How do peer networks support people with personal budgets? A review of the research evidence from the UK

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Abstract

This literature review was conducted to describe the range of organisations and informal groups providing peer support to personal budget users in the UK between the launch of direct payments in 1997 and 2016. Forty-five research reports included relevant evidence. This has been aggregated to show how peer networks supported individual users, as well as to describe their wider role in policy development and implementation. Despite their diversity, the support they provided often had common characteristics. Peer networks fostered collaboration, enhanced communication, built confidence amongst people who were entitled to a personal budget, and applied specialist knowledge that was often derived from the lived experience of network members. None of these characteristic was exclusive to peer networks. However, they may have been more deeply culturally embedded here than in other settings, which perhaps accounts for the positive experiences of support reported in the research literature.

Key words
Personal budgets, direct payments, personalisation, cash for care, literature review, peer network.

1. Introduction

It is now more than twenty years since United Kingdom (UK) citizens were first able to take the money used to pay for adult social care services as ‘direct payments’ (Department of Health 1997a-c). Direct payments built on earlier forms of individualised payment such as the Independent Living Fund, and Indirect Payment Schemes (Zarb & Nadash 1994, Glasby & Littlechild 2009). Internationally, similar initiatives have become known as ‘cash for care’ schemes (Ungerson 2004, Timonen et al. 2006). In the early 1990s the British Council of Organisations of Disabled People (BCODP) campaigned for direct payments, and set up a National Centre for

Independent Living to support their implementation (Evans 2002, Glasby & Littlechild 2009). The earliest providers of support for direct payment users were local user-led Centres for Independent Living (CILs), but in the following decade a much broader range of providers, including impairment-specific charities and for-profit organisations, were commissioned (Riddell et al. 2006, Davey et al. 2007). By the start of the present decade electronic media were enabling users to collaborate in new ways (Ayres 2011).

New Labour's policy of devolution meant that from 1999, policy-making for adult social care began to move to the devolved assemblies (Jervis et al. 2003). This led to some variation across the UK, with the English Department of Health being more proactive with implementation than responsible bodies in the other parts of the Union (Riddell et al. 2006). The following decade saw policy changes to extend the availability of direct payments in adult social care across the UK, and introduce them into the English National Health Service (NHS) (Her Majesty's Government 2003, 2004a, 4004b, Scottish Executive 2003a, Health and Social Care Act 2009 Schedule 1). These changes were can be seen as part of a wider policy narrative of modernisation and increasing choice and control (Baldwin 2008, Needham 2011), with England often functioning as a 'proving ground' for policies later implemented in other parts of the UK (Jervis 2008, 97).

Across the whole period during which cash for care schemes have been operating in adult social care, researchers have investigated the ways in which peer networks (PNs) have supported users. Support provided through CILs was initially researched intensively, often by teams linked to the UK disabled people's movement (Witcher et al. 2000, Barnes et al. 2000). Successful implementation was statistically linked with the presence of a CIL or similar organisation (Riddell et al. 2006). This review article will draw together the research evidence, exploring the ways in which peer networks have supported people to obtain and subsequently to manage their own support. It may be useful to begin with a description of policy developments in relation to key terms and how they have been interpreted.

a. From direct payments to personal budgets

One of the objectives of the *National Health Service and Community Care Act 1990* was to introduce market mechanisms into health and social care services, with the aim of increasing quality and efficiency (Langan 1998). Some purchasing decisions were devolved from local authority social services departments to individual 'care managers' (typically social workers), but crucially not to individual service users. A pilot study commissioned by the BCODP showed that making payments to people for them to purchase their own care could promote independence and save money (Zarb & Nadash 1994). Legislation and subsequent regulations then created discretionary powers for local authorities to make 'direct payments' to adults who were entitled to state-funded social care in all parts of the UK (Her Majesty's Government 1997a-c).

Table 1: Direct payment users in each country/province of the UK between 2000/1 and 2003: number and rate per thousand people with LTID

Country/ province	Population	% Long Term Illness / Disability [LTID]	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)

Reproduced from Table 2 of Riddell et al. 2006, p.7

Initially the uptake was low. There was concern that many people were being unnecessarily denied access, either because regulations explicitly excluded them (as in the case of older adults), or because their impairments meant they were unable to demonstrate the willingness and ability to manage the money recommended in statutory guidance (Department of Health 2001). Changes in regulations removed the prohibition of payments to older adults (Her Majesty's Government 2000a-d) and subsequently reduced the barriers faced by other potential users (Her Majesty's Government 2003, 2004a, 4004b, Scottish Executive 2003a). For people perceived as being unable to manage a direct payment, 'personalised', 'individual', or 'personal' budgets were developed (Poll et al. 2006, Department of Health 2008, Scottish Executive 2010). These offered direct payments alongside a wider range of mechanisms through which people could exercise '…maximum choice and control…' (Department of Health 2009b, 2). Though most of the initial development work took place in England, similar mechanisms were subsequently introduced in Scotland under the banner of self-directed support (Scottish Government 2010) and Wales (Welsh Assembly Government 2011), where they formed part of a strategy for citizen-centred support (Roulstone & Hwang 2013). However Northern Ireland still lacks a suitable legal vehicle for enabling informal carers to manage funds (Health and Social Care Board 2012).

