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Personal Assistance Co-operatives: Possibilities and Pitfalls of Alternative Models of ‘Independent Living’

Steve Graby

Personal assistance for disabled people is a field in which co-operatives have not yet had large-scale involvement in the UK. However, in other European countries such as Sweden and Norway there is a well-established co-operative sector providing personal assistance services. This paper draws on evidence from those contexts and on the author’s doctoral research. Conducted in the UK, the research used semi-structured qualitative interviews to explore how personal assistance provision could be improved both for disabled people and for those who work as personal assistants. The paper argues that there is significant potential for developing co-operatives in this field in the UK, which as yet is only starting to be realised in some small-scale experiments. There is also a potentially productive resonance between the Disabled People’s Movement concept of ‘independent living’ and the values and principles of the co-operative movement, which may suggest ways forward in challenging the political economics of austerity. However, the use of co-operative forms in this context is not without its limitations and dilemmas, and needs to be recognised as only a partial solution to disabling barriers that have deep material and ideological roots.

Introduction: Independent Living and Personal Assistance for Disabled People

Personal assistance is central to the lives of many disabled people in the UK and worldwide. While the job title ‘personal assistant’ (PA) has other meanings in other contexts, the Disabled People’s Movement (DPM) in the UK describes a PA as a person who is employed by a disabled person to assist them in their everyday life with activities of daily living that they are unable to do, but that would be considered ‘normal’ for non-disabled people to do for themselves. These tasks include, but may not be limited to, those often thought of as ‘care work’ (e.g., helping people get out of bed, dress, use the toilet, cook, eat, do housework, etc.), and personal assistance is generally considered in the UK to be part of ‘social care’ provision. The crucial difference between personal assistance and more traditional models of ‘care’ is that it is the disabled person, not the PA, who is ‘in charge’ of what they do and when and how they do it (Vasey, 2000).

The term ‘disabled people’ is used here according to the social model of disability, which is a core principle of the DPM (Hasler, 1993). In the social model, ‘impairment’ and ‘disability’ are distinguished from one another. Impairment is a physical difference from the norm, such as lacking a limb or being blind or deaf, while disability is a form of social oppression, caused by society failing to accommodate the needs of people with impairments (Barnes & Mercer, 2006). This is linked to an anti-capitalist historical analysis of the origin of the modern category of ‘disabled people’ in the development of the idea of a ‘normal’ worker during the Industrial Revolution (Oliver, 1990). The term ‘disabled people’ therefore does not describe an essentialist category but refers to people who are ‘disabled’ (oppressed/excluded) by (modern capitalist) society. For example, a wheelchair user is disabled, not by the physical condition of being unable to walk, but by barriers within the built environment, such as stairs without an alternative such as a lift or ramp.

Another core concept within the DPM is ‘independent living’, which emerged from campaigns for deinstitutionalisation of disabled people in the US in the 1960s and spread to the UK and other European contexts by the 1970s (Barnes & Mercer, 2006). Morris (1993, p. 21) describes the philosophy of independent living as based on four core assumptions:

- that all human life is of value;
- that anyone, whatever their impairment, is capable of exerting choices;
- that people who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives;
- [and] that disabled people have the right to participate fully in society.

Independent living, as conceptualised by the DPM, is not about living alone or doing things by oneself or without help, but about having choice and control over when, how, and by whom one receives assistance. Thus, in this context the term 'independence' is redefined to mean not self-sufficiency but self-determination, while recognising that everyone, disabled and non-disabled, is interdependent (Morris, 1993; Oliver, 1990). Personal assistance is one of many services regarded as necessary for achieving independent living (Barnes & Mercer, 2006). However, it is regarded as fundamental to and almost synonymous with independent living by many disabled activists, because of the crucial importance of the shift in power relations between disabled people with daily assistance needs and those who deliver that assistance for moving from a paternalistic institutional model of 'care' to an independent living model (DeJong & Wenker, 1983; Vasey, 2000).

Not all disabled people need or use personal assistance, but it is used in various forms by disabled people with all types of impairments, including learning difficulties and/or mental health conditions; however, in the UK it has often been seen as a service primarily for people with physical impairments (Hall, 2009). The model of personal assistance that was campaigned for by the DPM and eventually established in the UK was one in which PAs are directly employed by disabled individuals, who have all the rights and responsibilities of employers; this is generally regarded within the DPM as the best way to achieve the choice and control that is central to independent living (Morris, 1993; Priestley, 1999). This direct employment model became a part of official UK social policy with the Community Care (Direct Payments) Act of 1996, which legalised direct payments to individuals by local authority (LA) social services departments for the purposes of employing PAs or purchasing other services (Barnes & Mercer, 2006). Direct payments from LAs are still the main source of funding for personal assistance in the UK but increasing numbers of disabled people also employ PAs using NHS 'continuing healthcare' budgets; those who are in paid work or full-time education may also use Access to Work funding or Disabled Students' Allowances for this purpose (Dunn, 2016; Hale, 2017; Perry, 2017).

Barriers to the Realisation of the Direct Employment Model of Personal Assistance

This paper draws on qualitative interviews conducted in 2015-16 as part of the author's doctoral research (Graby, 2018). The study investigated the potential contradictions in the direct employment model of personal assistance within the context of the anti-capitalist analysis at the foundation of the DPM, and with a conceptual focus on autonomy (both that of disabled people in daily living and that of PAs as workers, and whether they are inevitably in opposition to one another).

