

***'It was clear from the start that [SDS] was about a cost cutting agenda.'* Exploring disabled people's early experiences of the introduction of Self-Directed Support in Scotland**

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Abstract

The adoption of personalisation represents a global paradigm shift in the organisation of social care. However, such approaches have been criticised for failing to bring about transformative change. The passage of the Self-Directed Support (Scotland) Act (2013) was intended to bring about a significant change in the organisation of social care in Scotland, giving increased choice and control to new user groups. The implementation of the policy at a time of significant financial constraint for local government has cast doubt on this potential. This paper presents findings reflecting disabled peoples' lived experience of this change during the early stages of implementation. Drawing on one-to-one qualitative interviews with disabled people living across the central belt of Scotland, this early snapshot suggests that the policy had not significantly increased choice and control for service users, and that austerity was leading to an erosion of gains made by existing Direct Payments users.

Keywords: *Self-Directed Support, Direct Payments, Personalisation, Independent Living, Citizenship.*

Introduction

Since the 1970s disabled people in the global north have pioneered policies to support independent living through so called ‘cash for care’ schemes (Pearson 2012; Beresford 2014a). The principle of ‘personalised’ care (Leadbetter 2004), whereby individuals receive upfront payments in lieu of direct care, has since become an important feature of health and social care policy internationally (Alakeson 2010), albeit often drawing on a different ideological basis from the disabled people’s movement (Needham and Glasby 2015).

Personalisation has come to be described as having represented something of a paradigm shift (Flemming, McGilloway and Barry 2016). However, there has been concern that both personalisation, and policies pioneered by the disabled people’s movement such as Direct Payments (DP), have been of benefit to only a small proportion of social care users (Hart 2014; Slasberg and Beresford 2016a). The approach to personalisation in the UK context has been criticised for failing to address wider issues such as the underfunding in social care, limiting potential to deliver significantly improved outcomes for disabled people (Slasberg and Beresford 2016b).

Scotland has historically resisted the adoption of personalisation (and indeed user-led DP policies – Pearson 2000), due to concerns over undermining the role of the public sector (Pearson, Ridley and Hunter 2014; Manthorpe et al 2015). The introduction of Self-Directed Support (SDS) in Scotland in 2014 has been characterised as representing a new approach with the potential to achieve ‘the best of both worlds’ (Needham and Glasby 2015) emphasising concepts such as co-production and the expansion of choice and control to new service users (Pearson, Ridley and Hunter 2014). Nevertheless, the policy’s implementation at a time of unprecedented financial constraint for local government in Scotland (Spowart 2011; Pearson and Ridley 2017) has cast doubt on the ability to achieve these aims (Pearson, Watson and Manji 2018). Based on interviews with disabled service users conducted in the

early months of implementation, this article examines the policy's potential for extending opportunities to exercise choice and control to new user groups. It also explores the impact of austerity on new and existing service users' experiences of this change.

Challenges to exercising choice and control

An important criticism of personalisation in the UK, and 'cash for care' schemes more broadly, has been that the benefits of increased choice and control have been enjoyed by only a small proportion of service users (Slasberg and Beresford 2016a). This is equally true of the original DPs pioneered by the Independent Living movement, as it is for more recent policies pursued in England such as Personal Budgets (PBs) and Individual Budgets (IBs) (Slasberg and Beresford 2015). The Community Care (Direct Payments) Act (1996) was a significant (and often under acknowledged – Beresford 2014b) win for the disabled people's movement. However, the legislation only enabled, rather than required, the provision of DP to those who were eligible to receive community care (Pearson and Riddell 2006; Morris 2004). Local authorities had considerable discretion over how they delivered the policy, and social workers continued to retain significant power over who could access them (Ellis 2007). As a result, provision developed inconsistently, with access restricted to those with physical or sensory impairments (Pearson 2000; Pearson and Riddell 2006). Implementation saw the emergence of significant regional inequalities in access to DPs with take up significantly higher in England, where the personalisation agenda was more openly embraced by local authorities, than in Scotland, Wales, and Northern Ireland (Pearson and Riddell 2006). This section explores some of the challenges to exercising choice and control in a UK context.