It has been suggested that the devolved administrations within the UK have their own organisational cultures, which impacted on the understandings of and commitment to policy in this area (Pearson 2004). Greer and Rowland (2007) have similarly argued that policy values in England stand apart in their closer alignment with market reforms and technological innovation. This is reflected in the different nomenclature, which has also changed over time. The term 'personal budget' (PB) is used throughout this review to encompass the spectrum of mechanisms through which state resources for the provision of health and social care are placed under the individual control of patients or service users. It does not refer to any particular legal or bureaucratic definition. Table 2 gives approximate numbers of people receiving personal budgets (or broadly equivalent forms of self-directed or citizen-centred support) across the UK. However, the divergence of policy, definitions and consequently of statistical returns inevitably makes comparisons inexact.

Table 2: Direct payment and personal budget users in the UK, 1st April 2016

Country/ province ~	Population	Personal Budget Users (Adult Social Care)	Of which, Direct Payment users	% DP users/popn.
England	55,268,100	463,645	109,835	0.199
Scotland	5,404,700	4,840*	2,020	0.037
Wales#	3,113,200	N/A	5,859	0.188
Northern Ireland	1,862,100	N/A	3,159	0.170

** SDS Option 1, 2 & 4 (Option 3 is support chosen and provided by the Council)*
 # Figures for 2016-17 (2015-16 not available)
~ Mid-year population estimate 2015-16
Sources: Department of Health of Northern Ireland 2018, NHS Digital 2017, Scottish Government 2017, StatsWales 2018, Office for National Statistics 2018.

Uniquely among devolved National Health Services, England pilot-tested personal health budgets in 2009 (Forder *et al.* 2012), with eligibility becoming permanent in 2013 (Her Majesty's Government 2013). However the numbers have remained comparatively small with only 7,600 users by April 2016 (NHS England 2017).

b. Peer networks

The first non-statutory organisations involved with supporting direct payment users were CILs. These were often commissioned to provide support to direct payment users (Morgan et al. 2001). In 2002 the English Department of Health announced a £9 million Direct Payment Development Fund, approximately half of which went to smaller organisations to increase their capacity to support direct payment users (Community Care 2003). A similar initiative in Scotland made £1.18M available 2001-2006 (Scottish

Executive 2003b), although most local authorities did not use it to establish support from peer networks as the guidance had recommended (Homer & Gilder 2008). In Wales and Northern Ireland CILs were also commissioned to provide support, but the extent of central funding is not known (Jolly & Priestley 2004, Pearson 2004). Organisations controlled by disabled people were pivotal in establishing successful local schemes (Witcher et al. 2000, Riddell et al. 2006). Nevertheless a national survey conducted in 2004-5 found that commissioners were also purchasing support from a wide range of other providers (Davey et al. 2007). In England these tended to be pre-existing organisations, and were often national charities. In Scotland and Wales they were more commonly smaller local organisations with fewer employees. The vast majority were non-profit organisations.

CILs and impairment-specific charities were usually legally constituted entities with formal plans to provide support, often in the form of contracts with statutory commissioners (Davey et al. 2007). Research and associated debate about the ideal forms of CILs tended to focus on organisational control by disabled people (Evans 2002, Morris 2006, Maynard-Campbell et al. 2007). However, support for direct payment users was available in many other forms. Local authorities frequently hosted informal support groups (Witcher 2000, Glendinning et al. 2008). With assistance, these groups could sometimes grow into legally constituted organisations such as Independent Living Trusts or new CILs (Luckhurst 2005, Maynard-Campbell et al. 2007). 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 supporting PB users (Ayres 2011). Simultaneously, disability activism 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). Unlike CILs and charities these looser networks cannot be classified in terms of formal procedures and lines of accountability (Gilchrist 2009). Within this article, the term ‘peer network’ (PN) is used to describe the continuum from formal organisations to loose associations.

2. Methodology

a. Aims

The review formed a part of a larger study with the following objectives:

(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 peer networks.

(3) To describe the features of peer support that personal budget users find helpful or unhelpful.

b. Conceptual approach

The overarching study used an emergent design consistent with the principles of naturalistic inquiry (Lincoln & Guba 1985) situated within a social constructionist epistemology (Berger & Luckman 1966). This recognises that the researcher, the research participants and the report itself are inextricably bound with the social contexts of which they form a part. Elements of this social context include the strong links between eligibility for a personal budget and disability, poverty, and other forms of disadvantage (Roulstone 2000, Burchardt 2003, Rogers & Pilgrim 2003). A critical perspective has therefore been adopted. Throughout the review process, the project was advised by a group including disabled people, informal carers, care workers and academics.

c. Search

The search started with electronic databases, followed by a ‘chain’ or ‘snowball’ search of reference lists of included publications (Patton 1990, Greenhalgh & Peacock 2005). Some publications were already known to the authors, or were recommended by colleagues (see Table 3). The database searches were carried out in the autumn of 2014, and refreshed in the spring of 2016. Three databases were thought likely to hold publications relating to the topic: Applied Social Sciences Index and Abstracts (ASSIA), the Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Social Care Online (SCO).