A total of 27 participants were interviewed, split equally between disabled direct employers and current or former PAs (two participants were in both categories, having worked as PAs before acquiring impairments and becoming direct employers). Participants were recruited strategically, seeking a wide variety of experiences of, and perspectives on, providing and receiving personal assistance. The in-depth semi-structured interviews focused on the participants' experiences of working as and/or employing PAs, and their thoughts about how personal assistance could be changed and improved for those on both sides of the relationship.

Textual analysis of interview transcripts, using the qualitative analysis software NVivo, resulted in several emergent themes. While some (such as the emotional dimensions of the relationships between direct employers and PAs, or the ambiguous role in PA work of the construct of 'professionalism') are beyond the scope of this paper, one prominent theme was that of barriers preventing the direct employment model of personal assistance from working as it was originally intended.

When asked about what they would like to change about personal assistance, rather than suggesting possible alternatives to or modifications of the direct employment model itself, both PAs and direct employers generally talked about wanting there to be more funding, better administrative support or changes in attitudes within eligibility assessment systems. For direct employers in particular, having to deal with administrative aspects of employment such as tax, payroll and insurance as individuals constituted significant barriers to successfully using personal assistance. Recruitment of PAs was also mentioned by many direct employers as a difficult and time-consuming process that they would have liked more support with than was available to them.

One participant, Anne, explicitly said that she did not want to be (as she currently was) the direct employer of PAs herself. Instead, she wanted her LA to be the employer because of the possible legal risks to an individual direct employer if things went wrong in the relationship between employer and PA, potentially resulting in an individual disabled person facing an employment tribunal with no formal support:

What are you going to do if the day dawns when you're employing a carer who turns out to be abusive or who turns out to steal from you, or any other of all sorts of potential horrendous terrible things that might happen — who are you supposed to turn to for help if you are legally responsible as the employer? I guarantee you that if I contact [my LA], they'd say 'it's nothing to do with me because you're the employer.

While most other direct employer participants wanted to remain the legal employers of their PAs, almost all felt that their LAs (or other funding providers such as Access to Work) did not give them adequate support with the responsibilities of being an employer. This was also an issue of concern for PAs; for example, Joanna (a PA who was at the time of interview experiencing problems such as delayed wages because of her employer's impairment-related difficulties with numeracy and organisation) said:

When someone is a private employer, it's a bit difficult to know who to go to with problems ... if you have a dispute with your manager [in other jobs] you go to a higher manager, but everything has to be resolved between us.

Several direct employers did use support services provided either by local authorities, local disabled people's organisations (DPOs) or other private or voluntary sector organisations, but these services were often insufficient or unreliable, which could create barriers to being able to use personal assistance effectively. As one employer, Dawn, said:

What I've often felt over the years is that I'm on my own, and it seems to be a choice between no one else helping me with anything, or ... having it all done by an agency — so, no, I don't like that decision, all or nothing.

Thus, it can be argued that, for many if not most of the direct employers interviewed, the direct employment model did not live up to its promise of delivering autonomy in daily life equal to that of non-disabled people and had actually never been fully implemented as intended. This complements the argument of Leadbeater et al. (2008, p. 31) that "the original aims of direct payments have been frustrated" by excessive regulation, including restrictions placed by local authorities on which activities PAs could be employed to do, as well as the aforementioned administrative burdens on individual direct employers.

The Scandinavian Model of Personal Assistance Co-operatives

In the UK, there is a history of DPOs providing administrative support with employing PAs to individual direct employers, and at times some DPOs have even taken on the legal role of employer of PAs on behalf of individuals who did not want to take on that responsibility (Barnes & Mercer, 2006; Priestley, 1999). Luckhurst (2006) argues that such “intensive support schemes” may provide the “advantages of direct payments without the administrative disadvantages” (p. 233) enabling many disabled people who otherwise would have found personal assistance too difficult to access, particularly those with learning difficulties, to gain the benefits of it. However, this provision has always been local and patchy. In the present political and economic climate of the UK, many local areas do not have DPOs and those that do are frequently struggling financially and not in a position to provide such services (Alliance for Inclusive Education et al., 2018). In contrast, in the Scandinavian countries, particularly Sweden and Norway, co-operatives have taken on a similar role and have been a core part of the landscape of personal assistance provision since the 1980s.

In Sweden, disabled people who receive support under their personal assistance laws can employ PAs directly, or they can have LAs, private agencies or co-operatives take on the role of employer (Askheim et al., 2014). The first personal assistance co-operative in Sweden, the Stockholm Co-operative for Independent Living (STIL) was founded in 1984 by a group of disabled people, including Adolf Ratzka, who were affiliated with the international independent living movement (Ratzka, 2015; Westberg, 2010). In this co-operative model, which was followed by many other Swedish cities and municipalities, the disabled members of the co-operative pool their direct payments (which in Sweden come from a combination of municipal and national funding sources) to fund the co-operative, which then is the legal employer of the PAs managed by individual members. The co-operative is controlled by an elected board who are all personal assistance users (Bowman, 2001; Ratzka, 2015). It is therefore not a workers’ co-operative but can more accurately be characterised as a consumer co-operative of personal assistance users, whose PAs are employees of the co-operative, but not members.