Expanding opportunities to new service users

Despite the dominance of the personalisation narrative in public policy since the mid-2000s (Pearson 2012), as of 2012 DPs users in England represented no more than 5% of all social care recipients (Beresford 2014a). The introduction of PBs in England has seen this increase to 10%, however the evidence of this leading to better outcomes for disabled people has been heavily contested (ibid). Personalisation then, has not necessarily been synonymous with an increase in choice and control for those receiving ‘personalised’ services. Where positive outcomes have been noted, this has involved service users who have used PBs to hire their own staff in the mode of a DP, rather than to purchase traditional services (Slasberg and Beresford 2016b). However, becoming an employer requires considerable administrative and organisational skills, as well as a willingness to adopt personal risk (Flemming, McGilloway and Barry 2016). Understandably therefore many service users, including those with learning difficulties¹, have been reluctant to take on this role (Lockwood 2014; Hamilton et al 2017). As a result the most comprehensive packages of support have tended to be secured by the most articulate and vocal individuals, while those who lacked these assets have had to make do with a more one-size-fits-all model of traditional service provision (Hart 2014). In England, the introduction of Managed Personal Budgets and Individual Service Funds has suggested one mechanism to overcome the issue of risk (Needham and Dickinson 2018). However, prior to the introduction of SDS there was no equivalent at a Scottish level.

The original user-led schemes in the US and UK, which predated DPs, operated on a peer support model with centres for independent living (CIL) providing information and advice as well as assistance with accounting, payroll and employment law (Pearson 2012). Though the

¹ There is considerable debate on terminology with ‘learning disability’ or ‘cognitive impairment’ being the dominant phraseology. The author has adopted ‘people with learning difficulties’ as this is the terminology used by members of People First (Scotland), a disabled people’s organisation who contributed to the research, and who work to ensure that people with learning difficulties have choice and control in all areas of their lives. <http://peoplefirstscotland.org/about-us/>

New Labour Government of 1997-2010 committed to the creation of CILs in every local authority in the UK (Prime Minister's Strategy Unit 2005), this has fallen far short in the implementation. However, the provision of high quality information and support to enable disabled people to make appropriate decisions about how best to organise care to suit their needs has been identified as an important means of overcoming these barriers both in the UK and internationally (Alakeson 2010; Bond 2014). This is particularly so in supporting the transition from traditional services to employing Personal Assistants (PAs) (Flemming, McGilloway and Barry 2016).

Funding for transformative change

Better information and support may help to overcome some of the barriers to exercising choice and control on an individual level. However, a major structural limitation to the expansion of true choice and control in the UK has arisen through historical inconsistencies in the funding and organisation of social care. Despite numerous attempts at policy change (Pearson 2012; Beresford 2014b) path dependencies have been difficult to shift (Slasberg & Beresford 2017). The success of campaigning by disabled people in the UK in 1990 which led to the introduction of DPs was aided considerably by research (Zarb and Nadash 1994) that indicated that the approach would likely result in a reduction in spending per head in social care. This was a tempting lure to the then Conservative Government (Pearson 2012). However, in reality the policy has proved more costly, with spending for DP users typically 80% higher than traditional services (Slasberg and Beresford 2015). Nevertheless, while personalisation has become the dominant policy paradigm in social care in the UK since the mid-2000s, there has been no accompanying increase in funding. This has been compounded by the requirement on local authorities to deliver a balanced budget. (Beresford 2009; Slasberg and Beresford 2016b; Slasberg and Beresford 2017). As a result councils operate

strict eligibility criteria to identify those who qualify for support (Slasberg and Beresford 2016b). Inequalities in local authority funding have also meant that social care users face a significant postcode lottery in provision (Slasberg & Beresford 2016b).

