values can be thought of as a sub-type type of norm, which the group holds as valuable. Historically, peer identity and the associated political values have been of central significance in defining the norms of reciprocity within PNs, for example in the 'Independent living principle' that disability services should be delivered by disabled people for disabled people (Evans 2002). This value is explicit in the rules of 'user-led organisations', but may also be implied in latent understandings of peer support. In the present context, social capital can be described as social networks and their associated norms and values of reciprocity.

Following Gittel & Vidal (1998), Putnam (2002, 2004) argues that different forms of social capital are necessary to explain the different norms governing access to resources within groups which are like one another in important respects ('bonding' social capital), and which those which act between dissimilar groups ('bridging' social capital). Within the current study, bonding social capital manifests principally in the norms and values of reciprocity that exist within PNs, and in the relationship between peer supporters and those being supported. Bridging social capital can be seen in relationships between PNs and different organisations and groups. Szreter and Woolcock (2004:65) propose a further division within bridging capital to differentiate between situations where identities are merely dissimilar and where they are "...interacting across explicit, formal or institutionalized power or authority gradients in society." They term this 'linking social

capital'. These three types of social capital can be applied directly to the types of interaction in Figure 9 (p.128). Relationships within PNs can be thought of in terms of bonding social capital, dealings with other PNs (and other charities and groups where there is no hierarchical relationship) can be depicted in terms of bridging capital, and relations with statutory bodies may be conceptualised in terms of linking capital. This relationship is depicted in Figure 10.

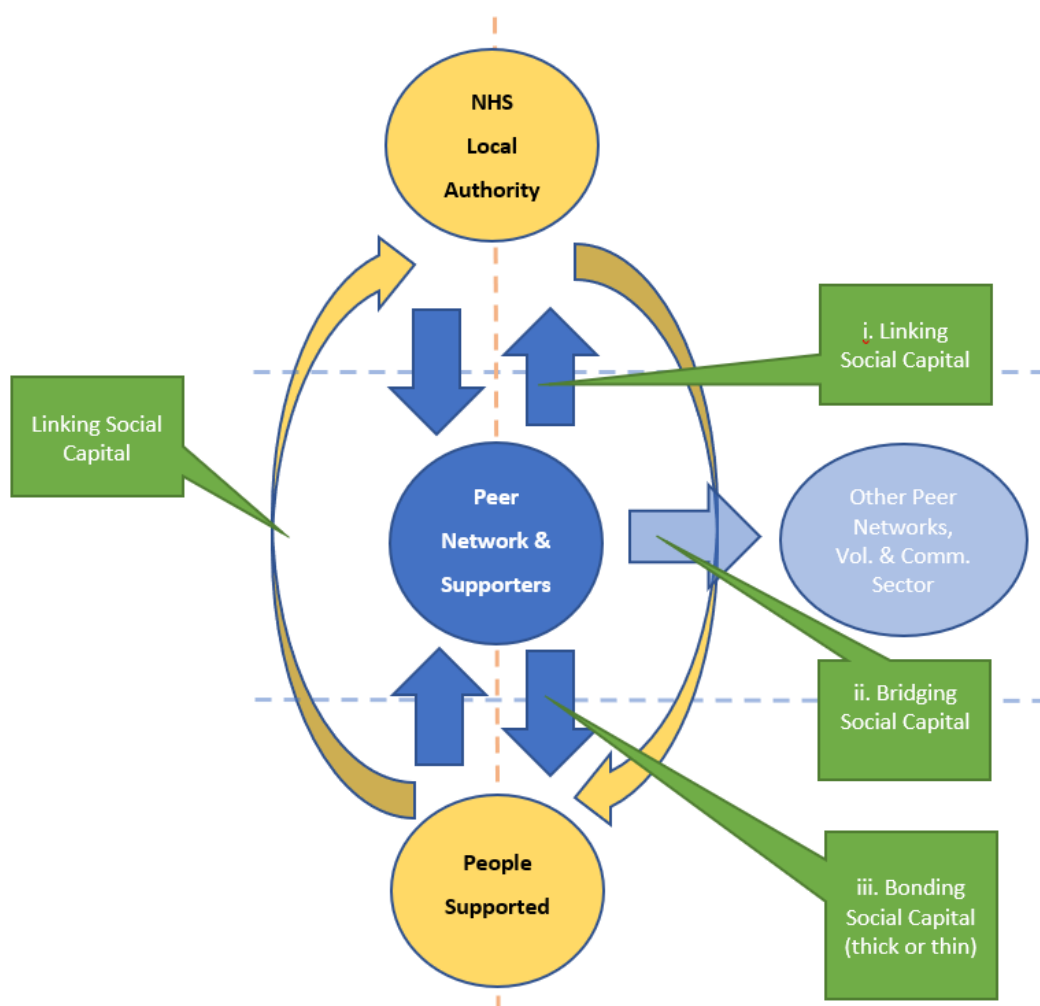


Figure 10: Peer networks and the different forms of social capital

Alongside the division between bridging and bonding capital, Putnam offers three other axes which form "...complementary lenses through which social capital might be understood and evaluated." (2002:9). Inward-looking and outward-looking social capital broadly correspond to bonding and bridging/linking. The axis between thick and thin social

capital describes the different extent of bonds forming, for example between people who have met regularly for many years as a peer support group, and between those who may have met once at a training event. This is useful here, because it is only thick social capital that is likely to allow the reproduction of the complex and sophisticated approached to independent living pioneered within PNs. The distinction between formal and informal forms of capital relates to whether the norms and values of reciprocity are explicit or implicit. This is a useful way of separating the formal expectations of access to support framed as commissioned services from discretionary resources that might be made available from one network member to another.

5.2.3 Scaffolding

In their work applying practice theory to apprenticeships, Lavé and Wenger (1991) described this process in terms of the entry of the apprentices into the social fields of their masters. By doing so, they are allowed to participate in the craft, through observation and imitation as well as instruction. Lavé and Wenger argue that treating learning as information acquisition risks eclipsing these social and relational aspects of the process. In their application of Bourdieu's practice theory, they borrow from Wood's concept of 'scaffolding' (Wood et al. 1976, Wood 1998). Within this model, the role of the educator is to perform a task with someone until they can do it for themselves, often providing instruction and explanation at the same time.

"So what I did was ... I went round with my support worker, and lent them for a few weeks until they became more confident."

Female participant in defined volunteer role.

The scaffolding is both the presence of the instructor and the theory or information that underpins the practice. This matches very closely with practices depicted by focus group participants, summarised in the description of tapering educational support in section 4.6.2.1. Lavé and Wenger (1991) highlight the cultural and social dimensions of the support provided, arguing that it is not only the person designated as the 'learner' who learns from

the process. New understandings can also accrue to the instructor (in this case the peer supporter) and hence pass into the shared social world of the peer network. The concept of scaffolding can therefore account not only for the educational support provided by PNs, but also for the way that networks can continuously learn from the process of provision. This theme is revisited in section 5.2.5, below.