STIL takes care of administrative aspects of managing direct payments, such as tax and payroll, but recruitment remains the responsibility of the individual disabled member, so the one-to-one relationship between disabled person and PA remains as if they were an individual employer (Roulstone & Hwang, 2013, 2015). STIL also provides mandatory introductory training to its members on the role of ‘boss’ or ‘supervisor’ and further optional training on specific aspects of the management relationship (Bowman, 2001), as well as some training for PAs (Roulstone & Hwang, 2013; Westberg, 2010). STIL allows the appointment of a ‘vice supervisor’, whose role is to manage PAs on the member’s behalf, for those who find self-management difficult, although all disabled members are meant to “take on as much of the supervision as possible” (Westberg, 2010, p. 63).

There is also a nationwide co-operative called JAG, which specialises in personal assistance for people with “multiple extensive disabilities, one of these being an intellectual disability” (Westberg, 2010, p. 42). Every member of JAG, which was founded by a group of parents of disabled children inspired by the example of STIL, has a ‘service guarantor’, often a family member, who is responsible for “recruiting, instructing, supervising and scheduling the assistants in accordance with the user’s preferences” (Tengström 1996, para 11). Perhaps because of the availability of these services, Sweden has a higher proportion of people with intellectual or cognitive impairments accessing user-controlled personal assistance than many other countries, including the UK. This may also be because “persons with learning disabilities, people with autism or conditions similar to autism” are specifically guaranteed eligibility for personal assistance under Swedish laws (Askheim et al., 2014, p. 6).

While most personal assistance co-operatives in Sweden, other than JAG, are local to cities or municipal areas in a similar way to DPOs in the UK, in Norway there is a single nationwide co-operative, Uloba. Uloba was founded in 1991 and in 2013 was running 27% of all personal

assistance programmes in Norway (Roulstone & Hwang, 2013). Similar to STIL, Uloba is also a campaigning DPO and involved in 'marketing' personal assistance to disabled people (Andersen et al., 2014). It also offers peer support for disabled members as a core service (Roulstone & Hwang, 2013). In Norway, disabled people who are eligible for personal assistance services can also choose between joining Uloba, employing their own PAs directly, or having the municipality as legal employer. The latter is the most popular arrangement, but Uloba has a substantial 'market share'; 33% of personal assistance users in 2010, up from 25% in 2007 (Askheim et al., 2014; Christensen, 2010).

In Denmark there is similarly a nationwide PA user co-operative called LOBPA with the double function of co-operative and campaigning organisation. The latter function is perhaps even more explicitly articulated in LOBPA, as (unlike Uloba and the Swedish co-operatives) LOBPA also allows PA users who do not use its employment services (e.g., those who employ their own PAs directly) to be members (Andersen et al., 2014; Askheim et al., 2014). In Denmark, unlike Sweden and Norway, local authority responsibility for employment of PAs is not possible.

All the 'Scandinavian model' personal assistance co-operatives centre the empowerment of disabled people as a core value in contrast to both for-profit agencies and traditional state-provided 'care' models. They are aligned with, or even effectively constitute, the independent living movements in their native countries. In their model, the roles of (legal/financial) employer and of 'boss/manager' are clearly distinguished from one another. Uloba, for example, uses the phrase 'work leaders' to describe its disabled members, as opposed to Uloba itself as the 'employer' of PAs (Uloba, 2021). STIL similarly "distinguishes between a leader and an employer", defining a 'leader' as "a disabled person who decides on the key questions of who, what and when of personal assistance" (Roulstone & Hwang, 2013, p. 30). The advantage for disabled people of this co-operative model over direct individual employment is that it can satisfy the demands of disabled people for choice and control over assistance while mitigating the isolation and administrative barriers.

Co-operative Values and the Disabled People's Movement

This co-operative model has not been implemented on a large scale in the UK, although some small-scale experiments have begun in the last few years. However, co-operatives arguably have potential to be appropriate models for organising personal assistance because of the resonance between their organisational principles and those of the Disabled People's Movement. Bowman (2001, p. 51), for example, describes the "fit between user-directed personal assistance and co-operation" as "logical", especially in the Scandinavian context. Additionally, Beresford (2016, p. 255) argues that both DPOs and "micro employers" (as he categorises direct employers of PAs) continue the "socially committed legacy" of the co-operative movements of the 1970s-80s in the UK. Similarly, Roulstone and Hwang (2015, p. 861) argue that:

there is a powerful affinity between co-operative principles, direct payments and disabled people's organisations. Shared ownership, user control, a concern to ameliorate provider and market-led 'solutions' and a belief that people are experts in their own life characterise both co-operatives and disabled people's organisations.

Dodd (2016) argues that the emancipatory project of the DPM can be positioned against both the paternalism and managerialism of the post-war welfare state tradition and the 'free market' values of neoliberalism; it is thus implicitly both libertarian and socialist. The co-operative tradition can also be seen as a radical alternative to both capitalist individualism and authoritarian or paternalistic forms of socialism, thus forming a model of social support distinct from and opposed to both direct state provision and privatisation (Beresford, 2016; Restakis, 2010). In its core concepts of the social model of disability and independent living, the DPM has emphasised both collective social responsibility for the social inclusion of people with impairments and individual autonomy and self-determination; similarly, in establishing networks

of mutual aid through collective self-interest, co-operatives “socialise individuals without extinguishing their individualism” (Restakis, 2010, p. 237).