This geographical inconsistency is replicated in the adequacy of provision within local markets. Local authorities have not invested significantly in ensuring that service users are able to explore creative alternatives to either private sector service providers or the direct payments model taking on the role of an employer, which could lead to greater choice and control (Lockwood 2014). Instead there has been a tendency to assume that the market would provide (Beresford 2009). As a result, it has been argued that rather than empowering service users, the concept of ‘choice’ under personalisation has served to empower providers and to undermine the role of the state (Rummery 2002). The imperative for care providers within this context to produce a profit has further impacted on stretched local authority finances, but without notable increases in service quality (Morris 2011). Since the financial crisis, and the adoption of austerity across the global north (Farnsworth and Irving 2012), social care budgets have faced further constraint in the UK. Personalisation policies have been embraced in this context as a cheaper alternative to traditional service provision, leading to the closure of specialist services such as day centres (Hamilton et al 2017). One consequence has been the fragmentation of social networks of disabled people who have relied on these services, leaving them increasingly isolated as a result (ibid).

Self-Directed Support in Scotland: ‘the best of both worlds’?

Scotland has historically been sceptical of both DPs and personalisation policies (Glasby & Needham 2014). Despite efforts following the creation of the Scottish Parliament to require local authorities to provide a DP to all eligible social care users requesting them, uptake consistently lagged behind England (Manthorpe et al 2015). This was largely due to a reticence from within Scottish Local Authorities driven by concerns over the marketisation of care, and in particular that increased user control would undermine the role of the public sector (Pearson and Riddell 2006). Concerns also rested on assumptions around some individual's capacity to exercise choice and control over their care, as well managing risk (Pearson 2004). The Community Care (Direct Payments) (Scotland) Act 2002 placed the onus on individuals to request DPs, rather than on local authorities to offer them (Elder-Woodward 2016). This has meant that power to grant DPs continued to rest in the hands of local authorities and there was little impetus for change.

In announcing the move to SDS in 2009, the Scottish government signalled a rhetorical shift away from previous policies emphasising co-production of public services and greater control by the service user (Manthorpe et al 2015). SDS is part of an assortment of approaches to the commissioning and provision of community care. While it is often used synonymously with DP, SDS in the Scottish context refers to a range of options, including but not limited to DPs, that disabled people can 'choose' from in order to receive their support (Pearson, Ridley, and Hunter 2014). The four options available under SDS are: having a DP (option 1); the local authority holding funding but allowing the care recipient to decide how that should be spent (option 2); traditional services chosen and provided by the local authority (option 3); or a mixture of all three (option 4) (Scottish Government 2014a).

The potential for innovation is most evident in option 2 which, by enabling individuals to instruct the local authority fund holder on how they wished their allocated budget to be spent, provides individuals with the opportunity to control how care is provided, but with significantly reduced personal risk (Kettle 2015). Similarly, the ability to mix traditional services with more personalised approaches would enable service users to exercise greater flexibility over their care arrangements (Rummery et al 2012).

Despite this potential, early evidence has suggested that the traditional care culture has been hard to shift. In 2015, the majority of those in receipt of local authority community care in Scotland continued to receive support from option 3 (traditional services chosen by the local authority [Pearson and Ridley 2017]). This calls into question the amount of choice and control service users have been able to exercise under the new system. The guidance on SDS adopted open language allowing for innovation and adaptation to local needs (Manthorpe et al 2015). However, this has also caused challenges for those charged with implementing the policy (Pearson, Watson and Manji 2018)

Nevertheless, SDS has involved a shift in language around the purpose of community care. While traditional services have focused on tasks such as toileting, washing, dressing, etc., SDS focuses on the ‘outcomes’ individuals wish to achieve as a result of the support they receive (Pearson, Ridley, and Hunter 2014). These could include being able to socialise more with friends, or taking up new hobbies. While there has been some suggestion that this change is more significant in the rhetoric than in the practice (Glasby and Needham 2014) this represents an important culture change, for both local authorities and disabled people. The traditional disempowering model of service provision has typically resulted in a gap between the aspirations of disabled people and their lived realities (Witcher 2014). SDS

therefore represents an important opportunity to increase these aspirations. However, as with other approaches internationally, without appropriate support, some disabled people may still struggle to articulate the outcomes they seek (Alakeson 2010, Beresford 2014a). The involvement of individuals and organisations of disabled people will therefore be critical to assessing whether SDS is able to live up to its rhetorical claims (Elder-Woodward 2016).