5.2.4 *Emotional capital*

The focus groups showed how PNs provided emotional support alongside educational support, and emotional capital provides a way of theorising this. The use of the term in Bourdieusian practice theory was pioneered by Nowotny (1981) to describe the specific types of cultural capital operating predominantly in the private sphere through affective ties between family members. The concept was further developed by Reay (2004) to theorise mothers' emotional investments in the cultural capital of their children. Reay differentiates between forms of emotional capital along lines of race, social class and particularly gender. Emotional capital is used to describe the various types of nurturing of children from different class backgrounds in terms of their orientations towards academic achievement (cultural capital) and psychological wellbeing (emotional capital). Women from disadvantaged groups often experienced negative emotions, which Reay equated with negative emotional capital. Cottingham (2016) disagrees with this attribution, arguing that it is through experiencing emotionally difficult situations that women develop useful emotional management skills (cultural capital) that can then be activated in other situations. This provides a useful template for the way people with lived experience of impairments can develop emotional capital from their own experiences of adversity. Based on empirical work with male nurses, Cottingham (2016,2017) suggests that emotional capital can be developed through both primary and secondary socialisation, and uses professional learning as an example of the latter. In a similar way, emotional capital developed from people's own experience of illness or disability and can subsequently be consciously propagated through PNs.

In common with earlier theorists, Cottingham (2016,2017) sees emotional capital as residing in people who possess 'trans-situational' emotional knowledge, for example being

able to read emotional states, and understand the emotional and other responses being called for. For this knowledge to be practically advantageous to others and therefore be fungible with other forms of capital, it must be accompanied by skills such as an ability to manage others' emotional states, and one's own emotional state if this is affected. In the present study focus group participants gave many examples of where they were reading or anticipating other people's emotional needs, managing other people's emotional states, and of the emotional impact that this sometimes had on them (see section 4.6.2.2). Citing Thoits (2004), Cottingham (2016) highlights the importance of social emotions associated with role. There were many examples of social emotions in the present research, such as the shared frustrations of people unable to get the support they perceived was necessary, which called for empathy from other group members. Peer supporters gave examples of how they would manage their own emotions.

"... just remember when the person is really horrible to you, it's not personal. I can think of a few cases where I have, having gone the extra twenty miles, and then they just turn round and be really horrible. But you just have to say 'OK', that's where the person is, that doesn't mean that they're excluded, they can come back any time they want, within reason. Because when people are ill, people are grumpy, and when people are frightened, people get angry really."

Female participant in defined volunteer role

The unstated result was that she was able to continue to tolerate this person's attendance, meaning that the network retained its functionality in terms of channelling the other forms of capital.

5.3.5 Culture, identity and agency

In *Identity and Agency in Cultural Worlds*, Holland and her co-authors (1998) develop practice theory from a socio-historical perspective. Their presentation offers a more detailed theorisation of the process through which practices coalesce and are subsequently shared, and presents a more explicit model for the relationship between culture, identity

and agency. Among the major exponents cited in this chapter there is general agreement that culture and identity are simultaneously produced through social practice (Bourdieu 1990, Lavé and Wenger 1991, Holland et al. 1998, Wenger 1998). Holland and others (1998) describe social fields as 'figured worlds' in recognition that they are inhabited by people in mutually-defining social roles and positions. Figured worlds also contain 'cultural artefacts', which may be culturally specific understandings of physical objects or of more abstract ideas such as independent living. Identities are described as 'positional' to reflect what Bourdieu might have described as the field rules that enshrine privilege, and 'figured' in the Bakhtinian sense that they carry "...disposition, social identification, and even personification just as surely as they carry meaning." (Holland et al. 1998:271).

When a person enters a figured world, specific understandings of cultural artefacts already exist. The boundary objects described in 5.3.1 could all be considered as cultural artefacts. An example from the focus groups was respite care. There is an understanding of its purpose in the figured world of health and social care services, and a different understanding in the world of the peer network.

"... we had a guy came to see me recently ... and I said 'have you got respite' and he said 'Yeah, but I don't want that', and I said 'What do you mean you don't want it', and he said 'Well, I'm not going into any residential care home', and I said 'Well, that's fine, it doesn't mean that', and so he said 'What does it mean?' so he started talking to me and he said that he liked Rugby and he wanted to go to the Rugby finals in [City], I said what you do [man's name] is that you take your son as your PA, stay for the weekend at a hotel in [City], go to the Rugby, that would be cheaper than respite care anyway, the Council would be quite happy because you've saved them money, and you'll have a better option."

Male participant in paid role

The unique solutions devised when applying the current understanding to the different circumstances of each client change the understanding of the peer supporter, and

ultimately within the peer network. The learning process is social, and the understanding is historical because it is changed by every application, hence the theory is social-historical.

The focus groups showed cultural artefacts in various stages of development. Lying between the spontaneous improvised understandings and well-developed cultural artefacts such as person-centred support plans were memes and aphorisms that were moving from the individual into the collective realm. In one group, a female participant with significant lived experience of disability drew an analogy between the impact of a progressive chronic condition and moving home.

“ [If] ... your mobility is limited to whatever the person who can push you is, you suddenly lose familiar places and people whose faces you recognise on the street, so you have to re-start again. It may not sound like much but if you can't walk anywhere and you don't have a car, then it will be the same as moving from one town to another if you see what I mean, because it's all different.”

Female participant in defined volunteer role

It is easy to see how such an apt analogy could be repeated within PNs. A more widely known example is Miserdano's (2003) spoon theory, initially based on a single incident when the author used canteen cutlery to illustrate the relative disadvantages faced by people with impairments, but now with a much wider use.

The two previous sections developed the concepts of scaffolding and emotional capital to highlight the relational aspects of peer support, which could be linked with the roles of peer supporters. These social roles are themselves often pre-figured within the figured worlds of PNs, in the sense that the peer supporter will come into an organisation with other peer supporters, and while the roles and tasks associated with providing peer support may be formally specified, the understandings of what is expected may also be held at a cultural level. It is not only practice but also identity that is socially reproduced within PNs. Cain draws on her study of Alcoholics Anonymous to explain the interaction between identity formation and the use of cultural artefacts (Cain 1991, Holland et al. 1998). Through the

mechanism of listening to others tell their life stories and then telling their own using the same format, some of those attending support groups would take on new identities as 'non-drinking alcoholics'. Poker chips are used by group members to as a cultural artefact to record the time for which they have been sober. The act of picking up the poker chip at the end of the meeting represents both the deliberate use of the cultural artefact for the purpose of reinforcing the intention to stay sober, and a public affirmation of the role of 'non-drinking alcoholic' (Cain 1991). Within the present study the important cultural artefacts may be concepts such as respite care in the example above, or the assessment document.

"I think the first thing people have to realise is that everything's in place for them to be in charge. You talking about your Care Manager doing your assessment; well they can't, it's a self-assessment. You could have the assessment form downloaded, for a fortnight or even longer, and every day you assess yourself, and make notes ... So if you had your assessment for you to think about every day, and just made a little note just as you went along, you would have a far better assessment than what any Care Manager could give you, and it's you that's in charge."