Co-operatives and the DPM share a core value of what Gordon (2018, p. 209) calls “subsidiarity”, or “the principle that people should have power over an issue in proportion to their stake in it”. This principle is exemplified in the co-operative movement by democratic member control being one of the seven core co-operative principles (Scott, 2016) and in the DPM by the international slogan “nothing about us without us”, which Charlton (1998, p. 17) characterises as “a demand for self-determination and a necessary precedent to liberation”. In the case of some DPOs, this principle has led to refusal to accept charitable status.

Similarly, the DPM opposes traditional disability charities because of their paternalism, collusion with economic injustice and individualistic portrayal of disabled people as objects of pity (Drake, 1996; Russell, 1998). DPM emphasises the difference between organisations ‘for’ disabled people and organisations ‘of’ disabled people, or DPOs, only the latter of which are considered part of the movement because they are run and controlled by disabled people (Barnes & Mercer, 2006; Beresford, 2016). While there are some DPOs in the UK which have adopted charity status for funding reasons, this has frequently been internally controversial, and such DPOs are generally still keen to stress their fundamental difference from traditional charities.

Co-operatives could therefore be a useful conceptual means to resolve tensions between individualism and collectivism within the DPM and discourses of ‘independent living’ (Askheim et al., 2014). They both have autonomy or self-determination as a central principle, and are inherently collective and aligned with a concept of common (rather than state or private) ownership of resources (Somerville, 2007). Notably, in Sweden the co-operative form, with its history of connection to labour movements, was specifically chosen by the DPM there to alleviate opposition from left-wing parties and trade unions who saw user-controlled personal assistance as a form of privatisation and feared it would lead to increased exploitation of workers (Bowman, 2001; Westberg, 2010). In fact, the success of STIL influenced the passing of laws which allowed direct employment of PAs by individuals (Bowman, 2001).

Potential Models for Personal Assistance Co-operatives in the UK

While co-operatives and the DPM both have a central value of self-determination, an important question is whose self-determination. All co-operatives aim to increase the self-determination of their members, but there are several possibilities for who constitutes members of a co-operative operating in the field of personal assistance. Roulstone and Hwang (2015, p. 852) identify three potential models: service user co-operatives (such as the ‘Scandinavian model’ personal assistance user co-operatives), employee-owned (or workers’) co-operatives, and multi-stakeholder co-operatives, in which both service users and PAs could be members.

While the UK does not as yet have a direct equivalent of the Scandinavian service user co-operatives, both workers’ and multi-stakeholder co-operatives do exist in the ‘social care’ field in the UK. Several take the form of social enterprises or employee-owned care agencies (Fisher et al., 2011) operating in local areas, such as Sunshine Care (Rochdale) CIC (a community interest company), and Care and Share Associates (relaunched as Be Caring in 2019), an employee owned enterprise, which operates in a range of urban and rural localities across the North of England (Conaty, 2014; Roulstone & Hwang, 2013). In some cases, they have been formed out of former local authority services; for example, Leading Lives in Suffolk was created from the former ‘in-house’ learning disability service of the county council when the council moved from providing services directly to commissioning them from the private sector (Brindle, 2016). Disabled people using the services of these co-operatives would thus engage with them as individuals, using their direct payments to pay for their services in the same way as with any other (non-employee-owned) agency. These co-operative agencies have generally not had any connection to the DPM, and thus have not necessarily had a concept of personal assistance as distinct from more traditional models of ‘social care’.

Workers' co-operatives and 'Scandinavian model' service user co-operatives both have advantages and disadvantages, which can be related to the group of people in the personal assistance relationship (disabled people or PAs) whose interests they primarily represent. A possible problem with workers' co-operatives for disabled people who employ PAs is that there is a potential clash between their ethos and the central independent living principle of choice and control over when, how and by whom assistance with daily living tasks is provided. Workers' co-operatives "reject the hierarchies of owner and non-owner, employer and employee, manager and worker" (Sandoval 2016b, p. 103). As the Radical Routes handbook on setting up a workers' co-operative says: "in contrast to traditional workplaces, a workers' co-op tries to be a fair and empowering environment where everyone — and no-one — is the boss" (Footprint Workers Co-operative & Seeds of Change Lancaster, 2016, p. 10).

However, it is precisely being able to legitimately be the 'boss' (or 'work leader', as Uloba terms it) of one's PAs that makes directly employing them appealing, despite the administrative difficulties. Several of the direct employers interviewed had concerns about PAs having contact with each other or organising together because they felt that that could weaken their position as employer. These concerns could be assumed to apply even more acutely to the formation of a worker-owned business than to forms of organisation, such as trade unions, which assume that workers will remain in a relationship, albeit potentially an oppositional one, with an external employer. Worker ownership of personal assistance services could easily be seen as relegating disabled people to a status of 'clients' without meaningful control over the services they 'purchase'. This potential conflict was recognised by one PA, Phoebe:

It would be potentially possible [to set up] some sort of workers' co-op ... with PAs mutually co-ordinating between themselves, but for the most part it has to be subject to your employer's needs, so the employer's needs are paramount, and that's — the whole point of the job is satisfying their needs for assistance in independent living, so it would be very difficult for workers to be in control of that, per se.

