Published in final edited form as:

J Intellect Disabil. 2011 September ; 15(3): 195–207. doi:10.1177/1744629511419615.

Keeping it in the family? People with learning disabilities and families employing their own care and support workers: Findings from a scoping review of the literature

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Abstract

This article focuses on people with learning disabilities and their families who employ care or support workers using public (government) and/or private (self and family) funds. Such consumer-directed support takes place in England through personal budgets and direct payments. Research and material relevant to these employment relationships were explored in a scoping review undertaken by the authors in 2010. The review identified a small number of studies that involved people with learning disabilities as respondents, although more relied on family carers as proxy respondents. The findings from these studies covered recruitment and administration, employment of family members, training needs, the nature and content of employment relationships, and ending employment. The review observed that employment relationships, practices, and dynamics are surprisingly little explored in the literature and generally unobserved. The article concludes with specific messages from the review for family carers, for people with learning disabilities and for care and support workers.

Keywords

carers; direct payments; employment; family; personal budgets; self-directed support

Introduction

Internationally there is strong endorsement for the principles of consumer-directed support (OPM, 2007; NDS, 2009; Alzheimer's Australia, 2007). Examples of funding mechanisms for self-directed support (SDS) include home care grants (Ireland), service vouchers (Finland), and personal budgets (The Netherlands) (Timonen et al., 2006). In England, while a variety of terms are used, including consumer-directed or self-directed support (SDS), these funds are often referred to as personal budgets or direct payments. They are seen as a way of empowering all disabled people who are entitled to publicly funded social care to obtain support that is tailored to their needs (CSCI, 2009; HM Government, 2010). This is a legacy of the Valuing People Initiative (DH, 2001) which encouraged person-centred approaches to support planning for people with learning disabilities, giving them greater choice and control over services (Wigham et al., 2008).

In England, one forerunner of personal budget experiments involved people with learning disabilities. A pilot project called In Control was set up in 2003 by the Department of Health (DH), six local authorities and the charity Mencap. It found that a small group people with

learning disabilities experienced overall improvements in outcomes when they were given greater opportunities to be involved in their own assessment and given the means to access more flexible support (Poll et al., 2006). Higher satisfaction with support, some cost savings, and increased use of community facilities were also reported. These benefits were confirmed in a study by Hatton et al. (2008), which argued that costs to the public purse were not higher if support was individually tailored for this group. The In Control model (Hatton et al., 2008) was highly influential in the general adoption of personalization as a policy priority for the Labour Government (DH, 2007) and its successor elected in 2010 (HM Government, 2010) which has signalled direct payments as the preferred form of support for people entitled to publicly funded social care. This will enable more people to act as direct employers since more people are likely to receive money directly to fund the support they want following agreement of their proposed support plan by the local authority.

Evidence from research, such as the evaluation of the individual budget (IBSEN) pilots (another forerunner of personal budgets), has confirmed that in many instances the ability to exercise greater choice and control over social care support leads to better outcomes for individuals (Glendinning et al., 2008). Using similar research methods in their evaluation of personal budgets (here termed self-directed support, SDS) in Northamptonshire, Woolham and Benton (2009: 5) observed higher levels of satisfaction among SDS users with learning disabilities compared with people receiving 'traditional' social care packages. However, they found that people with learning disabilities were more likely than people from other care groups to have completed their questionnaires with help from someone else. They consequently speculate that some of the higher satisfaction levels may have reflected the satisfaction of people completing the questionnaire on behalf of the person with learning disabilities. Woolham and Benton (2009) also observed that people with learning disabilities were less likely to know how much money was being spent on meeting their needs for care irrespective of whether they were in the 'traditional' or SDS groups, pointing to the fact that the employment of a care and support worker is sometimes undertaken by a proxy or surrogate acting on a person's behalf. In fact, there has recently been a substantial growth in direct payments to carers in England, with 33,883 carers receiving them for the first time in 2009–10 (Care Quality Commission, 2011).