Female Participant in defined volunteer role

The understanding of the cultural artefact within the peer network is explicitly empowering, and the process of learning how to use it presents an opportunity to take on a more empowered identity in terms of the relationship with statutory workers. In their work applying practice theory to apprenticeships, Lavé and Wenger (1991) describe learning in terms of the entry of the apprentices into the social fields of their masters. Cultures encompass systems of social relationship in which roles and activities have meaning. Learning therefore implies "...becoming a different person with respect to the possibilities enabled by this system of meanings." (1991:53). This accurately reflects the process of mutual learning described by peer supporters. Whilst the primary *habitus* of people with relevant lived experience may make it easier for them to take on the role of the peer supporter, there is nothing in this model which precludes the entry of others into the social world of the peer network, and into the role of peer supporter. Processes for

becoming a competent peer supporter and for developing as a capable a personal budget user can both be thought of in terms of identity acquisition within the social field or figured world of the peer network. Of course such transformations are not always possible. Cain (1991) gives examples of people who regularly attend AA meetings, often gaining benefits on their own terms without ever entering into the role of non-drinking alcoholics. Similarly, the model reported in section 4.6 shows varying levels of engagement and different effects resulting from them.

Holland and her colleagues (1998) describe two main aspects of the relationship between identify and agency. The first is derived from Bourdieu's concept of habitus, which is embedded through improvisation in relation to a task. The extent of improvisation is regulated by the prevailing cultural norms (Bourdieu 1977). Once mastery has been achieved, it can help the individual to gain personal advantage, although Bourdieu is cautious about the extent to which it can challenge patterns of disadvantage in the wider social system. Holland and others extend this idea further, giving an example of how women from a very patriarchal culture were able to re-purpose a traditional all-female singing festival by developing songs that challenged male privilege (Holland et al. 1998). This parallels many of the activities of PNs, such as the example of self-assessment on the previous page. The second process involves a more deliberate use of inner speech and particular types of cultural artefact termed 'mediating objects' to cultivate behaviours conducive to performing roles effectively (Holland et al. 1998). In the focus groups, this was evident in the ways peer supporters learned to manage their own behaviours in response to the demands of the role. Holland and her colleagues cite Hochschild's (1983) example of flight attendants learning to moderate their anger towards obnoxious passengers by imagining that it is caused by fear of flying. Arguably this example does not adequately communicate Vygotsky's original conception of mediating objects, in which mediating processes are improvised from cultural resources already available as within the user's social field (Wertch 1985). A better example might be the participant quoted above who reminded herself that "...when people are ill, people are grumpy..." in a successful attempt to moderate her own feelings, or the man who did extra unpaid work because he was "human being" who cared about disabled people. The approaches to peer support developed within PNs can be seen in terms of a simultaneous development of specific

approaches to peer support, social roles associated with using a personal budget and providing peer support, and human agency.

CHAPTER 6: CONCLUSIONS

This chapter will appraise the present study in terms of the goals of emancipation (Oliver 1996) and trustworthiness (Lincoln & Guba 1985, Guba & Lincoln 1989), before going on to describe its relevance as a development of Bourdieusian practice theory and the theory of independent living, and its potential implications for personal budget policy and person-centred practice.

6:1 Reflection on the limitations of the study

Several potential weaknesses have been discussed in the relevant methods section for the literature review (section 2.3, p.34) and focus groups (section 3.8, p.89). The main frameworks used to draw them together were Lincoln and Guba's concept of trustworthiness (Lincoln & Guba 1985, Guba & Lincoln 1989), and the concept of emancipation in disability research (Oliver 1996, Barnes & Mercer 1997). The extent to which research is emancipatory depends on its impact, as does the 'trustworthiness' criterion of tactical authenticity (Oliver 1996, Guba & Lincoln 1989). Emancipatory disability research also has the wider goal of changing the social relations of research production, by putting disabled people in charge of it (Oliver 1996). Where research participants are not in control of the research process, involving them in other ways can still be advantageous. Within the field of health and social care research there has been a growing consensus about the importance of involving service users, what this entails, and the potentially beneficial impacts for researchers, participants and service users (Boote et al. 2006, Staley 2009, Barber et al. 2010, Morrow et al. 2010). Turner and Beresford (2005) argue that is important to distinguish between research under the control of people who use health and social care services from that which merely involves them, although they note that both can be emancipatory in their effects. Within the resources available it was not possible to involve personal budget users as full partners in the present research. Although steps were taken to ensure that they had a voice during the development of the research question and the refinement of methods for focus groups, this was not carried forward in the facilitation of focus groups and the subsequent analysis.

Focus groups with two facilitators can have advantages, for example by multiplying the opportunities to pick up on subtle issues, generating additional insights during the debriefing process, and providing greater capacity to monitor the engagement of participants who are not speaking (Morrison-Beedy et al. 2001). Following research showing that evaluations led by mental health service users could draw out different and perhaps more honest feedback (Rose et al. 1998), others have developed focus group methods involving service users as facilitators or co-facilitators (e.g. Faulkner 2007, Kaehne & O'Connell 2010, O'Brien and Rose 2010). Running groups with a single facilitator missed the specific opportunity to include a peer-supporter in the research team as well as the more general benefits of a second facilitator. Methods have also been developed to include research participants in the process of analysis to varying extents, ranging from full participation (Leamy & Clough 2006) to choosing vignettes to illustrate themes derived by researchers (Ross et al. 2005). Such an approach was discussed at one of the advisory group meetings, but implementation proved impractical. Arguably a study with such a clear focus on lived experience should have made greater efforts to draw that experience into the process of analysis.

6.2 Implications for theory, policy and practice

The present study forms a part of a wider revival of interest in Bourdieu's work, particularly amongst researchers interested in social class, gender and inequality (Skeggs 2015, Savage 2016). It also offers another explanation alongside user-control for the advantages of support provided by PNs. The evidence from this and earlier studies suggests that PNs could play an important role in delivering current policy goals such as those set out in *The NHS Long Term Plan* (NHS England 2018). It is also likely that some of the practices developed by PNs and set out in this thesis could be useful to health and social care professionals, and other groups working with personal budget users.

6.2.1 Theoretical approach

The first question arising from the analysis of the focus group data was whether a single theoretical model could account for the way that PNs integrate learning from a range of

different sources to develop the coherent approaches to providing peer support reported in section 4.2. Bourdieu's (1977, 1986, 1990) practice theory was developed to provide such an account, by focusing on the practice of providing support. The habitus, or disposition towards acting in a particular way, is in a constant state of refinement through repeated performance of tasks associated with peer support, bounded by the cultural norms in place. The cultural norms operating within a PN, although defined differently in terms of the different understandings of 'peer', were usually determined by people in those groups (for example in their roles as founders, peer supporters and members of the governing bodies). PNs also had access to information available through other PNs, and contact with statutory services. It is therefore unsurprising that they should develop similar approaches to peer support, which can be thought of as cultural capital within Bourdieu's model. Within this model, the norms operating within PNs can be thought of as 'field rules'. The field rules operating within PNs were different to those of intersecting health and social care systems. Moving the economic capital (personal budget) from one field to another allowed it to be deployed in ways that were more congruent with people's life goals, partly explaining the benefits of peer support for personal budget users.