Service user co-operatives on the Scandinavian model are in the converse situation; they are run and controlled by disabled people as the co-operative members, and PAs are non-member employees. This means that they satisfy the demands of disabled people for choice and control over assistance while mitigating the isolation and administrative barriers, and thus could be seen as the 'best of both worlds' for PA users. Even so, at first sight, their model does not necessarily have many advantages for PAs over being directly employed by an individual. However, it is possible that support services that would benefit PAs (for example training, networking opportunities for PAs, or conflict resolution support, all of which were brought up by PAs interviewed as having the potential to improve PAs' experience of their work) could be provided by a service user co-operative. Christensen (2010, p. 249), for example, describes Uloba's "regular meetings ... between personal assistants working for the same disabled person, controlled by the disabled person, thus creating a forum in which reflections can be exchanged". While the research findings suggest that some direct employers in the UK may fear PAs having contact with one another because of the risk of undermining the control of the employer, these fears could potentially be allayed to some extent if this was done in the context of an organisation run and controlled by disabled people.

If PAs employed by the co-operative had the option of working for multiple individual 'work leaders', a service user co-operative might also be able to provide more consistent working hours than would working directly for one or more individuals. For many PAs this could be a material improvement in working conditions, but it would still not necessarily give them any more control or 'ownership' of their work. PAs might also have reason to suspect that a service user co-operative would inevitably prioritise the interests of its members over those of its non-member employees.

Multi-stakeholder Co-operatives

It can be argued that the best solution for representing the interests of, and providing the best outcomes for, both employers and PAs, would be a multi-stakeholder co-operative. This is an organisational form, Lund (2011, pp. 25-26) argues, that has “a special applicability for involving ... marginalised populations in the oversight and governance of institutions that have an important impact on their lives”. In a multi-stakeholder personal assistance co-operative, PAs and personal assistance users would form the two primary ‘stakeholder’ groups. This could help to establish solidarity between direct employers and PAs, enabling them to join together to “maximise the pressure for adequate resources” (Spandler, 2004, p. 205). This model is advocated by the Co-operative Party in the UK (Scott, 2016), while multi-stakeholder social care co-operatives exist as an established model in Italy (Bland, 2011; Restakis, 2010) and Japan (Marshall, 2013), although these examples are not based on a concept of personal assistance as understood in the UK or the Nordic countries.

A few multi-stakeholder social care co-operatives already exist in the UK. One example is Cartrefi Cymru, which operates across Wales and is a company limited by guarantee and registered charity. It was originally founded by parents of people with learning difficulties. In 2016, it changed its name to Cartrefi Cymru Co-operative Limited and included the Co-operative Principles in its memorandum of association reflecting its organisation as a multi-stakeholder co-operative (Roper, 2017). Cartrefi has both disabled people and support workers as members and has recently introduced ‘community supporters’ as a third category of membership. As well as providing direct support with daily living, Cartrefi collectively involves itself in voluntary action in wider local communities, decided on by its members. This and other social care co-operatives in Wales have been supported by the Social Services and Well-Being (Wales) Act 2014, which places a duty on Welsh LAs to promote “user-led services, co-operatives, social enterprises, and the third sector” (Roper, 2017, p. 53).

In England, which lacks equivalent legislation, two recently established examples are Equal Care in Calderdale (a registered multi-stakeholder co-operative society) and North West Care Co-operatives, based in (though intending to operate beyond) Chester. Equal Care describes itself as a ‘platform co-operative’ in which “Independent caregivers and receivers choose one another for the best chance of creating lasting, respectful, quality care and support relationships” (Equal Care, 2018a). It has four categories of members: supported members (disabled people with assistance needs); advocate members (relatives or unpaid carers who represent disabled people who lack capacity to be co-operative members themselves); worker members (which includes both paid PAs and volunteer ‘peer supporters’); and investor members. The voting system used by Equal Care is somewhat ‘weighted’ in that investor members are only allowed a maximum of 10% of votes (Equal Care, 2018b).

North West Care Co-operatives (NWCC) was founded by a consortium of DPOs from across the North West of England, led by Cheshire Centre for Independent Living (CCIL) funded as an action research pilot project by Disability Research into Independent Living & Learning (DRILL), but aiming to become financially self-sustaining. It consists of a ‘service company’ which administers local ‘care co-operatives’ consisting of ‘user members’ (disabled people) and ‘employee members’ (PAs); currently, one care co-operative exists in Chester, but there are plans to set up more across the region (DRILL, 2019; Roberts, 2019b and c). These local co-operatives are intended to remain small-scale, with employee members in each working as a self-managing team. NWCC was created in response to “a gap in the market for disabled people who wish to have as much control as possible over their support provision but who do not want to become a direct employer” (DRILL 2019, para 2) and many of its initial user members are people with learning difficulties (Roberts, 2019a).

These multi-stakeholder co-operatives have clear practical benefits over conventional direct employment for both disabled people and PAs, particularly by providing support with, and/or removing from the responsibility of the direct employer, administrative tasks which may be onerous and inaccessible. NWCC in particular has an express commitment to values of

choice and control for disabled people over the assistance they receive. However, some direct employers may still have concerns about a multi-stakeholder co-operative model which would arguably assume a “symmetrical relationship between users and assistants” (Guldvik et al., 2014, p. 59), given that the relationship between disabled person and PA is in some respects necessarily asymmetrical. Ratzka (2015), for example, expresses scepticism about the idea that “assistance users, their relatives and assistants can be members with equal rights” in personal assistance co-operatives, arguing that disabled people and PAs are not in comparable positions with regard to their stake in the issue:

My background in residential institutions and living with local government community-based services has made me very sensitive to having my life controlled and restricted by structures that I cannot impact directly and by people who are not in the same boat as I am. I am dependent on personal assistance almost 24/7. My assistants work part-time. Personal Assistance is the foundation on which I built my life, my family, my work, my lifestyle. For my assistants it's just a job. In my co-operative [STIL] with roughly 200 members and 1,200 assistants, assistance users would never be able to get their positions through, if assistants had equal voting rights. Assistants as equal members may look politically correct but will not be conducive to self-determination of assistance users (Ratzka, 2015, para 16: Self-determination and equal membership for all stakeholders?).