This article draws on a scoping review of the literature that was commissioned by Skills for Care, the strategic workforce development body for adult social care in England, to inform a major study of care and support workers from the perspective of people employing them directly and the workers themselves. This covered adults with all types of disabilities and needs for social care, employing someone using public (state) and/or private (self and family) funds. The scoping review investigated what is known about the scope and dynamics of the employment relationship in these circumstances. The scoping review data were reanalysed to inform a later study covering care and support workers employed by adults with learning disabilities and/or their family carers (funded by the National Institute for Health Research School for Social Care Research). There are important reasons for such a focus. Firstly, people being unable or unwilling to act as employers themselves, where this is the case, having to rely on carers as proxies or surrogates complicates employment practices and relationships. Secondly, the availability and experiences of family members as supporters of people with learning disabilities may mean they are also likely to be candidates for undertaking the paid care and support work required; this is a development about which we know little. Thirdly, there is a well-developed literature investigating the social relationships of people with learning disabilities and those who provide them with care and support on a professional basis, which raises the question of what learning there may be from this literature for those situations where family carers are paid to act as care workers.

Method

As noted, this article draws on a scoping review (see Davis et al., 2009, for a more detailed explanation of the conduct of such reviews) of the research literature about direct employment of care and support workers. The review was undertaken in 2010 and covered research about adults of all ages with disabilities and long-term health conditions employing their own care and support workers using both public (state) and/or private (self and family) funds. It focused on the dynamics of the employment relationship. Scoping reviews are useful for assessing the size of the literature on a given topic and for capturing salient issues (Moriarty et al., 2011). While using some methods common to a systematic review, they do so in a limited manner, for example, there is no attempt to rank items included in the review in terms of quality appraisal (Mays et al., 2001; Arksey and O'Malley, 2005). They are also appropriate when there is a need to explore definitions and concepts that may be unclear or overlapping. For example, the variety of terms around job roles in social care is considerable (Manthorpe et al., 2010). Terms such as 'carer' may be used to mean paid workers or unpaid family members. Further, while the term 'care' may be used to describe the tasks undertaken, there is call for the term 'support' to be used to reflect a less passive relationship, and for the term 'care worker' to be replaced by the term 'support worker' or 'personal assistant' (Hatton et al., 2008). Researchers need to be aware of changes in terminology to ensure that search terms include older and more recent terms to maximize the number of relevant items retrieved.

The search strategy for the scoping review was designed to cover research literature, user experience reports, articles and commentaries, published mainly since 2000, on the subject of direct employment of care and support workers by adults with disabilities and long-term health conditions. While there is a focus on social care, some of the literature accessed touches upon health care, some on housing support, and a very small amount on employment support. The day-to-day support of many people with disabilities and long-term conditions has been, until recently, generally the task of people employed by social care providers and often family carers (combined with significant input from disabled people themselves). These latter arrangements were not covered by the review.

Search terms used included 'personalization', 'consumer-directed care', 'individual budgets', 'personal budget', 'direct payments', 'flexible funding', 'self-directed care', 'self-directed support', 'self-managed care', 'self-managed support', 'user-directed care', and 'user-directed support'. We followed the example of Ottmann et al. (2009) in seeking publications from the Internet as well as commonly used data sources. Material published or commissioned by Skills for Care, at national or regional level, was also included. Publications were accessed through searches of the following bibliographic databases: Medline, BioMed Central, CINAHL, Social Care Online, Social Sciences Citation Index, Sociological Abstracts, and Web of Science. In light of rapid changes of policy and practice (see HM Government, 2010; Manthorpe et al., 2011), priority was given to articles and reports that reflected the context of personalization in England and the policy commitment to rolling out personal budgets and direct payments.

The search retrieved a large number of publications and data were extracted using a specific data extraction tool to summarize the approach and the findings. These were then investigated to see if they covered features of the employment relationship. For the purposes of this article, the material has been reanalysed to explore reports of family carers' work in this area, either in providing support, or in being employed as care workers by a person with learning disabilities. This work was undertaken to inform the further study of carers' work.

Findings

Recruitment and administration

There is evidence that recruitment of directly employed care and support workers relies heavily on personal contacts or social networks. Reid Howie's (2010) review of the literature noted that few self-directed support clients have had previous experience of recruiting staff in any respect. OPM (2010) found that disabled people in Essex sometimes initially knew whom they wanted to employ but that others made enquiries among extended social networks. People with strong support networks appeared better placed than those with weaker networks and were less reliant on 'unproven' personal assistants whom they did not know previously or who were not known to others close to them.