The following search strategy was adapted for all three databases. Firstly, the database (or a separate index of search terms) was searched for terms relevant to the twin *foci* of the inquiry: PBs and PNs. Where databases lacked sufficiently specific terms free text strings were developed using Boolean operators and truncation where appropriate (e.g. where no term for personal budget existed, ‘personal* budget*’ OR ‘individual budget*’ OR ‘direct payment*’). Secondly, terms were tested for specificity and optimised. Thirdly database options were set to exclude literature beyond the scope of the review. Fourthly, titles and abstracts were used to exclude publications obviously not relevant. Finally, publications were obtained and read to see if they contained pertinent findings.

Because of the differing bureaucratic, constitutional and social contexts, studies from before 1997 and outside of the UK were not included. Publications that did not report empirical research were also excluded. There was no attempt to restrict the search to peer-reviewed literature, which could have excluded relevant evidence (Hartman 2006). Personal budgets for children and young people have a separate although closely related policy background, and fall outside the scope of the present review.

d. Description and appraisal of the literature

The forty-five publications detailed in Table 3 met the criteria for inclusion. Their sources are summarised, alongside the decision process.

Table 3: Search results

	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

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

The largest group of literature (n=29) consisted of research reports, typically published on the web site of the commissioner or the organisation carrying out the research. Thirteen publications were articles in peer-reviewed journals, and two were pieces published in professional journals that did not mention a peer review process. One was a book.

Twenty-nine publications reported on studies with research questions relating either to PBs or PNs, with a small overlap focussing on both (n=6), and sixteen had not set out to investigate either but had reported relevant findings. The lack of investigatory focus on the topic of this review partly explains the proportionately small number of papers identified through the database search, with a lack of widely shared terms for peer networks being another factor.

Standard appraisal tools were used to profile the literature as part of a process aimed at establishing trustworthiness (Lincoln & Guba 1985). However, prevailing notions of 'high quality' evidence can contain hidden value judgements (Cheek 2007), and privilege the views of academic researchers and devalue those of people who use or work in health and social care services (Glasby & Beresford 2006). Consequently, publications were not excluded on the basis of quality measures. Taking an inclusive approach was also consistent with the overall aim of the review, in terms of capturing a broad picture of developments.

Forty of the publications used qualitative methods, most commonly individual or group interviews, or surveys. Many of the larger studies used multiple methods (for example following up surveys with individual telephone interviews or focus groups). Of the five remaining studies, one was an evaluation of several pilot sites using a variety of methods (Slay 2011), two involved service users in a loose emergent design (Witcher 2013, Mackay et al. 2013), and two used quantitative methods (Jolly & Priestley 2004, Stainton et al. 2009).

Qualitative elements were appraised using the consolidated criteria for reporting qualitative research (COREQ) (Tong et al. 2007), and the surveys using a set of criteria developed for a large systematic review (Greenhalgh et al. 2004). In both cases the average scores were low (37% and 57% respectively) perhaps reflecting brief methodology sections in publications intended primarily for a wider readership.

A potential problem when attempting to review evidence from across such a long period is the loss of context. Within interpretivist epistemologies, it is the reader who must make a judgement about whether two contexts are sufficiently similar to allow data to be aggregated or synthesised (Noblit & Hare 1988). Clearly it is not appropriate to provide summaries of all forty-five publications here, but it is possible to give some indication of the evolving public policy on PBs and the way this was reflected in the research. For simplicity, studies have been grouped into three periods, corresponding to policy developments across the UK (see Table 4). 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. The second period from 2003 to 2008 reflects increased availability to people in other groups, particularly people with cognitive impairments. The third period from 2009 onwards corresponds to the development of additional mechanisms for allowing people to control the support purchased without having to manage a direct payment. Publications did not always give the dates during which data was collected, field work sometimes straddled two periods, and policy developments were not simultaneous or identical in the devolved territories of the UK. The classification is therefore tentative.

Table 4: Included publications and public policy goals

Authors (listed alphabetically)	Publication Year
Direct payments available & extended to older adults: from 1997 to 2003	
Brandon, D., R.A. Maglajilic, and D. Given	2000
Dawson, C.	2000
Gardner, A.	1999
Gramlich, S., G. McBride, N. Snelham and B. Myers with V. Williams and K. Simons	2002