SDS and the local government funding crisis

SDS became the default approach to social care across Scotland from April 2014, though local authorities were encouraged to adopt the outcomes-focused approach and introduce service users to the range of options as early as 2012 (Pearson, Riddley and Hunter 2014). However, as with personalisation reforms in England, the Scottish legislation did not address the funding of social care in Scotland (Pearson and Ridley 2017). While the SDS test sites were given innovation funding, which was used in some areas to ensure continuity of care for those transitioning from traditional services (option 3) to a DP (option 1), this was not the case for the national rollout (Manthorpe et al 2015).

The implementation of SDS at a time of considerable financial scarcity for local government may have further reduced the policy's potential to bring about the changes it promised (Pearson and Ridley 2017). A disproportionate share of the cuts to the Scottish Budget have been placed on local authorities (Spowart 2011), and these have in turn been unequally distributed to social services (Pearson and Ridley 2017). In addition, the ability of local authorities to increase revenues through tax raising powers was severely constrained during this time due to the ongoing council tax freeze implemented in 2007 (Pearson, Watson and Manji 2018). This has inevitably inhibited the potential of SDS to bring about the culture change required, and has diverted attention away from outcomes in favour of issues around

resource allocation and budgetary management (Ridley et al 2011). As a result there is a risk that local authorities may view the change as an opportunity to claw back resources by redrawing eligibility (Pearson and Ridley 2017) as has been the model in England (Slasberg and Beresford 2016b).

Community care charges: recouping the costs of SDS from service users?

A further challenge to the ability of SDS to achieve its potential is that a growing expectation has been placed on service users to meet the costs of their care. Since 2003, social care activities related to personal care (washing, dressing, toileting, etc.) in Scotland have been provided free of charge to those over the age of 65 (Bell, Bowes, and Dawson et al. 2007). However, adults in receipt of social care aged under 65 are often expected to pay a contribution towards the cost of providing their care. Charges are generally calculated on a proportion of all income (including from benefits) over a certain threshold (around £120 per week for a working-age adult), with those earning below this threshold exempted from charges (COSLA 2013). Although the Coalition of Scottish Local Authorities (COSLA) provide guidance on how charging policies should be developed, including that they be fair and developed in co-production with service users, local authorities have considerable discretion over how charges are implemented. This means there is significant variation in local policies including whether to disregard income from some benefits, as well as what proportion of income to levy the charge on (COSLA 2013). In 2013 the proportion of income on which the means test was applied ranged from 0% all the way up to 100% (Learning Disability Alliance 2013). This meant that some social care users who were in work could face charges on the basis of 100% of their earned income over the cap. Local authorities are not required to impose community care charges, and in 2014 two councils in Scotland, Edinburgh City Council and Fife Council, had abolished care charges for all adult social care

users (Learning Disability Alliance 2013). In this context, SDS in Scotland faced many of the same funding challenges as has personalisation in England.

The foregoing discussion has highlighted a number of challenges to personalisation or cash for care policies internationally and within the UK, focusing in particular on the challenges of bringing about change in an era of budgetary scarcity in social care, as well as limitations to the expansion choice and control to new user groups. It has also sought to examine the potential for SDS to overcome some of these challenges in the Scottish Context. The remainder of this article will provide an early snapshot of service users' experiences of this policy, during the early months of implementation. It will seek to answer two questions: firstly, whether the policy had expanded opportunities to exercise choice and control to new groups of service users, and secondly what impact the context of austerity and financial constraint was having on this aim.

Methods

The findings presented here are derived from a three year ESRC/Scottish Government funded PhD studentship looking at the impacts of the Coalition Government's Welfare Reform Programme on Disabled People living in Scotland. While the focus of the project was participants' experience of UK-level reforms, the passage of the SDS Scotland Act, just prior to the commencement of fieldwork, provided an additional and important sphere of change. Interviews were conducted between November 2013 and July 2014.

The main study involved one-to-one semi-structured interviews with 23 disabled people in receipt of UK government benefits such as Incapacity Benefit (IB), Employment Support

Allowance (ESA), Disability Living Allowance (DLA), or payments such as from the Independent Living Fund (ILF). This paper presents findings from a sub-sample of interviews with 13 participants who were in receipt of a local authority community care package. This sub-sample included 6 women and 7 men ranging between 32 and 67 years of age (see table 1 below). None of the participants in the study came from a non-white ethnic minority background. Scotland is largely ethnically homogeneous with ethnic minorities making up only 4% of the Scottish population (Scottish Government 2015). All of the participants experienced physical impairments, of whom two also experienced depression, three also experienced learning difficulties, and one also experienced a sensory impairment. Six had used a direct payment to employ their own personal assistance (PA) prior to the introduction of SDS, while 2 had started using a DP (option 1) following the change. A further five were using traditional services (option 3) such as home care provided through an agency.