Carers UK (2008) found that carers included in their study were often managing a direct payment on behalf of a relative and undertaking necessary administration, accepting this as their responsibility. This is not new; parents have long played significant roles as initiators, managers and administrators of direct payments for their adult disabled sons or daughters (Williams et al., 2003). In terms of outcomes, Williams et al. (2003) reported that direct payments facilitated arrangements that were felt to be generally better and that carers were able to take more breaks from direct caregiving.

The literature on administration has generally focused on recruitment, dealing with payment and timetabling, rather than contractual matters. The first major study of direct payment use and the implications for the social care workforce (IFF, 2008) found that few workers had been provided with job descriptions. There also seemed to be various interpretations of what a 'formal' job description might mean and what might be construed as an employment contract. Other studies do not shed any greater light on these matters.

Employing family members

Many commentators (e.g. Henwood and Hudson, 2007) have predicted that people with funds from SDS will not generally need to rely on outside or formal recruitment because they will employ family, neighbours and friends as their care workers. The IFF (2008) study found this was a very satisfactory arrangement for many people using direct payments. Poole (2006) argued that this could lead to the creation of a hybrid: a 'quasi-informal' or a 'paid informal' worker. This situation is not confined to the UK; in The Netherlands about a third of budget holders employ their relatives to provide care, while a third purchase care from formal service agencies and a third use a combination (cited in Glendinning, 2010). In comparing social care arrangements in the UK and The Netherlands, Arksey and Moree (2008) have taken up this theme and have suggested that paying family carers runs the risk of them being financially dependent on their disabled relative and that this might negatively affect family relationships and dynamics.

In England, the IFF (2008) study found that already about half of the 526 people interviewed had recruited care and support workers from amongst family or friends, using direct payments to fund this (at a time when there was little clarity among local authorities on whether this was permitted). Dittrich (2008) noted varying attitudes among English local authorities to agreeing the employment of family members, with some considering that this places undue strain on family relationships and increases the risk to the disabled person; accompanied by wider concerns that paying relatives for care work will entail greater public expenditure because previously they would have undertaken such support unpaid. However, times have changed in respect of earlier prohibitions on paying family carers and many English local authorities now accept paying relatives as a matter of user choice. Nonetheless, uncertainties remain, and the sister study of the IBSEN research, which focused on outcomes for carers (Glendinning et al., 2009), found guidance was often not clear for carers

who had taken responsibility for managing an individual budget (particularly when in the form of direct payments), for example, about how and on what it could be used to pay for. The researchers uncovered local and even client group inconsistency in whether family members were able to be paid from the direct payment (individual budget as then was) of their disabled relative; whether the local authority set any conditions (such as employment contracts) that should be attached when paying relatives; and what might be the interactions between direct payments and carers' entitlements to social security and other benefits. More generally, the researchers noted that little is known of the possible implications of personal budgets on family income as a whole, including its impact on receipt of (un)employment and other welfare benefits.

In November 2009, Government regulations changed in respect of direct payments for people lacking sufficient mental capacity to agree to, and manage, their own care decisions. These provide new opportunities for proxies, generally likely to be family members, to manage direct payments on behalf of their relatives. However, as yet, there is little research about the ways in which such arrangements are affecting employment relationships in the UK.

Lastly, a small study of nine families in the United States (US) found that family members felt that they were being judged negatively by others for accepting payment from the state to care for their adult children (aged 19–47) (Caldwell, 2007). It may be that peer support could be helpful in addressing such stigma. Richards et al. (2009) reported the introduction of 'circles of support' groups, comprising family, friends or other community members, to meet regularly with the aim of helping disabled people plan and accomplish their personal goals. It is not known if these have been sustainable, effective in reducing stigma or significant in other ways.

Training and preparation for staff and employers

In a consultation study undertaken by the care provider ARC (2008a), there are several accounts from people who employ care workers expressing a wish for training in how to manage employment relationships. However, there appear to be no long-term studies covering the impact of training, its cost-effectiveness or issues arising in relation to training for family members. Most of the consultations undertaken by the ARC reported people wanting such training to be publicly funded. Cloverleaf Advocacy (2008) has reported disabled people keen to deliver training to others. Its typology of potential training programme contents covered core values, core skills and specialist skills. One example of user-led training is a programme of training devised by Connect in the North (2009). This was developed on the premise that service-user-led training is preferable, popular and addresses disabled people's priorities (this training was in the context of people with a learning disability). As Mansell (2010) noted, providing personal assistance to adults with profound intellectual and multiple disabilities is not an unskilled job and may involve high-level skills.