Maglajlic, R.A., D. Brandon and D. Given.	2000
Maglajlic, R.A., M. Bryant, D. Brandon, and D. Given.	1998
Ridley, J. and L. Jones	2002
Stainton, T., S. Boyce and C.J. Phillips	2009
Stainton, T., and S. Boyce	2004
Wilson, L.	2003
Witcher, S., K. Stalker, M. Roadburg, and C. Jones	2000
Availability extended to other ‘client groups’: 2003 to 2008	
Adams, L. and L. Godwin	2008
Clark, H., H. Gough and A. Macfarlane	2004
Davey, V., T. Snell, J.L. Fernandez, M. Knapp, R. Tobin, D. Jolly, M. Perkins et al.	2007
Glendinning, C., D. Challis, J.L. Fernandez, S. Jacobs, K. Jones, M. Knapp, J. Manthorpe et al.	2008
Hurstfield, J., U. Parashar and K. Schofield	2007
Jolly, D. and M. Priestley	2004
Lewis, S.	2005
Luckhurst, L.	2005
Maynard-Campbell, S., A. Maynard, and M. Winchcombe	2007
Newbigging, K. and J. Lowe	2005
Poll, C., S. Duffy, C. Hatton, H. Sanderson, and M. Routledge.	2006
Priestley, M., D. Jolly, C. Pearson, S. Ridell, C. Barnes, and G. Mercer	2007
Riddell, S., M. Priestly, C. Pearson, G. Mercer, C. Barnes, D. Jolly and V. Williams	2006
Spandler, H. and N. Vick. 2004	2004
Swift, P.	2006
Individual and personal budgets: 2008 onwards	
Beresford, P., J. Fleming, M. Glynn, C. Bewley, S. Croft, F. Branfield, and K. Postle	2011
Campbell, N., R. Cockerell, S. Porter, S. Strong, L. Ward and V. Williams	2011
Darling, P., N. Mane, and M. Derry	2012
Doheny, S., and P. Milbourne.	2013
Mackay, K., B. Brown, J. Bruce, M. Conway, B. Cross, N. Dunn, F. Gaffney et al.	2013
Manthorpe, J., and M. Stevens.	2010
National Audit Office	2011
Newbronner, L., R. Chamberlain, K. Bosanquet, C. Bartlett, B. Sass, and C. Glendinning.	2011
NHS Confederation	2009
Patel, R. and Pridmore, A.	2010
Ridley, J., H. Spandler, A. Rosengard, and A. Menhennet	2012
Roulstone, A. and Morgan, H.	2009
Slay, J.	2011
Sowerby, D.	2010
Tew, J., J. Larsen, S. Hamilton, J. Manthorpe, N. Clewett, V. Pinfold, and P. Szymczynska.	2015

The Fed CIL	2012
Williams, V. and S. Porter	2011
Williams, V., S. Porter, and A. Marriott	2014
Witcher, S.	2013

During the first period, regulations gave local authorities a discretionary power to make direct payments to people who appeared '…to the authority to be capable of managing a direct payment by himself or with assistance.' (Her Majesty's Government 1997a-c). In 2000, regulations were changed to give access to older adults (Her Majesty's Government 2000a-d), but the requirement to be able to manage a direct payments largely restricted access to people with physical or sensory impairments (Riddell et al. 2006). In this first period, research often related to the rate of 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). Two studies specifically looked at barriers faced by people with learning disabilities and how they could be overcome (Gramlich et al. 2002, Gardner 1999), and one examined similar issues for mental health service users (Ridley & Jones 2002). The PNs from this period were typically Independent Living Schemes, CILs or similar supports provided by disabled people's organisations.

At the start of the second period the bureaucratic barriers facing direct payment users with learning disabilities, cognitive impairments and in mental distress were lowered (Her Majesty's Government 2003, 2004a, 4004b, Scottish Executive 2003a). This period was characterised by a steady uptake amongst these groups as well as a continuing growth in use amongst people with physical and sensory impairments (Riddell et al. 2006). Of fifteen publications included from this period, eleven were interested in PNs as providers of direct payment support services. An overlapping group of ten publications describe the growing involvement of other organisations, particularly impairment-specific charities. This was seen as a challenge by many user-led organisations, which frequently regarded organisational control as an essential feature of successful support (Gibbs 2005, Morris 2006, Maynard-Campbell et al. 2007).

During the third policy period, policies created additional mechanisms for an individual allocation of resources to be managed on someone else's behalf (Department of Health 2008, 2009, Scottish Government 2010). Perhaps because the aim was to develop a range of mechanisms that worked for everyone, only a minority of studies focused on specific impairment types (Doheny & Milbourne 2013, Newbronner et al. 2011, Sowerby 2010, Manthorpe & Stevens 2010, Tew et al. 2015). However, researchers often sought to explore the divergent experiences of different groups as one variable, or purposively selected participants with a view to being able to comment on differences (Campbell et al. 2011, Williams & Porter 2011, Darling et al. 2012, Patel & Pridmore 2010, Williams et al. 2014). Much of the support provided by PNs in the third period consisted of 'brokerage' or 'support planning'. Eight publications discussed 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, Newbronner et al. 2011, Darling et al. 2012, Doheny & Milbourne 2013, Tew et al. 2015).

Another important development in this final period was the availability of personal health budgets (PHBs) in England. PHBs were the exclusive focus of only one study included here (NHS Confederation 2009), although others commented on their potential (Campbell et al. 2011, Newbronner et al. 2011, Tew et al. 2015).