Table 1: Participant characteristics

[table 1 here]

Participants were recruited from across the central belt of Scotland, through both disabled people's organisations (DPOs) (N= 8), and charities working for disabled people (N=5). Contact with DPOs utilised the author's personal relationships within the movement, while contact with charities was arranged cold via email. Two participants were recruited through a charity, following an event the author presented at. Both types of organisations circulated information about the project purpose and sampling criteria with the authors contact details and an invitation to participate. Inclusion criteria for the wider sample was that participants should be aged between 18 and 65 (though one exception was made to this based on the participant's expertise within the social care sector), and be in receipt of a UK level disability

related benefit or payment such as ESA/IB DLA, or ILF. The sub sample was composed of participants who also received social care from their local authorities.

As a result of these recruitment methods the sample is weighted in favour of participants who have had some political involvement in the wider disabled people's movement, and was therefore likely to include more participants with experience of using direct payments, than would be expected from the wider population. The size of the sample, drawing on a sub sample of a wider research project, is also acknowledged as a limitation. Nevertheless, the timing of fieldwork coinciding with the implementation of SDS enables a useful early snapshot of disabled people's direct experience of the new policy.

Interviews were transcribed verbatim and a thematic analysis was conducted, supported through coding in NVivo 10 for Mac (2014). The project received approval from the University of Glasgow College of Social Sciences Research Ethics Committee. Participants' anonymity has been protected through the use of a pseudonym, and any identifying details have been removed.

Self-Directed Support: expanding choice and control to new user groups in Scotland?

The above discussion highlighted that the benefits of exercising choice and control through personalisation have tended to be enjoyed by those using DPs to employ PAs (Beresford 2014a). This has historically limited the exercise of choice and control to a minority of social care users. This section will examine the extent to which the introduction of SDS in Scotland had resulted in an expansion of opportunities to exercise choice and control among this small sample.

Six of the thirteen participants in the sub-sample were already using direct payments, prior to the introduction of SDS, while one other had been exercising choice and control through an indirect payment scheme run by his local authority. Although all of the existing DP users discussed the additional work that was involved in managing a DP, they were overwhelmingly positive about the benefits it had brought to them:

It means security, it means being able to go out and do things, not feeling anxious about going out on my own... very fundamental things... some things I just couldn't do at all... Other things I might be able to do but it would be more hassle and awkward and difficult. (Pat, 67)

It's as much, I suppose... about assisting me to do things rather than them [PA] doing things for me. Now there are times when I have to say to [PA] 'will you do this' you know and they just go ahead and do that. But for the majority of the part I try and be involved in that too. (Susan 62)

Prior to the implementation of SDS, participants who had not been using DPs had received social care through traditional services provided through an agency, or by attending a day centre funded through their local authority. In contrast to the testimonies above, this second group felt significantly less control over the support they received, and expressed scepticism over the capacity of agencies to truly meet their needs:

They [agency] don't do a good job of it at the best of times [but] they keep mucking up [wife's] rota, which doesn't help. Keep giving us inaccurate information. (Michael, 41).

Well, I've never heard anything about them being effective and able to help people properly... I mean, things that I need done, like if I needed to change a light bulb. Or if I had to go any great distance, I would have a carer with me. Which is my brother... Anything else that I need, anything as simple as a light bulb. I can't see [agency] coming out to help with that. (Peter 41)

This group therefore arguably stood to gain the most from the opportunity to have greater influence over how their care was organised. Nevertheless, they expressed mixed views about the potential that SDS might hold for them:

There's a lot of people terrified of it. Because they're then bound by employment laws and all that gambit. Do they have to have fire extinguishers in their house? You know, there's a whole host of issues that it brings in. (Lewis, 46)