Flynn's (2005) study of a small number of personal assistants and their employers found that many of the personal assistants had a background in social care work and had undertaken relevant training. This was confirmed by the IFF (2008) study where 87 percent of personal assistants reported having care work experience. The IBSEN evaluation encountered some local authorities who were prepared to offer training to such workers but others did not see this as their responsibility (Manthorpe et al., 2009; 2010), despite believing it might be beneficial. In contrast, from the US, Simon-Rusinowitz et al. (2001) found that when people with developmental disabilities (the term they used for a learning disability) were asked whether they would want help or training themselves with various cash option tasks, the great majority who were interested in this option wanted such support. The researchers

noted that the state of Florida required all consumers and surrogates/proxies to participate in some training. Their survey is one of the few large-scale surveys of people with learning disabilities on this subject, obtaining a response rate to their telephone survey of 53 percent (378 respondents). However, only 100 of these were responding on their own behalf as the majority of respondents were surrogates or proxies, mainly relatives.

The nature and content of employment relationships

Earle (1999) explored the particular question of what are the boundaries of the employment relationship in the context of a small group of disabled people's requests for what was described as 'facilitated sex' (help with sexual activity) from their personal assistants. She raised this as an example of the differences that may arise in defining needs, wants and the limits of work relationships. Other research (Ponting et al., 2009) has reported people with learning disabilities being interested in employing people who they feel have a more equal relationship with them (than traditional staff) and, for example, shared interests. The capacity for employment to merge into friendship and for affective, rather than instrumental, relationships to emerge is clearly a possible development. There is also the potential for such emotional bonds to be in place prior to the employment relationship if family members are employed.

Askheim (2003) found personal assistants of people with intellectual impairments in Sweden reported feelings of isolation and not being confident that they knew what their employer wanted them to do. There was little emotional support available to such workers from, for example, regular supervision or mentoring, even though their work could be stressful or distressing (James, 2008). Nonetheless, Benjamin and Matthias (2004) concluded that people should be permitted to employ friends and family members partly because they found that agency workers were no happier or better off in this regard than paid family carers. On most levels of worker satisfaction and stress in their US study of 618 workers, there were no significant differences between the two groups.

Relationships with employers have sometimes been described as family-like, even by non-kin (Leece, 2006). However, Leece (2008) further identified a small number of direct payment employers who made efforts to avoid this sort of relationship and the consequent blurring of boundaries it entailed. Later, Leece and Peace (2010) conceptualized direct payment employers as experiencing 'enhanced autonomy' due to the type of supportive care they received from the workers they directly employed. However, they suggested that this might be at the expense of their workers' feelings of dignity because such workers were required to provide support in unobtrusive ways, rendering them 'invisible'. Such unobtrusive care and support and relative emotional distance may be hard to maintain in the case of directly employed family members.

One study focusing on the experiences of 32 personal assistants in Sweden observed that people undertaking these roles needed to be able to demonstrate empathy and sympathy; needed to be aware of the general and specific situation of the employer/disabled person; needed to be able to enter 'the other's world'; should experience a degree of mutuality in the relationship; should be able to handle the relationship, including with the employer/disabled person's family; and should be able to negotiate difficulties around blurred boundaries and possible boredom or feelings of being used. Many of the workers in this study held qualifications and were providing support to unrelated younger adults and this may have affected some of their responses (Ahlstrom and Wadenstern, 2010).

Nonetheless, people using direct payments or having a personal budget in the large Northamptonshire study (repeating some of the IBSEN measures) (Woolham and Benton, 2009) found that they accessed different types of support than people using 'traditional'

social services care packages. The former were more likely to employ personal assistants and to pay other people to help them at home, and were less likely to access informal care and support from family and friends, to use day care services or to take short-term breaks in care homes. The impact of this on day services is likely to be substantial and possible closures of such facilities are widely reported (Hussein and Manthorpe, 2010). Personal assistants for this group were not generally family members and it will be interesting to see if this changes.