In campaigning for direct payments, the goal of the disabled people's movement was to capture the resources of the state and use them to resource independent living (Evans 2002, Glasby & Littlechild 2009). However locating this process within a market-oriented economic framework is problematic, for two main reasons. Firstly because of tensions between the individualistic emphases of free-market capitalism and the collectivist ideology of the disabled people's movement (Roulstone & Morgan 2009). Secondly because this risks responsibilising individuals for meeting their own support needs (Ferguson 2007, Lymbery 2012), providing legitimisation for cuts to adult social care budgets (Slasberg et al 2012). In contrast the Bourdieusian theoretical framework developed here locates the empowering potential of personal budgets explicitly within a collective context, and shows how cuts to social care and other budgets have constrained it. Firstly, practice theory is used to show how peer supporters and peer networks developed the conceptual tools to enable personal budget use within social systems. Secondly the norms and values of reciprocity (social capital) are applied to explain how PNs reproduce these tools internally and externally, and how they collaborate with others to achieve the wider systemic conditions necessary for

personal budgets to work effectively. Thirdly Bourdieu's wider theory of capital is used to model the responses of PNs to disinvestment in adult social care and other forms of social protection, and to show how this is reducing the cultural capital within PNs and in the wider health and social care system. In the past decade Bourdieu's theories have enjoyed a resurgence amongst academics interested in inequalities in gender and social class (Skeggs 2015, Savage 2016), and this is now filtering into disability studies (Byrne 2018). This thesis can be thought of as making a theoretical contribution to these developments.

In the 1980s and 1990s the first two English CILs adopted different approaches to independent living, one based on expertise around direct payments and the other providing a list of specific services designed to meet various types of 'basic need', including peer support (Evans 2002). This early fork in the road was followed by extensive debates about the essential features of CILs which often confounded research that aimed to link these features with the effects claimed for them (Barnes et al. 2000, Maynard-Campbell et al. 2007, N Campbell et al. 2011). The theoretical model developed in the present study provides a potential explanation for several apparently paradoxical results from earlier studies, including how effective 'peer support' can be provided by people who are not themselves 'peers' in the sense being used within individual PNs (Glendinning et al. 2008, N Campbell et al 2011), and how approaches to support based on cultural understandings held within PNs can still be effective even when personal budget users do not share them (Roulstone & Morgan 2009). Practice theory as developed in this thesis acknowledges that peer supporters with relevant lived experience may have a greater intuitive sense of the role of peer supporter, embodied in their own primary *habitus*. But the role of peer supporter itself is largely embedded through the process of providing peer support, meaning that those who have not experienced illness or disability can also learn how to fulfil it. Social processes operating within PNs guide this process and then allow the social reproduction of the roles and the associated skills and knowledge. Through applying these in practice peer supporters learn how to empower personal budget users, and personal budget users learn how to manage their own care and support. This thesis therefore offers a supplementary explanation for the benefits of services provided by user-led organisations that does not depend on peer support being provided exclusively by people with relevant lived experience, or organisational control by user groups.

6.2.2 Implications for policy

Section 4.7 (p.136) reported that in order to provide peer support, networks had to manage complex sets of relationships with members and personal budget users, with statutory agencies and with other PNs. These were conceptualised in terms of the different types of social capital resulting from the labour invested in the relationships (see Figure 10, p.156). The norms and values of reciprocity within these different types of relationship were often in tension with one another. For example personal budget users expectation of fearless advocacy could be in tension with the local authority's expectations as the commissioners of the service. Individual PNs managed these tensions differently, and the situation was dynamic. However at all three focus groups there were discussions about funding cuts and the impact they were having. A key element of Bourdieu's (1977, 1986) theory of capital is that the different forms of capital can be exchanged for one another. For example, the funding of meeting rooms and administrative support (economic capital) helped local groups of personal budget users to meet (social capital), and provide learning about personal budget systems that could be used within PNs and fed back to commissioners (cultural capital). Participants described a consistent pattern of reduced economic investment, for example in the funding for PNs, in the time given to statutory workers to prepare support plans, and in the amounts of money available to people as personal budgets. Each of these corresponded to a reduction in the other forms of capital in the system, whether this was the availability of peer support, the knowledge-base of statutory sector staff or the good will between PNs and statutory bodies.

The successes of the UK disabled people's movement in pressing for disability rights and independent living in the previous decade seems to have undergone significant reverses under the austerity policies of successive governments since 2010 (Morris 2014, Leonard Cheshire 2016). Recently senior figures within the disabled people's movement have raised concerns about the rate at which user-led organisations are closing (Leicester Centre for Integrated Living 2018, Beresford 2019). Perversely this appears to be happening at the same time as the English NHS is planning significant increases in the numbers of people able to access PHBs as part of a strategy that also involves extending personalised

approaches to care and peer support (NHS England 2017a, 2019). The present study has shown that the skills to support PB and PHB are embedded in the cultures of PNs, and that providing the economic capital to sustain them can have significant benefits both in terms of improved support for personal budget users and of the wider system changes necessary to help people live independently. Conversely the failure to resource them is pushing surviving PNs into more adversarial relationships with local statutory bodies and is resulting in the loss of valuable cultural capital, often developed at significant expense to the state during the previous decade (Community Care 2003, Department of Health 2007, 2010).

6.2.3 *Implications for practice*

Whilst frequently conceptualised in terms of information about using personal budgets, peer support also had educational and emotional dimensions, the positive qualities of which were associated with support provided by peers. Lavé and Wenger's (1991) description of 'scaffolding' matches the additional but typically temporary instruction and support that personal budget users need to perform certain tasks effectively. Cottingham's (2016) elaboration of emotional capital can be applied to describe peer supporters' anticipation of the emotional needs of personal budget users and concurrent management of their own emotional states. Both of these processes can be applied more widely than in PNs, for example by health and social care workers who are often the first point of contact for new PB users. Cottingham's (2017) research has shown that emotional capital of nurses could be enhanced by training. The socio-historical extension of practice theory (Holland et al. 1998) provides further detail about how cultural artefacts, for example specific cultural constructions of concepts such as respite and self-assessment, can emphasise control and choice by the personal budget user. Again these artefacts can be reproduced outside of PNs and applied effectively by others. The practice theory developed in the present study emphasises the increased effectiveness of learning by doing together. This suggests that approaches exemplified in the focus groups such as involving PNs in education and training, developing practice placements for student health and social care professionals within PNs, and structuring local collaborations between PNs and statutory bodies, can all be effective in helping people working outside PNs to improve the way they support PB users.