This is very a legitimate concern, and as discussed above reflects one of the biggest challenges of the shift away from traditional service models (Bond 2014; Lockwood 2014). Lewis was also concerned about what transitional support would be available to him if he changed his existing arrangements:

Social work [told] me that it's complicated... for them... So I could be left without care for I don't know how long. There would be this break. It wouldn't just be seamless ... three months is a guess. It could be longer. (Lewis, 46)

This further highlights the need for consistency in the transition to ensure that individuals are able to get the most out of SDS (Bond 2014, Manthorpe et al 2015, Fleming, McGilloway & Barry 2016). Lewis had decided to continue receiving support from his day centre and home help service (option 3) rather than explore a DP (option1) or other arrangement that might have given him more input into the support he received. Like the other participants above, it was clear that Lewis was not completely happy with his existing care arrangements, and had found them to be disempowering at times:

I feel I can't do a lot of stuff. I feel frustrated, I feel lost, a lot of the time... you just feel so inadequate... even in your own home, you feel so inadequate a lot of the time. (Lewis 46)

Given his reluctance to become an employer, Lewis might have benefitted from an option 2 package, giving him the flexibility of being able to have greater influence over his care while not having responsibility to hold the budget. However it was unclear whether this option had been discussed with him. This has been identified as a wider challenge in the implementation of SDS with local authorities lacking clarity in how an option 2 package might be implemented (Pearson, Watson and Manji 2018).

While there was significant and understandable hesitancy from Lewis, another respondent living in a different area had clearly benefitted from the ability to play a bigger role in directing her own support. Sophie had received support from the same home-care service for fifteen years, and had built a strong relationship with the staff who supported her. However, when her main carer retired the council had discussed the options available to her through SDS and she had decided to move to a DP (SDS option 1). This had enabled Sophie to meet an important aspiration of hers which was to be able to get out and about more in her community:

We go to museums, art galleries, we just go out for coffee, something that I don't feel able to do [alone] you know? Which is good. It gets me out of the house. (Sophie 47)

Nevertheless, she felt that her local authorities' strict interpretation of the outcomes focused approach, although positive, had come at the cost of meeting her ongoing need for more traditional support services:

The thing that really annoyed me was when [local council] came back and said, yes you can have [a DP] but you can't use it for housework. ... I can't wipe stuff up, and if I started walking on wet floors I'd end up with broken legs. I slip and fall anyway, and it's just going to get really dangerous. So I do use it for housework; I just don't tell them. (Sophie, 47)

Sophie's experience demonstrates the potential that SDS has to make a difference to disabled people's lives. Prior to the change, Sophie had become socially isolated following a disability hate crime incident. Being able to pay someone to accompany her to do the activities she enjoyed had made an important difference to her ability to live independently. At the same time, underpinning her desired outcomes was her ongoing need for practical support within the home, which was no longer being met because of the way the policy was being interpreted. This suggests that, at least in the interim, a balance needs to be struck between the traditional approach of task and time and an outcome-focused approach that empowers participants while still enabling their needs to be fully met.

Though based on a small sample of interviews conducted early on in the implementation of SDS, these findings indicate that the new approach had yet to make significant headway in opening up opportunities for exercising choice and control to new user groups in Scotland. While participants who already used DPs were well networked and supported by user-led and peer support organisations such as CILs, participants who had not previously used DPs had relatively little knowledge about the changes. This echoes a concern raised by one of the existing DP users:

...There's not enough support, not enough infrastructure to make sure that people are able to use SDS properly...There could be a real question placed over the future of SDS if people are not helped to manage it. And I don't mean monitoring. I mean help to use the system properly.

As with personalisation policies internationally (Alakeson 2010), without adequate support service users are unlikely to be able to make the most of the opportunities presented by SDS.

SDS and austerity: a cost cutting agenda?