This argument would likely be echoed by many, if not all, of the pioneers of independent living in the UK. However, it is based on the assumption that in a multi-stakeholder co-operative, ‘work leaders’ and PAs would be equal members in a single decision-making body. This would not necessarily be the case depending on how the co-operative is organised; for example, in a multi-stakeholder personal assistance co-operative, PA and employer members could have different jurisdictions of decision-making. While not necessarily exactly fitted to a personal assistance co-operative, the ‘FairShares’ model (see Ridley-Duff et al., 2020) is a useful example of differential representation of stakeholders with different interests, designed to create solidarity between them.

Somerville (2007, p. 6) suggests that a core co-operative principle of one member one vote could be modified for multi-stakeholder co-operatives “to fit the context of an institution with different categories of membership, so that “where one category of stakeholder ... is more deeply affected by the outcomes of the enterprise than another ... it would follow that the votes of the former should count for more than the votes of the latter”. Lund (2011, p. 11) similarly suggests that stakeholder groups with “a more compelling interest in the success of the co-operative” could justifiably have a proportionately higher number of seats on the board of a multi-stakeholder co-operative. Provisions like these could help to prevent the ‘outnumbering’ situation that Ratzka describes.

Taking into account these arguments, in order to satisfy the concerns of the DPM, the ideal personal assistance co-operative would arguably be a multi-stakeholder co-operative with decision-making somewhat weighted towards the disabled ‘work leader’ members; this reflects the power balance of the PA relationship. In practical terms, this might be most easily achieved by starting from the ‘Scandinavian model’ and incorporating a category of membership for PAs. NWCC is arguably the closest currently existing co-operative to this model in the UK.

Limitations of Co-operative Models for Personal Assistance

Co-operatives may solve some of the problems with personal assistance as it currently exists in the UK, in particular those around the administrative burdens and some of the relational tensions of individual direct employment. However, they are not a solution to every barrier that was highlighted by the PAs and direct employers interviewed. In particular, there is no realistic way for personal assistance co-operatives to address the issues that result from insufficient funding for personal assistance from local and/or national government. They do not generate income for PAs in themselves and rely on the funding awarded to individual disabled members from LAs or other sources. While the increase in flexibility that may be achieved by co-operative approaches could mitigate some financial difficulties by allowing individuals to share costs, the

scope of this is inevitably limited. Therefore, co-operatives should be seen as complementary to, rather than substituting for, public services (Restakis, 2010; Roulstone & Hwang, 2015); as a partial rather than a complete solution to the barriers to day-to-day autonomy and full social participation faced by disabled people with significant personal assistance needs.

There is also danger in using cost-based arguments in favour of co-operative approaches, as these may then be used by local and/or national government as an excuse to cut budgets if co-operatives are considered to be a cheaper option. Parallels can be drawn here with the cost-based arguments used by the DPM in the 1990s for the legalisation of direct payments on the grounds that they would be cheaper than traditional 'care' services (Zarb & Nadash, 1994). While this argument was successful in that it led to the passing of the Direct Payments Act 1996, it contributed to the tensions between social justice and market discourses in the implementation of direct payments (Askheim et al., 2014; Pearson, 2000) which have arguably led to some of the barriers to the realisation of the movement's original vision of independent living.

This argument complements that made by Sandoval (2016a, p. 58) that the co-operative concept "can ... be integrated into neoliberal discourses of entrepreneurship and individual responsibility". For example, co-operative business models were endorsed by Conservative prime minister David Cameron as fitting into his ideal of a 'Big Society' replacing state-funded services. As Beresford (2016) argues, both co-operatives and the DPM are among the self-organised initiatives whose emancipatory aspirations have been appropriated into reactionary 'cost-cutting' policy in the UK over the last several decades.

Concluding Thoughts

Sandoval (2016b, p. 109) calls for alliances between co-operatives and "other radical and progressive organisations" which, while she does not explicitly mention disability, could include the DPM — "in order to formulate joint demands" as part of a wider political movement and critique of capitalism. In the current economic and political context in the UK, it is imperative for both movements to collaborate in building the day-to-day material basis of a society based on values of autonomy and solidarity, while avoiding the subversion of their opposition to paternalistic authoritarianism exercised in the service of 'social protection' into defence of individualistic marketisation, and vice versa (Dodd, 2016). There are many possible points of connection for this; however, personal assistance has potential to be a particularly fruitful one, particularly considering the precedent of successful personal assistance co-operatives in the Scandinavian countries. The involvement of DPOs in co-operative experiments such as NWCC is a promising beginning, but it can be hoped that further initiatives can be developed to strengthen both the expansion of co-operatives into this field, and mutual awareness and dialogue between the co-operative movement and the DPM.