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APPENDIX 1: LITERATURE REVIEW

Table A1:1 Codes used for studies in following tables

Code	Full Reference
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6	Williams V, Porter S and Marriott A (2014) Your life, your choice: support planning led by disabled people's organisations. <i>British Journal of Social Work</i> 44(5) pp.1197–1215
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N001	Stainton T and Boyce S (2004) 'I Have Got My Life Back': Users' Experience of Direct Payments. <i>Disability & Society</i> 19(5) pp.443–454
N002	Gramlich S, McBride G, Snelham N et al. (2002) <i>Journey to Independence: What self-advocates tell us about Direct Payments</i> . Kidderminster: British Institute of Learning Disabilities.
N004	Beresford P, Fleming J, Glynn M, et al. (2011) <i>Supporting People: Towards a Person-Centred Approach</i> . Bristol: The Policy Press
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N006	Gardner A (1999) <i>Making Direct Payments a Reality for People with Learning Disabilities</i> . Clitheroe: NWTDT
C014	Stainton T, Boyce S and Phillips C J (2009) Independence pays: a cost and resource analysis of direct payments in two local authorities. <i>Disability & Society</i> 24(2) pp.161–172
A009	Maglajlic R, Brandon D and Given D (2000) Making direct payments a choice: a report on the research findings. <i>Disability and Society</i> 15(1) pp.99-113
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Table A1:2 Geographical focus of studies, and periods in which research was conducted

	England	Wales	Scotland	NI
First Period				
A009	Y	N	N	N
77	Y	Y	Y	Y
122	Y	N	N	N
136	Y	N	N	N
152	N	N	Y	N
210	N	N	Y	N
371	Y	N	N	N
N001	N	Y	N	N
N002	N/A	N/A	N/A	N/A
N006	Y	N	N	N
C014	N	Y	N	N
Second Period				
43	Y	Y	N	N
133	Y	N	N	N
178	Y	Y	N	N
197	Y	N	N	N
198	Y	N	N	N
203	Y	N	N	N
205	Y	Y	Y	Y
209	Y	Y	Y	Y
211	Y	N	N	N
257	Y	N	N	N
298	Y	N	N	N
358	Y	N	N	N
365	Y	N	N	N
662	Y	Y	Y	Y
A016	Y	Y	Y	Y
Third Period				
2	Y	N	N	N
6	Y	N	N	N
16	Y	N	N	N
29	Y	N	N	N
33	Y	N	N	N
54	Y	Y	N	N
65	Y	N	N	N
76	Y	N	N	N
150	N	N	Y	N
153	N	Y	Y	Y
173	Y	N	N	N
185	Y	N	N	N
192	Y	N	N	N
262	Y	N	N	N
263	N/A	N/A	N/A	N/A

414	Y	N	N	N
457	N	N	Y	N
N004	Y	Y	Y	N
N005	Y	N	N	N

Table A1.3 Appraisal of qualitative studies using COREQ (Tong et al. 2007)

Study No.	2	6	16	29	33	43	54	76a	122	136	152a	173	178	185a	192	198a	203
D1 Totals	1	5	2	3	0	1	2	0	5	3	2	0	3	3	2	0	2.5
Domain 1: Research team and reflexivity	1	0	0	0	0	1	0	0	0	0	0	0	1	0	0	0	0
	2	0	1	0	0	0	0	0	1	0	0	0	0	0.5	0	0	0.5
	3	0	1	1	0	0	1	0	1	1	1	0	1	1	1	0	1
	4	0	1	0	0	0	0	0	1	1	0	0	1	1	0	0	1
	5	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	6	1	1	1	0	0	1	0	1	1	1	0	0	0	1	0	0
	7	0	0	0	0	0	0	0	0	0	0	0	0	0.5	0	0	0
	8	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0
D2 Totals	9.5	8	5	10	2.8	0	2	5	7	6	8	6	5.5	3.5	11	8	3
Domain 2: study design	9	1	1	0	0	0	0	0	1	0	0	0	0	0	1	1	0
	10	1	1	1	1	0	1	1	1	0	1	1	1	1	1	1	1
	11	1	1	0	0.3	0	0	1	1	1	1	1	0	0	0	0	0
	12	1	1	1	1	0	1	1	1	1	1	1	1	1	1	1	1
	13	1	1	0	0	0	0	0	0	0	0	0.5	0.5	0.5	1	1	0
	14	0	0	1	0	0	0	1	1	1	1	0	0	0	1	0	0
	15	1	0	1	0.2	0	0	0	1	0	0	0	0	0	0	0	0
	16	1	1	1	0.3	0	0	1	0	0	1	0	0	0	1	1	1

Study No.	209	210	211	257	262	263	298	358	365	371	414	457	N001	N002	N004	N005	A009	A016
D1 Totals	0	2	1	0	3	6	1	1	2	5	4	2	5	2	3	2	1	0
Domain 1: Research team and reflexivity	1 0	0 0	0 0	0 0	0 0	1 0	0 0	0 0	0 0	1 0	0 0	0 0	1 0	0 1	0 1	0 0	0 0	0
	2 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	1 1	1 1	1 1	0 1	0
	3 0	1 0	0 0	0 0	1 0	1 0	0 0	0 0	1 0	1 0	1 0	0 0	1 0	0 0	0 0	0 0	0 0	0
	4 0	1 0	1 0	0 0	0 0	1 0	1 0	0 0	1 0	1 0	0 0	0 0	1 0	0 0	0 0	0 0	0 0	0
	5 0	0 0	0 0	0 0	1 0	0 0	0 0	0 0	0 0	0 0	1 0	1 0	0 0	0 0	0 0	0 0	0 0	0
	6 0	0 0	0 0	0 0	0 0	1 0	0 0	0 0	0 0	1 0	1 0	1 0	1 0	0 0	1 1	1 1	0 0	0
	7 0	0 0	0 0	0 0	0 0	1 0	0 0	0 0	0 0	1 0	1 0	0 0	1 0	0 0	0 0	0 0	0 0	0
	8 0	0 0	0 0	0 0	1 0	1 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0
D2 Totals	6	7	7	2	7	1	3	3	7	4	5	8	9	2	9	6	4	6
Domain 2: study design	9 0	0 0	0 0	0 0	1 0	0 0	0 0	0 0	1 0	0 0	0 0	0 0	1 0	0 0	1 1	1 1	0 0	0
	10 1	1 0	1 0	1 0	1 0	0 0	1 0	0 0	1 0	1 0	1 0	1 0	1 0	1 0	1 0	0 0	1 1	1
	11 1	1 0	1 0	0 0	1 0	1 0	1 0	0 0	1 0	1 0	1 0	1 0	1 0	0 0	1 0	0 0	0 0	1
	12 1	1 0	0.5 0.5	1 0	1 0	0 0	1 0	0 0	1 0	1 0	1 0	1 0	1 0	0 0	0 0	1 1	1 1	1
	13 0.5	1 0	0.5 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0.5
	14 0.5	1 0	1 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	1 0	1 0	0 0	0 0	0 0	0.5
	15 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0
	16 1	1 0	1 0	0 0	1 0	0 0	0 0	0 0	0 0	0 0	0 0	1 0	1 0	0 0	1 1	1 1	0 0	1
	17 0	1 0	1 0	0 0	1 0	0 0	0 0	1 0	1 0	0 0	1 0	1 0	1 0	0 0	1 1	1 1	1 1	0
	18 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	1 0	1 0	0 0	1 0	0 0	0 0	1 1	1 1	0 0	0
	19 1	0 0	0 0	0 0	1 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	1 0	0 0	1 1	1 1	1 1	1
	20 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	1 0	0 0	0 0	1 0	1 0	0 0	1 1	0 0	0 0	0
	21 0	0 0	0 0	0 0	0 0	0 0	0 0	1 0	0 0	0 0	0 0	1 0	0 0	0 0	0 0	0 0	0 0	0
	22 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0 0	0
	23 0	0 0	1 0	0 0	0 0	0 0	0 0	1 0	0 0	0 0	0 0	0 0	0 0	0 0	1 0	0 0	0 0	0