e. Data extraction and analysis

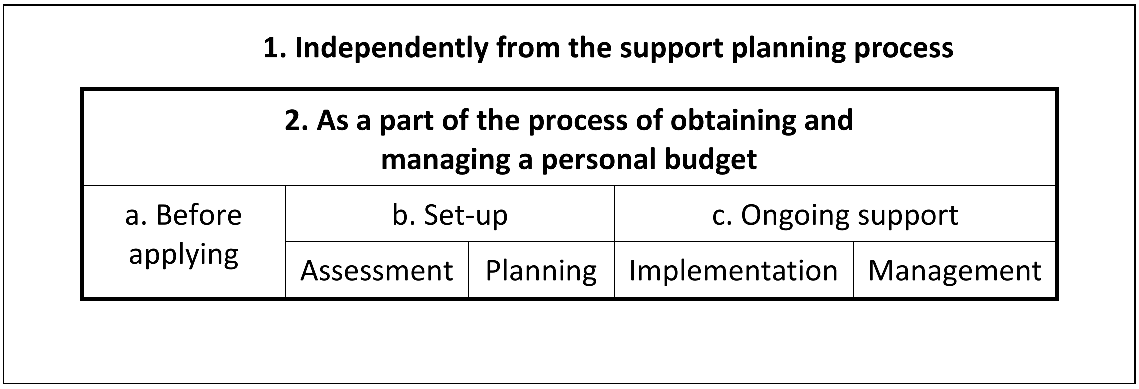
Relevant sections of each publication were imported into NVivo, a computer application developed for qualitative data analysis (QSR 2016). An initial aggregative process aimed to classify and categorise all the data extracts (Noblit & Hare 1988, Dixon-Woods et al. 2006). A secondary thematic analysis was then used to interpret the data, exploring the characteristic approaches and qualities of PNs that underpinned the support they provided (Boyatzis 1998, Braun & Clarke 2006). The practice of counting extracts from different publications is problematic, for example because a long extract of one paragraph could have been coded as six shorter sections. However, it may be appropriate to note that about half of the included publications were coded for between one and five extracts, with a progressively higher density of data being extracted from the remaining literature. The publications contributing the most data included the three reports from the Support Planning and Brokerage study (Campbell et al. 2011, Williams & Porter 2011, Williams et al. 2014). Data for both analyses were drawn fairly evenly from across the three policy periods described above.

The aggregative process aimed to minimise interpretation, and simply assemble data according to a scheme that was '…largely secure and well specified.' (Dixon-Woods et al. 2006, 36). Arksey and Baxter (2012) highlighted 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 PBs. The support provided by PNs proved to be amenable to a similar classification, shown in Figure 1.

Once the data had been organised, a thematic analysis aimed to interpret the characteristics of PNs that affected the way they provided support, and which impacted on personal budget users' experience of that support. The main approach was to develop lines of argument (Noblit & Hare 1988). A large number of possible themes were refined and reduced. Counter-examples were retained and are discussed in the relevant sections.

3. Results

3.1 Aggregative description: what did peer networks do?



1. Independently from the support planning process

2. As a part of the process of obtaining and managing a personal budget				
a. Before applying	b. Set-up		c. Ongoing support	
	Assessment	Planning	Implementation	Management

Figure 1: Coding scheme for aggregative description of the activities of PNs aimed at helping people to obtain and manage a PB.

Following their introduction in 1997, the temporal aspects of obtaining and managing a direct payment inevitably reflected the local authority processes already in use. These included an assessment of needs, the development of a care plan, the appointment of a keyworker, and regular reviews (Department of Health 1990, Social Services Inspectorate 1991). Although there have subsequently been many variations, the process at the time of writing remains remarkably similar (Department of Health & Social Care 2018). The scheme in Figure 1 represents the support provided by PNs, and so divides the continuum differently to systems commonly used by professionals. For example, implementation is grouped with ongoing support because the help provided by PNs at both stages included assistance to find potential employees and advice about employment law.

PNs frequently became involved with the implementation of direct payments through Independent Living Schemes and similar joint working arrangements. Their activity in these contexts often went beyond supporting individual PB users. This is depicted as a separate, outer layer in Figure 1.

3.1.1 Independently from the support planning process

An early case study of four local authorities in Scotland found that all 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). In their survey of organisations providing support to personal budget users across the UK, Riddell and others (2006) found that:

> 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)

Having a PN in every local authority area later became an explicit policy goal in England (Prime Minister's Strategy Unit 2005), although the extent to which it was met is unclear. Larger and more established PNs had a critical role in helping newer, smaller groups and organisations to get started (Maynard Campbell et al. 2007, Luckhurst 2005). In Parts of Wales and Scotland where low population density made it hard to establish new networks, commissioners sometimes worked with local branches of larger charities (Stainton & Boyce 2004, Doheny & Milbourne 2013, Ridley et al. 2012).

3.1.2 As a part of the process of obtaining and managing a personal budget

Before an individual can choose to apply for a personal budget, she or he must be aware of their existence, and have some knowledge of their purpose and functioning. Lewis (2005) provided examples of how PNs achieved this. Strategies included:

- appointing a development manager to produce materials,

- publicising PBs in the local media,
- operating ‘surgeries’, and providing briefings to planning forums, user groups and conferences.

PNs were often involved in providing training to potential users, and sometimes to statutory sector workers (Witcher et al. 2000, Maynard-Campbell et al. 2007, Campbell et al. 2011).