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References

Alliance for Inclusive Education, Black Triangle, British Deaf Association, Deaf Scotland, Disability Action (Northern Ireland), Disabled People Against Cuts, Disability Wales, Inclusion London, Inclusion Scotland, Lothian Centre for Inclusive Living, Merton CIL, National Survivor and User Network,

- People First Scotland, People First (Self Advocacy), Reclaiming Our Futures Alliance, Sisters of Frida, & Transport for All. (2018). *Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland: Alternative report from civil society*. Inclusion London. <https://www.inclusionlondon.org.uk/campaigns-and-policy/facts-and-information/equality-and-human-rights/evidence-for-the-alternative-report-from-civil-society/>
- Andersen, J., Hugemark, A., & Richter Bjelke, B. (2014). The market of personal assistance in Scandinavia: hybridization and provider efforts to achieve legitimacy and customers. *Scandinavian Journal of Disability Research*, 16(sup1), 34–47. <https://doi.org/10.1080/15017419.2014.880368>
- Askheim, O. P., Bengtsson, H., & Richter Bjelke, B. (2014). Personal assistance in a Scandinavian context: similarities, differences and developmental traits. *Scandinavian Journal of Disability Research*, 16(sup1), 3–18. <https://doi.org/10.1080/15017419.2014.895413>
- Barnes, C., & Mercer, G. (2006). *Independent futures: creating user-led disability services in a disabling society*. BASW/Policy Press.
- Beresford, P. (2016). *All our welfare: towards participatory social policy*. Policy Press.
- Bland, J. (2011). *Time to get serious: International lessons for developing public service mutuals*. Co-operatives UK.
- Bowman, V. (2001). *Home care, home support, personal assistance: The co-operative model in context*. British Columbia Institute for Co-operative Studies, University of Victoria.
- Brindle, D. (2016, November 3). Social care co-ops draw on first-hand experience. *The Guardian*. <https://www.theguardian.com/social-care-network/2016/nov/03/social-care-co-ops-draw-on-first-hand-experience>
- Charlton, J. I. (1998). *Nothing about us without us: disability oppression and empowerment*. University of California Press.
- Christensen, K. (2010). Caring about independent lives. *Disability & Society*, 25(2), 241–252. <https://doi.org/10.1080/09687590903537562>
- Conaty, P. (2014). *Social co-operatives: A democratic co-production agenda for care services in the UK*. Co-operatives UK.
- DeJong, G., & Wenker, T. (1983). Attendant Care. In N. M. Crewe & I. K. Zola (Eds.), *Independent living for physically disabled people* (pp. 157–170). Jossey-Bass.
- Disability Research into Independent Living & Learning [DRILL]. (2019). *North West Care Cooperative and Social Enterprises*. DRILL. <http://www.drilluk.org.uk/pilot-projects/north-west-care-cooperative-social-enterprises/>
- Dodd, S. (2016). Orientating disability studies to disablism austerity: applying Fraser’s insights. *Disability & Society*, 31(2), 149–165. <https://doi.org/10.1080/09687599.2016.1152952>
- Drake, R. F. (1996). A critique of the role of the traditional charities. In L. Barton (Ed.), *Disability and society: Emerging issues and insights* (pp. 147–166). Longman.
- Dunn, A. R. (2016, January 27). Disabled students like me rely on funding at uni. Now it’s been cut. *The Guardian*. <http://www.theguardian.com/education/2016/jan/27/disabled-students-like-me-rely-on-funding-at-university-now-its-been-cut>
- Equal Care. (2018a). *Home — About our care and support*. <https://www.equalcare.coop/>
- Equal Care. (2018b). Our rules and byelaws/members. <https://work.equalcare.coop/the-byelaws/members>
- Fisher, J., Rayner, M., & Baines, S. (2011). *Personalisation of social care and health: a co-operative solution*. Manchester Metropolitan University/Co-operatives UK. <https://e-space.mmu.ac.uk/205274/>
- Footprint Workers’ Co-operative Ltd. & Seeds for Change Lancaster Co-operative Ltd. (2015). *How to set up a workers’ co-op* (4th ed.). Radical Routes. <http://www.radicalroutes.org.uk/publicdownloads/setupaworkerscoop-lowres.pdf>
- Gordon, U. (2018). Anarchism and nationalism: On the subsidiarity of deconstruction. In N. J. Jun (Ed.), *Brill’s Companion to Anarchism and Philosophy* (pp. 196–215). Brill.
- Graby, S. (2018) *Personal Assistance: The Challenge of Autonomy* (Publication No.: uk.bl.ethos.770075) [PhD Thesis, University of Leeds]. <https://etheses.whiterose.ac.uk/23231>
- Guldvik, I., Christensen, K., & Larsson, M. (2014). Towards solidarity: working relations in personal assistance. *Scandinavian Journal of Disability Research*, 16(sup1), 48–61. <https://doi.org/10.1080/15017419.2014.897644>
- Hale, C. (2017). *Barriers to work: A survey of deaf and disabled people’s experiences of the access to work programme in 2015/2016*. Inclusion London. https://www.inclusionlondon.org.uk/wp-content/uploads/2017/10/Barriers-to-Work_InclusionLondon_Oct-2017-1.pdf
- Hall, E. (2009). Being in control: Personal budgets and the new landscape of care for people with learning disabilities. *Mental Health Review Journal*, 14(2), 44–53. <https://doi.org/10.1108/13619322200900014>
- Hasler, F. (1993). Developments in the disabled people’s movement. In J. Swain, V. Finkelstein, S. French & M. Oliver (Eds.), *Disabling barriers — Enabling environments* (pp. 278–284). Sage.
- Leadbeater, C., Bartlett, J., & Gallagher, N. (2008). *Making it personal*. Demos.