Other items that have emerged from consultations with direct payment employers (or possible employers) with learning disabilities are the importance of care workers guaranteeing confidentiality (ARC, 2008a; 2008c; 2008d; 2008e; 2008f), which may be hard to do in family settings. There is little investigation into the parameters of this, and one emerging question might be the way in which workers who are also carers perceive that they are under a duty of care or should abide by any code of practice. Not all people using direct payments view confidentiality as so important. In one of the ARC (2008b) consultations participants were not so concerned about confidentiality; they prioritized knowledge of how to meet health needs.

Given the importance of the relationship with a person providing support, particularly intimate personal care, choosing who undertakes such tasks emerged as of prime importance in some studies:

[I] will have one or two carers providing care rather than lots of different ones provided by previous care agency to cover care hours. (person with learning disability, quoted by Glendinning et al., 2008: 54)

From Sweden, Ahlstrom and Wadenstern (2010) considered that 'personal chemistry' between employer and employee was important. Others have commented on the importance of having back-up or emergency assistance, and found having several care and support workers helped in this regard (Grossman et al., 2007). However, family members may be able to provide such back-up assistance.

Ending employment

There is little written about the end of the employment relationship, whether by mutual agreement or by one party. Reid Howie Associates' (2010) review of the literature reported that some people employing their own workers are concerned about the overall management of performance. Flynn (2005) found that disabled people, especially women, feared the subject of workplace discipline and contractual arrangements, characterizing this as a 'minefield'. Her study of 16 people using direct payments identified experiences of broken trust, dishonesty, discourtesy, incompetence and even abuse; one or more of these was reported by half of those participating, none of whom had raised formal complaints. Her findings were echoed by Grossman et al. (2007) whose interviews with 24 disabled people employing care and support workers through personal assistance schemes in the US reported dismissal of staff as difficult and distressing. Finally, there is a view that it may be particularly difficult to 'fire' or dismiss family members working as care and support workers (Moullin, 2008). This could apply to the disabled person as the employer or to another relative challenging a family member who has been receiving payment. There does not seem to be any evidence of this from practice, although a Canadian study found carers at risk of stress when responsible for care management, such as administrative tasks surrounding employment matters (Rosenthal et al., 2007), and this may be exacerbated if employment relationships are complicated by family bonds.

Discussion

This review of the literature focusing on the relationships between directly employed care workers, carers and people with learning disabilities has revealed little evidence of their nature and dynamics in the UK. There is emerging interest in this subject but little research as yet exploring its many facets. Interest has been prompted by the policy of personalization, but there are surprisingly few studies of the relationships between the very large numbers of people who employ their own care and support workers, their family carers and the people they employ. It is highly likely that greater numbers of people in receipt of public funds for social care will become employers; that the role of employer will be taken up by family members; and that the role of employee may be one taken up by family members. These potentially complex relationships will be played out around recruitment and administration, managing the employment of family members, training and preparation, the nature and content of employment relationships, and ending employment.

The limits of this review are that it has explored material in the English language alone and that the terms and classifications of many studies, reports and consultations are used interchangeably or reported in ways that are unclear. Few studies were identified that looked in depth at the employment relationship from the perspective of care and support workers, especially where the employee was a family member. Many of the studies reviewed were small scale or were descriptive accounts examining, or reporting, experiences of cash for care arrangements. Other studies were reviews or developmental materials related to the implementation in England of *Putting People First* (DH, 2007) or contained reflections on the role of personal budgets or their predecessor, individual budgets. Investigations into the implications of employing family members as care and support workers for employment practice and relationships in these studies were thin. At best, employment relationships and the significance of them were marginal considerations in many studies and reports; others had small samples or were unclear about their sources of evidence. Furthermore, there was some difficulty in establishing whether some authors meant family members giving informal care, or paid care and support workers, when using the term ‘carer’. Other points particularly relevant to people with learning disabilities were that such disabilities were not always clearly described – they might or might not include other disabilities or health care needs – and that the extent of people’s disabilities and the ways they affected their lives and capacity to manage employment arrangements and relationships were not always indicated.