D3 Totals	4	5	4	3	3	0	3	3	5	5	5	4	7	2	6	4	3
Domain 3: analysis and findings	24	0	0	0	0	0	0	0	0	0	1	0	1	0	0	0	0
	25	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0
	26	1	1	1	1	0	0	0	1	0	1	1	1	0	1	1	0
	27	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0
	28	0	0	0	0	0	0	0	1	1	0	0	0	0	1	0	0
	29	0	1	0	0	0	1	1	1	1	0	0	1	0	1	1	0
	30	1	1	1	1	0	1	1	1	1	1	1	1	0	1	1	1
	31	1	1	1	1	0	1	1	1	1	1	1	1	1	1	1	1
	32	1	1	1	0	0	0	0	0	1	0	1	1	1	1	0	1
Total	10	14	12	5	13	7	7	7	14	14	14	14	21	6	18	9	9
Total (%)	31%	44%	38%	16%	41%	22%	22%	22%	44%	44%	44%	44%	66%	19%	56%	28%	28%

Table A1:4 COREQ Criteria, domains and sub-domains (Tong et al. 2007)

Domain 1: Research team and reflexivity			
Personal Characteristics	1	Interviewer/facilitator	Which author/s conducted the interview or focus group?
	2	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>
	3	Occupation	What was their occupation at the time of the study?
	4	Gender	Was the researcher male or female?
	5	Experience and training	What experience or training did the researcher have?
Relationship with participants	6	Relationship established	Was a relationship established prior to study commencement?
	7	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>
	8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>
Domain 2: study design			
Theoretical framework	9	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>
Participant selection	10	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>
	11	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>
	12	Sample size	How many participants were in the study?
	13	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting	14	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>
	15	Presence of non-participants	Was anyone else present besides the participants and researchers?
	16	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>
Data collection	17	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
	18	Repeat interviews	Were repeat interviews carried out? If yes, how many?
	19	Audio/visual recording	Did the research use audio or visual recording to collect the data?

	20	Field notes	Were field notes made during and/or after the interview or focus group?
	21	Duration	What was the duration of the interviews or focus group?
	22	Data saturation	Was data saturation discussed?
	23	Transcripts returned	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findings			
Data analysis	24	Number of data coders	How many data coders coded the data?
	25	Description of the coding tree	Did authors provide a description of the coding tree?
	26	Derivation of themes	Were themes identified in advance or derived from the data?
	27	Software	What software, if applicable, was used to manage the data?
	28	Participant checking	Did participants provide feedback on the findings?
Reporting	29	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i>
	30	Data and findings consistent	Was there consistency between the data presented and the findings?
	31	Clarity of major themes	Were major themes clearly presented in the findings?
	32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?

APPENDIX 2: FOCUS GROUPS

A2.1. Ethics Committee Approval



Dr Jane Appleton
Director of Studies
Department of Psychology, Social Work and Public Health
Faculty of Health and Life Sciences
Oxford Brookes University
Marston Road

8 June 2015

Dear Dr Appleton

UREC Registration No: 150925
How do peer networks enable service users and informal carers to obtain and manage a personal budget?

Thank you for your email of 4 June 2015 outlining your response to the points raised in my previous letter about the PhD study of your research student Jon Hyslop and attaching the revised documents. I am pleased to inform you that, on this basis, I have given Chair's Approval for the study to begin.

The UREC approval period for this study is two years from the date of this letter, so 8 June 2017. If you need the approval to be extended please do contact me nearer the time of expiry.

Should the recruitment, methodology or data storage change from your original plans, or should any study participants experience adverse physical, psychological, social, legal or economic effects from the research, please inform me with full details as soon as possible.

Yours sincerely

Hazel Abbott
Chair of the University Research Ethics Committee

cc Helen Aveyard and Guida de Abreu, Supervisory Team
Jon Hyslop, Research Student
Jill Organ, Research Degrees Team
Louise Wood, UREC Administrator

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A2.2 Background Information Questionnaire

Section A: Demographic Information

The information in this section will be used to create a profile of participants to compare discussion groups with one another, and compare participants as a whole with the general population and with people who use personal budgets. Categories have been taken from the 2011 census.

Some of these questions may seem personal. If you prefer not to answer then please leave them blank.

1. Ethnicity

Please tick the box which best describes your ethnic background

White	
1. English/Welsh/Scottish/Northern Irish/British	☐
2. Irish	☐
3. Gypsy or Irish Traveller	☐
4. Any other White background	Please describe here:
Mixed/Multiple ethnic groups	
5. White and Black Caribbean	☐
6. White and Black African	☐
7. White and Asian	☐
8. Any other Mixed/Multiple ethnic background	Please describe here:
Asian/Asian British	
9. Indian	☐
10. Pakistani	☐
11. Bangladeshi	☐

12. Chinese		
13. Any other Asian background	Please describe here:	
Black/ African/Caribbean/Black British		
14. African		
15. Caribbean		
16. Any other Black/African/Caribbean background, please describe	Please describe here:	
Other ethnic group		
17. Arab		
18. Any other ethnic group, please describe	Please describe here:	

2. Sex

1. Male	
2. Female	

(Respondents to the 2011 census who did not regard themselves as male or female were advised to tick both boxes).

3. How is your health in general?

Very good	
Good	
Fair	
Bad	
Very bad	

4. Long-term illness and disability

Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? (Please include problems related to old age).

Yes, limited a lot	
Yes, limited a little	
No	

5. Age group

18 – 19	
20 – 24	
25 – 29	
30 – 34	
35 – 39	
40 – 44	
45 – 49	
50 – 54	
55 – 59	
60 – 64	
65 – 69	
70 – 74	
75 – 79	
80 – 84	
85 – 89	
90 and over	

Section B: Your Organisation and Role

The information you provide will help us to compare your views and experiences with those of other people in similar roles, or working in similar organisations. Categories have been taken from existing research on support for people using personal budgets.

6. Your organisation

a. Name

What is the name of your network or organisation?

b. Which of the following best describes the organisation you work or volunteer for:

Disabled people's organisation, or user-led organisation.	
Charity	
Community Interest Company, Co-operative or Social Business	
Club, society or informal network	
Other (please describe)	

c. What best describes the main focus of your organisation's activity?

Supporting people with a specific illness or impairment.	
Supporting people in a particular geographical area.	
Supporting people with specific processes or tasks.	
Other (please describe)	

7. Your role

a. Is your role:

A paid job	
A volunteer role	
What is the title of your job/role?	

b. What is your involvement in helping people with a personal budget to plan their own care?