To be eligible for a PB paid from public funds, people were first assessed. PNs sometimes provided training and support to self-assess (Manthorpe & Stevens 2010, National Audit Office 2011, Darling et al. 2012). PNs were often commissioned to work alongside local authorities during the process of developing a support plan, commonly as providers of brokerage. Within the literature reviewed, the term ‘brokerage’ was first used by Dawson in 2000 and then subsequently in more than twenty other publications. Of particular importance is the *Report on In Control’s First Phase 2003–5* (Poll et al. 2005), which advocated separating the function of assessment (which still remained the prerogative of local authority employees) and the help to develop and implement the plan (which could be provided by the local authority, but also by friends and family and PNs). This separation was pivotal in allowing PNs to develop their own distinctive approaches to support planning, which was often contrasted with that of local authorities (Beresford et al. 2011, Williams & Porter 2014).

Once a support plan has been agreed and the money released, it becomes necessary to arrange support. One very common use of a PB is to pay for the time of personal assistants (PAs) (Waters & Hatton 2014). A UK-wide survey of direct payment support schemes found that the majority offered help with recruiting and employing PAs (Riddell et al. 2006), and this type of support was reported in several other studies (Clark et al. 2004, Swift 2006, Adams & Godwin 2008, National Audit Office 2011, Slay 2010, The Fed CIL 2012). Support with bureaucracy existed on a spectrum from help with form-filling (Clark et al 2004, Spandler & Vick 2004) through to full payroll services (Dawson 2000, Ridley & Jones 2002)

PB users often found continuity of contact across the process helpful. Clark and others (2004) found that whilst local authority systems would often prioritise support for the first six months, user-led organisations could remain engaged for longer. Darling and others (2012) reported that the local authority often left PB users 'floundering' after the assessment stage with inadequate guidance on what the budget could be spent on, whereas the guidance from the local independent living scheme was more comprehensive.

3.2. Thematic analysis: characteristic approaches and effect on support for PB users

Four themes were identified across the data set. The first is that PNs typically worked collaboratively, both with organisational partners and by facilitating peer support. The second revolves around the ways in which PNs communicated with PB users. The third reflects the effect that support from PNs often seemed to have on PB users' confidence. The final theme explores the expertise held by peer networks, including in living with different types of impairment and in emancipatory and rights-based support models.

3.2.1 Fostering collaboration

Collaborative working was characteristic of the way in which many PNs have supported PB users. Collaboration can be divided into collaboration with peers (a), and collaboration with other groups, organisations, or individuals (b).

3.2.1.a Peer Support

Peer support is referred to in the overwhelming majority of the research literature, and was often asserted to be an essential feature of CILs (Evans 2002, Gibbs 2005, Morris 2006), but the meaning of 'peer' was not consistent. For example Witcher and others (2000) describe peer support as operating between PB users, but it could also mean someone with the same impairment type (Brandon et al. 2000, Swift 2006). Often no description was offered.

A survey carried out in 2003-4 found that 64% of fifty 'standard' direct payment support schemes offered some opportunity for peer support, a figure which at that time was regarded as surprisingly low (Luckhurst 2005, 25). A UK-wide survey of direct payment support schemes in 2004-5 found that 75% offered some type of peer support (Davey et al. 2007). Of the CILs on a national database in 2006, 51-75% either provided or facilitated peer support (Maynard-Campbell et al. 2007). Nevertheless, peer support was not the sole preserve of PNs, with some local authorities providing a space for PB users to meet one another (Glendinning et al. 2008). Additionally, PB users receiving support from local authorities often had their own pre-existing links with PNs (Williams & Porter 2011).

Many studies reported difficulties in establishing or sustaining peer support groups. Some researchers identified factors including lack of transport (Dawson 2000) concerns about confidentiality (Manthorpe & Stevens 2010) or mental distress (Newbronner et al. 2011).

3.2.1b Collaboration with other organisations, groups, or/and individuals

PNs worked alongside a wide range of partners including statutory health and social care bodies (Witcher et al. 2000, Williams & Porter 2011, Campbell et al. 2011, Poll et al. 2006, Lewis 2005, Slay 2011, Wilson 2003), informal carers (Luckhurst 2005, Campbell et al. 2011), local voluntary sector organisations and rights groups (Spandler & Vick 2004, Newbronner et al. 2011) and agencies employing personal assistants (The Fed CIL 2012). However, PNs did not always have the resources to work collaboratively (Witcher 2013). Some PNs were worried that this might lead to them being perceived as disinterested or inward-facing, which might in turn result in further funding cuts (Maynard-Campbell et al. 2007).

A study of user-led support in Essex, Surrey and Hampshire found that people who had contact with multiple PNs before they took on a PB were much more likely to be able to manage the planning and implementation stages (Williams et al. 2014). The same study reported that people with dementia and their informal carers would often fall back on voluntary organisations for supplementary advice, even where receiving ongoing support from elsewhere (Campbell et al. 2011). Ridley and Jones (2002) highlighted the importance of having a range of organisations for people to draw on for information and advice. PB users often used a number of different networks to identify potential employees, and to get advice about managing them (The Fed CIL 2012, Adams & Godwin 2008).