- Luckhurst, L. (2006). Can intensive support widen access to direct payments? In J. Leece & J. Bornat (Eds.), *Developments in direct payments* (pp. 221–236). Policy Press.
- Lund, M. (2011) *Solidarity as a business model: A multi-stakeholder co-operative's manual*, Cooperative Development Center, Kent State University. <https://ccednet-rcdec.ca/en/toolbox/solidarity-business-model-multi-stakeholder-cooperatives>
- Marshall, R. C. (2013). Does certification and self-governance professionalise co-operative home-care workers? The attractions of autonomy in Kōreikyō's co-operative model of home care. *Journal of Co-operative Studies*, 46(3), 24–35.
- Morris, J. (1993). *Independent lives. Community care and disabled people*. Macmillan.
- Oliver, M. (1990). *The politics of disablement*. Macmillan.
- Pearson, C. (2000). Money talks? Competing discourses in the implementation of direct payments. *Critical Social Policy*, 20(4), 459–477. <https://doi.org/10.1177/026101830002000403>
- Perry, F. (2017, January 10). *NHS Staff Can Decide Where Disabled People Live, Even Against Their Choice*. Disability United. <http://disabilityunited.co.uk/2017/01/nhs-staff-can-decide-disabled-people-live-even-choice/>
- Priestley, M. (1999). *Disability politics and community care*. Jessica Kingsley Publishers.
- Ratzka, A. (2015, March 24). *Self-determination through direct payments and personal assistance cooperatives* [Keynote address] Citizens Directed Co-operative Cymru launch, Cardiff, Wales. <https://www.independentliving.org/docs7/direct-payments-personal-assistance-cooperatives.html>
- Restakis, J. (2010). *Humanizing the economy: co-operatives in the age of capital*. New Society Publishers.
- Ridley-Duff, R., Schmidtchen, R., Arnold-Schararschmidt, M., Vuković, S., Klercq, J., Southcombe, C., Trzcinski, S., Wren, D. & Pataki, V. (2020). *Creating social enterprises in FairShares Labs*. FairShares Association Ltd. <http://shura.shu.ac.uk/25895/>
- Roberts, J. (2019a, June 4). Living Life Well: a co-operative approach to care. *Social Care Future*. <https://socialcarefuture.blog/2019/06/04/living-life-well-a-co-operative-approach-to-care/>
- Roberts, J. (2019b, November 8). *Our Local co-operatives* [Video]. YouTube. <https://youtu.be/KYqxtVkcIBc>
- Roberts, J. (2019c, November 8). *Our structure & how we operate* [Video]. YouTube. <https://youtu.be/HhZ52HV55T4>
- Roper, A. (2017). Transforming a social care charity into a multistakeholder co-operative: Some insights from cartrefi cymru co-operative. *Journal of Co-operative Studies*, 50(1), 51–54.
- Roulstone, A., & Hwang, S. K. (2013). *Co-operation and co-operatives in the development of direct payment schemes in Wales*. Wales Co-operative Centre and Disability Wales. <http://nrl.northumbria.ac.uk/id/eprint/16785/1/direct-payments-report-eng.pdf>
- Roulstone, A., & Hwang, S. K. (2015). Disabled people, choices and collective organisation: examining the potential of cooperatives in future social support. *Disability & Society*, 30(6), 849–864. <https://doi.org/10.1080/09687599.2015.1057317>
- Russell, M. (1998). *Beyond ramps: disability at the end of the social contract: a warning from an Uppity Crip*. Common Courage Press.
- Sandoval, M. (2016a). Fighting precarity with co-operation? Worker co-operatives in the cultural sector. *New Formations*, 88(88), 51–68. <https://doi.org/10.3898/NEWF.88.04.2016>
- Sandoval, M. (2016b). What would Rosa do? Co-operatives and radical politics. *Soundings*, 63(63), 98–111.
- Scott, J. (2016). *Taking care: a co-operative vision for social care in England*. The Co-operative Party. <https://party.coop/publication/taking-care-a-co-operative-vision-for-social-care/>
- Somerville, P. (2007). Co-operative Identity. *Journal of Co-operative Studies*, 40(1), 5–17.
- Spandler, H. (2004). Friend or Foe? Towards a critical assessment of direct payments. *Critical Social Policy*, 24(2), 187–209. <https://doi.org/10.1177/0261018304041950>
- Tengström, A. (1996, June 6-8). *Presentation of JAG* [Seminar presentation]. Seminar on personal assistance. STIL, Stockholm. https://www.independentliving.org/docs2/enilreporhelios_enilsem.html
- Uloba. (2021). *About working as an assistant*. Uloba — Independent Living Norge. <https://www.uloba.no/en/become-an-assistant/about-working-as-an-assistant/>
- Vasey, S. (2000). *The Rough Guide to Managing Personal Assistants*. Independent Living Institute. <http://www.independentliving.org/docs6/vasey2000.html>
- Westberg, K. (2010). *Personal Assistance in Sweden*. Independent Living Institute. https://www.independentliving.org/files/Personal_Assistance_in_Sweden_KW_2010.pdf
- Zarb, G., & Nadash, P. (1994). *Cashing in on Independence: Comparing the costs and benefits of cash and services*. British Council of Organisations of Disabled People. <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Zarb-cashing-in-on-indep.pdf>