This is the main focus of my role	
This is a part of a larger role	
Please give a brief description of your role.	

c. The support you provide

Please rank the following tasks in terms of the proportion of time which you spend doing them (1= most time, 2= second most time etc.)

Raising awareness of the service or organisation, and telling people what you do.	
Being the first point of contact for people, and helping them gain access to a personal budget.	
Helping people to develop a support plan.	
Helping people to put a support plan into place.	
Helping people to manage their support on an ongoing basis.	

d. The medium through which support is provided

Please rank the following in terms of the proportion of your contacts with personal budget users (1= most contacts, 2= second most contacts etc.)

Face-to-face	
Over the 'phone	
Through electronic media (text, email, online forum etc.)	
Post	

A2.3 Participant Information Sheet

Dear <type recipient's name here>

How Do Peer Networks Enable Service Users and Informal Carers to Obtain and Manage a Personal Budget?

I am writing to ask whether you would like to participate in a research study investigating the usefulness of peer support for people using personal budgets to plan their own health and social care support. This would involve taking part in a group discussion, and completing a short background information questionnaire.

Whether or not you participate is completely up to you. Please read the following information, which may help you make up your mind.

Background

As you may know, peer support has been available to some users of personal budgets since the original direct payment support schemes of the 1990s. After local authorities were obliged to make support available in the last decade, a wide variety of different organisations have developed different types of support. The main aims of the research will be to look at the different ways in which support is provided, and the advantages that these may have for people at different stages of obtaining or managing a personal budget.

The group discussions

The study is aiming to recruit around 50 people in total to take part in group discussions about their experiences of providing support to people using personal budgets. Four groups are currently planned – two in XXXX and two in XXXX

[Details of venues, times, dates and locations will be inserted here]

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If you decide you would like to participate, you will be asked to complete a short questionnaire in advance (this should take no more than 15 minutes). The discussion groups themselves will last approximately 1.5 hours, with a short break in the middle if needed. You will be provided with a short summary a couple of weeks after your group has taken place. This is so you can say if you think I have misunderstood anything you or the other participants have said, and let me have any additional comments about the subject.

We are able to pay for travel expenses, and if you decide to participate I will send you details about what you can claim for. Unfortunately I am not able to pay for overnight accommodation or for your time. If you need additional help in order to participate, for example because of an illness or impairment, then please let me know.

In the discussions

Only people in paid or defined voluntary roles are being asked to participate at this stage of the study. Discussions will focus on the work people do helping others to plan and manage personal budgets. Some participants may have their own experiences of using health or social care services, which they may choose to introduce as a part of the discussion. You may want to consider in advance whether you are happy to share this kind of information.

Life-changing illness and disability are serious subjects, and sometimes arouse strong feelings. Participants will be encouraged to respect one another's views, even where they strongly disagree with what is being said. I am an experienced facilitator with more than 20 years' experience of similar discussions. I will intervene if I think participants are challenging one another too harshly, and will be available after the group finishes if anyone becomes distressed and would like additional support. However, I do not think this is very likely. It is my experience that people generally enjoy the opportunity to take time away from the workplace, reflect on their roles and talk to other people who may be doing similar work in a slightly different context. I am hoping to recruit people from a diverse range of organisations, but would be happy to have two representatives of your organisation if you would like to

bring a colleague for moral support. Just let me know and I will invite her or him. Similarly if you are aware of other groups or organisations that might want to take part, please do let me know.

Confidentiality

Group discussions will be audio recorded and eventually transcribed and analysed. Recordings and transcripts will be stored electronically in a secure area of the University's computer system. All data will remain confidential (within the limitations of the law). Your name and background information will be stored separately, so that the only people who will be able to identify you will be members of the project team. I may use quotations from the discussions in publications stemming from the research; I will not identify you, but other people (e.g. colleagues from within your own organisation) may be able to guess it was you. If you want to participate; you can still decide to pull out at any time. However after the groups have taken place, it will not be possible to withdraw your comments, as this would affect the coherence of the discussion.

Once anonymised, data may be used for other projects and will be retained for a period 10 years, in line with the University's Code of Practice for Academic Integrity. These arrangements have been approved by the University Research Ethics Committee. If you have concerns about the way your data is being stored or used, or any other concerns about the way the project is being conducted, you can contact the Chair of the University Research Ethics Committee directly at ethics@brookes.ac.uk, or my research supervisor, Dr. Jane Appleton (jvappleton@brookes.ac.uk, Tel: 01865 482606)

After the discussions

The research itself could have a range of possible benefits. Firstly, I hope it will extend existing evidence of how peer support can be especially valuable for personal budget users. Research evidence can help to inform policy at a number of levels, for example national government, local government and individual organisation. Secondly, I hope the research will also inform training and education

for people doing similar jobs to the one you do. Finally I hope that the research will help to develop theory that explains the usefulness of peer support. There is a great deal of interest in peer support in a range of other health and social care settings, and I hope that this research will be useful to colleagues working in these areas.

I currently teach social work and healthcare students, and also work for a Community Interest Company that has provided free training on personal budgets. In both of these roles I am in a position to make use of the findings to improve the training available to those supporting personal budget users. I hope to publish the findings in academic journals. This research is being undertaken as a part of a programme of postgraduate study that will culminate in a published thesis. I will be producing a newsletter at intervals throughout the project that will provide easy access to any preliminary findings. I would be happy to add you to the circulation list whether or not you would like to participate in the focus groups – just let me know.

Thank you for taking the time to read through all this. If you would like to participate, please contact me by email, phone or post. You can still decide to pull out at any time. I am enclosing a blank consent form that I will ask you to complete immediately before the focus group (I'll bring spare copies).

If you have any other questions, please do get in touch.

Yours sincerely

Jon Hyslop

Postgraduate Research Student

Department of Psychology, Social Work & Public Health

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A2.4 Focus Group Schedule

- Thank participants.
- Ask participants to introduce themselves, and say how long they've been working on personal budgets.

Introductory

Ask participants to explain how the organisation/group/service they represent supports people who use personal budgets.

Transition

Ask participants about the way they think 'peer support' differs from support provided by health or social care professions.

Key questions

Prompt discussions about peer support at different stages of the support planning process.

Before contact

- Are many of the people you support already linked with disability or voluntary organisations by the time you come into contact with them?
- Why do people come to you for help with personal budgets?
- Have you had any contact with the people you support in other contexts before you help them with personal budgets?

Assessment

- Do you do any work supporting people with self-assessments?
- Do you support people with local authority or NHS assessments?

- How does peer support help people at the assessment stage?

Support planning

- What have been the benefits and drawbacks of having people from peer support organisations and groups involved with support planning and 'brokerage'?
- What are the differences between peer support and support offered through providers or through the NHS/local authority?

Ongoing support

- Do you provide ongoing support, or only support at particular stages?
- How can peer support help people who are managing their own care?
- Do you come into contact with people who need help with employing or managing personal assistants?
- As peer supporters, what kind of relationship do you have with the NHS/local authority?

Ending questions

- In what ways could peer support provide personal budget users with better help?

Closure

- Thank participants.
- Explain what happens after this focus group (summary for comments, transcription, analysis).
- Explain next stage of research and recruitment/selection process.
- Reiterate process for claiming expenses.