3.2.2 Enhancing communication

Peer networks were particularly valuable to local authority partners when they were attempting to promote the use of PBs to service users because of their '…direct and regular contact with the core constituency targeted by the DP [direct payment] scheme' (Stainton et al. 2009, 170). Sowerby (2010) reported that a long-term relationship was often necessary to communicate effectively with people with learning difficulties. Smaller local PNs sometimes had links with specific hard-to-reach groups (Maynard Campbell et al. 2007). Examples included people from transgender, lesbian, bisexual and gay communities, and people with HIV/AIDS (Newbronner et al. 2011). PNs sometimes '…saw themselves as having a wider and more experience-based information-giving role…' than their statutory sector partners (Newbronner et al. 2011, 25), and they often created specialist communication aids, such as DVDs, videos, computer-based information, pictorial and written information (Mackay et al. 2013, Williams & Porter 2011, Lewis 2005, Maglajlic et al. 2000).

Several studies contrasted the equality of communication within PN with the hierarchical communication PB users experienced with care professionals (Spandler & Vick 2004, Williams et al. 2014, Tew et al. 2015). This was linked with the desire to help people plan to meet their own aspirations, rather than accept professional judgements about what type of support might be most appropriate (Beresford et al. 2011, Williams et al. 2014, Tew et al. 2015). One study reported communication with PNs as being 'genuine', 'friendly', 'positive' and 'reassuring' (Williams & Porter 2011).

3.2.3 Building confidence among actual and potential personal budget users

Two features that seemed to help PNs inspire confidence were that they included people who were already using PBs successfully, and that they were viewed as independent from the statutory sector and were therefore trustworthy. A study comparing local authority with user-led support found that in two broadly comparable samples of potential PB users, nearly twice as many of those supported by PNs went on to use a PB (Campbell et al. 2011). The same study also compared impairment-specific charities and user-led organisations. While the former were trusted and valued for their expert knowledge, the best entry into the PB process was achieved by the latter, which typically provided the opportunity for contact with existing PB users (Williams &

Porter 2011). Many other studies highlighted the usefulness of putting actual and potential PB users in contact (Maglajlic et al. 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). (Maglajlic et al. 1998, 36)

Once people had started to use a personal budget, the ongoing involvement of a user-led organisation was key to helping them feel that they were still in control (Campbell et al. 2011). Several studies emphasised the emotional roles of PNs in helping people to feel that they could meet the challenges of managing their own support (Newbigging & Lowe 2005, Luckhurst 2005, Hurstfield et al. 2007, Newbronner et al. 2011).

The research also contained examples of where PNs did not inspire confidence. Some older adults did not want to get involved with one local coalition of disabled people because they were perceived as 'too militant' (Stainton & Boyce 2004, 447). People with learning disabilities were not necessarily as impressed by the expertise within user-led organisations as other PB users (Williams & Porter 2011). Not all people who met the statutory criteria for a PB saw themselves as being 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:

- Not focussing on the PB primarily as a means of containing public expenditure (Glendinning et al. 2008, Williams & Porter 2011, Campbell et al. 2011, Darling et al. 2012).
- Offering a real choice about taking a PB, and not pushing people to accept them (Williams & Porter 2011, Patel & Pridmore 2010). Newbronner and others (2011) found that some PB users believed that PNs were also required to promote PBs under the terms of their contracts.
- Taking a positive approach to risk. Statutory services were perceived as trying to steer the planning process, whereas support planners from PNs would start with people's ambitions for their own lives (Williams & Porter 2011, Beresford et al. 2011). Mackay and others (2013) found that by working with advocates, statutory sector workers were better able to appreciate service users' perspectives on risk and vice versa.

3.2.4 Specialist knowledge

Most of the studies included here made passing references to concepts such as independent living, the social model of disability, person-centred care and the recovery model. Although none of these were the sole preserve of PNs, they appeared to be more deeply embedded than in statutory organisations (Newbigging & Lowe 2005, Maynard-Campbell et al. 2007). A few of the studies included investigated how these concepts worked in practice. Person-centred planning meant starting assessment with what people wanted from their lives (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).

Wilson (2003) observed that providers who reported working with the social model of disability were more likely to be offering a choice of provision than those who did not. Services provided by CILs helped people use their budgets to live independently, rather than simply to purchase support (Davey et al. 2007). Similarly, time-and-task plans were much less likely to offer choice that those developed using a person-centred process (The FED CIL 2012).

Services provided by user-led organisations had a different type of expertise, which linked to knowledge of the process of obtaining and managing a personal budget from the perspectives of the people using them (Campbell et al. 2011, Williams & Porter 2011). Verbal explanations, for example of written materials produced by local authorities, were often necessary to help people understand what was happening:

> …because of their real understanding of the 'lived experiences' of disabled people, ULOs [user-led organisations] are able to provide a range of services that are both shaped and delivered by disabled people. (Campbell et al. 2011, 25)

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 (Maynard Campbell et al. 2007).

Some reports made passing references to the expert knowledge without describing it in detail (Witcher et al. 2000, Mackay et al, 2013, Newbronner et al. 2011, Newbigging and Lowe 2005, Clarke et al. 2004, Slay 2011, The Fed CIL 2012, Maglajlic et al. 2000). There were also forms of specialist knowledge which were possessed by statutory agencies. This included knowledge about complicated safeguarding issues, and about appropriate medical assistance for some types of impairment (Campbell et al. 2011).