Care work is a complex mix of instrumental and emotional labour and this review has revealed the paucity of information about this subject at a time when there is unprecedented and growing demand for greater choice of options around support and care (Stevens et al., 2011). Some have argued that the term ‘self-directed’ may even be a misnomer if the person ‘directing’ the budget is not the recipient of the care and support but is a family member. This is more likely if the person receiving care and support has severe learning disabilities or dementia (Woolham and Benton, 2009: 80). This will lead to legitimate questions about who is the employer in such circumstances.

The article concludes with messages from the review for family carers, for people with learning disabilities, and for people seeking employment as care and support workers from people with learning disabilities.

Family carers

Caldwell and Heller (2003: 364) observed that little research has explored outcomes associated with employing family members as care workers. They found that employing relatives was not significantly related to satisfaction among people with developmental disabilities or to continuity of care, but interestingly, employment of relatives was associated

with greater community involvement of individuals with disabilities. This current review has not identified much literature in this area since these observations were made, despite the growth of personal budgets and direct payments. The implications for family carers are that they may wish to be paid for their care and support as agreed in the care plan; and that this may have its advantages. To minimize the potential for dispute, it may be that contractual matters should be clear and that a third party may help in thinking through their terms and conditions. There may also be greater need for boundaries to be agreed around work patterns, financial accounting and the nature of care and support responsibilities. In light of the reported success of family members in such roles, it would be helpful for research to identify what are the common characteristics of positive outcomes for all. Descriptions of problem resolution, any engagement with training or skills development from local professionals or peer support networks might also be helpful in providing a rounded account of these new patterns of relationships. Other areas of interest might be how the relationships between paid family members and others in the family network may be affected and how any tensions might be reduced.

People with learning disabilities

Caldwell and Heller (2003: 364) further enquired how much control people with developmental disabilities possess in recruiting and directing staff under consumer- or self-directed care. They identified a lack of knowledge of how people with disabilities feel about employing their relatives. Again, we are not yet substantially better informed about the answers to these questions. While there may be some monitoring and review of the situation in which direct payments are operating, there will be little professional time or responsibility for such tasks unless things go wrong. This means that there will be greater onus on others in professional networks, for example, in primary health care settings to be alert to possible negative outcomes, such as isolation, exploitation or neglect. Support organizations may also have a role in being alert to safeguarding concerns if and when they are in contact with individuals with learning disabilities receiving care from a directly employed family member.

People seeking work as directly employed care and support workers

For family members, the ability to be paid to undertake care and support work may seem advantageous for all concerned. In order to avoid this becoming arduous or a job with no possibility of progression, it may be helpful to embark on training or development of skills and to combine this work with other paid or voluntary activity to widen experience. We have no real knowledge of what people do after they have been working for their family member, although some people who work for individuals may work for more than one employer, possibly to receive a living wage or to ensure that if one person is not able to employ them then there is a safety net of income.

Finally, for people seeking work in social care who are not family members there is some evidence that not all disabled people wish to employ relatives, even if they were available. While family may be at hand, employing relatives can be complex and may not be easy to manage if things go wrong. There may be a wish to maintain some boundaries and to engage with new or fresh faces or experiences. Some potential care and support workers will also have greater skills than family members and they will need to express how these may be of benefit in a practical sense rather than being simple descriptions of qualifications.

Conclusion

There is general agreement that self-directed support or the use of direct payments and personal budgets will increase in England and in the developed world. Despite the emphasis

on the potential for better outcomes from greater choice and control, there is surprisingly little information on the management and negotiations of employment relationships, particularly when family members step into paid roles. While this may be common among all user groups, in the case of people with learning disabilities there are added complications in that family members may have substantial roles in making decisions either formally or informally, especially since many are co-resident with the person receiving social care. This review has pointed to five areas where there is substantial room for personal accounts from individuals and families and from professionals who may approve or observe care transactions, and also from research examining employment relationships and out-comes, to inform practice and policy in this area.

Acknowledgments

We are grateful to the National Institute for Health Research School for Social Care Research for funding the study of carers' workers, and to Skills for Care for funding the scoping study of directly employed care and support workers. The latter study is being conducted by NatCen with the support of the authors and we are grateful to Dr Josie Dixon formerly of NatCen for her assistance with this article. The views expressed in this article are those of the authors alone and are not necessarily shared by the NIHR or Skills for Care.

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