APPENDIX 3: REFLEXIVE STATEMENT

Personal and professional identity in organisational contexts

I have worked in health and social care services since 1988. Other than some intermittent volunteering, my first significant experience of this type of work was as an Occupational Therapy Helper in a psychiatric hospital. I was surprised to be asked in interview “What would you think if we asked you whether the best place to hide a tree was in the woods?”. To extend the botanical analogy, there was a clear intention to ‘weed out’ people who conceptualised themselves as being mentally ill. Having experienced mental distress (but not hospitalisation) I struggled to find an authentic response that reflected both my confidence in my ability to do the job and my previous life experience. I have chosen this example from many similar situations where I have had to consciously navigate between the social fields of my work and personal life. This dichotomy, which has been a conscious consideration for over thirty years, inevitably informs my perspective on the professional and personal dimensions of peer support.

During my early (pre-qualifying) working in psychiatric hospitals, I found that my own experiences could help me form empathic bonds with patients, which could in turn yield clinical benefits. I also learned that too much self-disclosure put me at risk of manipulation or even threats. I took a year-long introductory course in group analytic psychotherapy, and through participation in therapeutic groups became conscious of the way that I often positioned myself in a dual role between authority figures and those over whom authority was exercised, which was congruent with my being an oldest child. Combined with my experience of facilitating therapeutic and activity groups, this course gave me a grounding in the theory and practice of group facilitation which informs my style as a focus group moderator and underpins my understanding of dynamics within the group. During this stage I was particularly influenced by the work of S.H. Foulkes (1964), W.R. Bion (1961), and R.D. Laing (1960, 1964).

My qualifying postgraduate course in Applied Social Studies (Social Work) gave me an important opportunity to apply theory to reflect on my previous roles. I was introduced to

sociology and organisational theory, which helped me to form a theoretical view of my previous experiences, and I can retrospectively summarise this in terms of three linked groups of insights. Firstly, from sociology I learned how deviance can be socially constructed, enforced and amplified (Lemert 1951, Goffman 1961, Becker 1973), which gave me an insight into the roles that professionals and hospital systems can inadvertently play in creating 'mental illness'. Secondly, I started to appreciate the mechanisms through which power and organisational structure impacted on behaviour and identity (Morgan 1986) which helped me to understand how mental health services organised as community teams rather than hospital hierarchies could create a potentially more empowering structure. Finally I learned how social policies (and the economic, social and political environments from which they emerged) could loosen the bureaucratic bonds which structured state welfare (Jordan 1987), and as a result increase the scope for providing meaningful mental health support.

My theoretical excitement at the emancipatory potential of statutory community mental health services was unfortunately not borne out in practice. Being asked the same 'woods in trees' question by the same human resources manager in one interview was not a good sign. The introduction of 'supervision registers', the re-centralisation of budgetary control, and guidance that led to unmet need being omitted from assessment documentation were amongst the early casualties during the implementation of the National Health Service and Community Care Act 1990. Fortunately for me, the 1990 Act had also launched a major process of de-institutionalisation, in which statutory community services were replaced by less expensive supports from the voluntary sector. I was lucky enough to work for a local branch of a national charity during a period of very rapid change. As a 'Joint Co-ordinator', I was responsible with others for staffing and developing community day services in a semi-rural county that had previously been served by four psychiatric hospitals. Our small team had very broad discretion with which to interpret our task, but a tiny budget. We had on and off-line managerial supervision, clinical supervision and most importantly for my own development, daily de-briefs after our long (five hour) open access drop-in sessions. We worked within a loosely humanistic psychodynamic framework influenced by the work of Rogers (1961, 1968) and Rowan (1983) as well as many others. Some of us had professional qualifications, though this was not a requirement, and many of us had experienced mental

distress, though this is an anachronous term (from memory we tended to talk about 'mental health problems'). We were able to be open with one another, and to develop and implement detailed strategies about the degree to which we would disclose information about ourselves to our members (a term originating from the people who used our services). To some extent budgeting decisions were democratised, although our own salaries and the overheads charged by our parent organisation were non-negotiable. Consequently both the parent charity and our local service had some features of peer support, but were not 'user-led' in the sense of contemporary discussions within the disabled people's movement.

Between 1997 and 1999 I embarked on a career as a researcher. I was appointed as one of two full-time staff working on a collaborative project between three academic institutions and a national mental health charity which had also become a large-scale provider of services. I was recruited primarily because of my experience of running groups with people with what were then categorised as 'severe and enduring' mental illnesses, and received training in and supervision on the use of qualitative methods from a group of researchers with a nursing focus. At the time they were heavily influenced by the group subsequently described as second the generation of grounded theorists (Birks & Mills 2015). The aim of the project was to develop two outcome measures which reflected the issues which were important to service users and carers, and which were also academically credible (sensitive, stable, reliable and valid) and clinically useful (Lelliot et al. 1999, 2003). Many responsibilities were shared, but I led on a sub-study of issues important to service users and carers (consisting of a literature review, semi-structured interviews with key respondents, and focus groups with service users and carers) and co-ordinated field trials within the voluntary sector and within the mental health service users' movement. Building these relationships posed another set of dilemmas about instrumentality and authenticity.

After two years in a more senior research role at another charity, I returned to a practice setting as the manager of a small local mental health charity providing a range of community-based mental health services. I held that post for nearly ten years. The majority of staff members and volunteers had had some lived experience of mental distress, though the degree to which they were prepared to make this public varied enormously, and this

posed dilemmas for me and for the organisation. For example our advocacy service styled itself as using a peer advocacy model (Conlan 1994), but there was no constitutional mechanism for ensuring a majority of 'service users' on the Board of Trustees, and no requirement for staff and volunteers to disclose experience of mental distress outside of the occupational health policy. Together with colleagues and Trustees we developed a consensus that information about people's experience of mental distress should be under their control, and the issue of representation of lived experience amongst Trustees, staff and volunteers could be dealt with through a confidential survey. Subsequently we extended our advocacy service to incorporate other approaches, such as non-instructed and professional models (e.g. Hyslop & Winder 2004).

Our information and advice service provided some support for direct payment users when the guidance was changed to encourage greater use amongst mental health service users, and when the Transforming Adult Social Care pilots were starting in 2008, we jointly developed a successful bid to run a brokerage service with other charities. This was initially provided by paid workers, but we had always intended to extend this to include provision by volunteers. In 2010 I and a colleague from another local charity set up a Community Interest Company to take this aspect of the work forwards. In 2012 we delivered our first set of 'peer broker' training courses, and in 2014 we were commissioned to review local support services for personal budget users (Birnie et al. 2014). In 2012 I had started to work as a Senior Lecturer in the social work team at Oxford Brookes University, and in 2014 I agreed to undertake a research degree as a part of a professional development plan. By this point, personal budgets and personalisation had become central themes in adult social work. Erlandson and others (1993) advise that social trends and personal interest can sometimes converge to produce a suitable topic for investigation, and in this case the subject also combined with professional concerns that were reflected in my teaching and research interests.