4. Discussion

The model of support in Figure 1 is consistent with the evidence from across the period, but this should not be taken to imply that provision remained constant. It changed continuously, reflecting not only innovation but also the changing needs of the different waves of PB users, the varying ideals of the different types of networks, and the funding and other resources available to them.

The earliest schemes were inevitably tailored to the people with physical and sensory impairments who were the first PB users (Davey et al. 2007), but as people with cognitive impairments started to be eligible new approaches were developed (Luckhurst 2005, Poll et al. 2006). Whilst the ideals of CILs usually fell within broadly defined parameters (Barnes et al. 2000, Maynard-Campbell et al. 2007), these were not shared by some of the other networks (Stainton & Boyce 2004). A diversification in ideology was not the only factor impacting on the support provided by PNs. As early as 2000, the overwhelming majority of CILs were already dependent on local authority funding (Morgan et al. 2001), and engaged in debates about how far they should compromise with commissioners to retain contracts to provide services (Barnes et al. 2000). Funding also impacted on the type of PN providing support. In the long run the larger national charities gained market share (Davey et al. 2007) and by 2007 CILs had become a '…small minority within a large and expanding market.' (Maynard-Campbell et al. 2007, 7).

Though the research found many benefits of support provided through PNs, it had no features that were completely unique to these organisations and groups. This is partly explained by the diffusion of approaches developed by PNs to larger charities and the statutory sector; several of the projects included here even had this as an explicit goal (Lewis 2005, Campbell et al. 2011, The Fed CIL 2012, Darling et al. 2012). At different points in history, PNs were clearly able to innovate and provide new and more effective approaches to supporting PB users. However these approaches were not unique to PNs, and cannot completely account for the different qualities of the support they provided.

Another potential explanation lies in the specialist models used by PNs. Again though, while concepts such as the ‘social model’ of disability and ‘independent living’ originated within the disabled people’s movement they are now applied much more widely. Similarly the ‘recovery model’ and ‘person-centred planning’ have a wide constituency that includes professional as well as peer groups. It is possible, though, that these models might operate differently when embedded in a sympathetic cultural space. Within the socio-historical approach, identity and culture are thought of as being mutually-constitutive and sequential; as people enter a new cultural space, they are changed by the process, and the living culture is changed by their participation in it (Holland et al. 1998). Socio-historical inquiries typically require long-term field work, and it is clearly not possible to apply the approach in a literature review. However, within the literature there were examples of where a shared sense of identity linked with each of the four themes; it was perceived as helpful to peer support (Clarke et al. 2004, Newbigging & Lowe 2005, Slay 2011, Williams & Porter 2011), assisted communication (Spandler & Vick 2004, Sowerby 2010), increased people’s confidence that they could also manage a PB (Williams et al. 2014), and provided assurance about the expertise of support providers (Glendinning et al. 2008, Williams & Porter 2011). Several studies went beyond this to look at the benefits to the PB user of contact with disability culture and politics, and the wider mission of disabled people's organisations. Tew and others (2015) gave a detailed account of how contact with the recovery model through peer networks helped to inculcate a recovery 'mindset'. Stainton and Boyce (2004) found that PB users regarded some staff at local Independent Living Scheme as 'role models'. It may be reasonable to view PNs as repositories of cultural knowledge that helps PB users develop more empowered identities, and to think that this process is responsible for the apparent success of support provided by PNs.

There are two main routes through which such a process of enculturation might have an impact on PB users. Firstly, PB users may themselves become active within a PN. PB users usually only had a small number of brief contacts with PNs, but when these were '… coupled with ongoing contacts, membership and active contributions…' it could achieve a '…sea change in the thinking and awareness…' of the PB user (Williams & Porter 2011, 64). This is consistent with the wider literature on disability activism, which often reports such 'light bulb' moments (e.g. Beresford 2008, 11). For a small number of people at the right stage on their lives, the conjunction of a PB and deep engagement with a PN could be transformational, but the literature suggests that such events would be extremely rare, and certainly not common enough to account for the reported advantages of support provided through PNs. A second, more promising path of action might be through peer supporters themselves. They were involved in nearly all the support provided by PNs, so changes in their understandings and abilities might reasonably account for differences in the experiences of the PB users they supported.

A cultural model might also be able to resolve some of the apparent contradictions in the research, for example that many people providing support on behalf of PNs did not necessarily have any lived experience of disability or impairment, or of managing their own PB (Glendinning et al. 2008, Campbell et al. 2011). While it might be reasonable to assume that enculturation would sometimes be easier or more profound for an individual with a common bond of lived experience, the sociocultural model emphasises the central role of shared practice in determining shared identity (Holland & Lavé 2009). The practice of providing support to personal budget users might plausibly provide a sufficient basis here.

5. Conclusions

It has been possible to use a temporal model to group the support provided by peer networks to people at the different stages of obtaining and managing a personal budget. Although this model is consistent with research data from across a twenty-year period, it has been built by aggregating findings depicting a rapidly changing pattern of support provided by a constantly evolving range of providers. The support provided through peer networks had some stable characteristics, many of which were experienced as helpful by personal budget users. Whilst none of these were unique to peer networks, many approaches originated within them and were subsequently applied more widely. It is possible that some peer networks have been able to enhance the transformational potential of their characteristic approaches by integrating them at a deep, cultural level.

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