Half of the participants in the sub-sample (N=6) were already using DPs prior to the introduction of SDS, and therefore were already exercising considerable choice and control. At face value then, they would appear to be unlikely to be impacted by the change (Beresford 2014a). However, interviews with participants in this group indicated that this was far from the case. The timing of implementation in a period of considerable constraint for local government finances was having noticeable implications for existing DP users. Four of the six had experienced a reduction in their care packages following the implementation of SDS in their area. One participant articulated clearly that she felt that the policy was being undermined by austerity:

SDS... in my view has been a fantastic opportunity, which has been entirely missed... I've worked in social work, and I know how difficult it is to balance resources [...] it's not an easy thing to do, and it's not easy for people to have to decide on priorities, [... but] it was clear from the start that [SDS] was about a cost cutting agenda. (Susan, 62)

Susan's council had taken the decision to re-assess all existing DP users as part of the introduction of SDS. Following her own re-assessment she faced a proposed cut of 47% on her existing package. Susan had managed to challenge this decision, but was still facing a

deficit of 26% at the time of the interview, which she was continuing to contest with her council.

I'd taken legal advice about this situation and I knew they were in breach of the statutory requirements. So I wrote to the council's monitoring officer. I got a six page response, honestly, full of gobbledegook...so it's just wearing people down, who challenge... Actually by that stage I was starting to feel very worn down by it, because it was taking up quite a lot of my time and energy.

Susan's background as a social worker had meant that she had a good understanding of the system, and she therefore had the experience and resources to challenge her assessment. However, for many social care users, particularly those who had not previously directed their own support, this would have been much harder to achieve.

Denis and Vanessa, a couple who both participated in the study individually, and lived in the same council area as Susan had also seen a significant reduction in their collective support. Vanessa had used DPs since the early 2000s, but had recently moved from a different local authority to live with Dennis so had been assessed for SDS as a new service user. Dennis had transferred from an 'indirect payments' system, an early precursor to option 2 which was being phased out following the introduction of SDS. This historic scheme had meant that Dennis had been able to hire his own staff and decide when and how his care was organised, but was not required to directly handle any funds, which were instead held for him by a third party. Crucially, this system meant that he had been able to hire his own PAs but without the

additional reporting required of a DP and with considerably reduced personal risk. While Denis would have been happy to move to an equivalent option 2 arrangement under SDS, his local authority had decided that social care recipients on option 2 could not use it to directly employ staff. Dennis had therefore decided, reluctantly, to move to a DP (SDS option 1). In doing so he had taken on a considerable administrative burden:

So, instead of the money going direct to the payroll company, it comes direct to me and I transfer it to the payroll company. But in doing that I need to then send in monitoring sheets to the council so I can demonstrate how direct payments get spent. It's more work for me, and it will take me longer to do, and that's why I resisted it for so long. (Dennis, 35)

Dennis had only been receiving his DP for one month at the time of our interview, however the process of moving had been a long complicated one, taking over a year. Dennis encountered a number of challenges along the way, including that the initial figure approved by the local authority finance department had proposed a significant cut to his allocated hours, from 31 to 23 per week.

...So I said to the social worker, 'I can't survive on that, you'll need to go back.' And my social worker said, 'oh, I don't think you'll get more because that's what your budget says... So I said, 'I'm not really negotiating. I can't work on that', and I said 'is that what his professional assessment says?' And [he] went 'well my professional assessment is different, my professional assessment

says you need at least 31 hours.’ So I said to him ‘well, we’ve got a bit of an issue here’. (Dennis, 35)

Denis had eventually secured an assessment of 35 hours support per week, on the surface an increase in his allocation. However, his fiancé Vanessa had not been as successful at defending the cut to her package from 72 hours per week, to 56, a cut of 16 hours per week. Because the couple shared carers, and in practice redistributed their allocation between them, this meant a cut to their collective allocation. Vanessa required access to personal assistance 24 hours a day to enable her to live and work independently, but her new assessment had left her with gaps when she had to manage without a PA. Dennis and Vanessa had managed to cover some of these gaps, but she was conscious that Dennis was doing less well out of this arrangement, despite the increase in his allocation:

He maybe only gets a shave once a week now, where he used to have a shave maybe every couple of days. And it’s not because I’m saying, ‘you’re not getting the PA’. It’s because I have higher support needs than him, and there isn’t quite enough funding there to [cover us both] (Vanessa, 32)

The experience of moving to SDS had not been a positive one for Vanessa and Dennis. The increased regularity of assessments under the new system had also left a lasting sense of anxiety:

It’s the worst experience of my life with social work. It’s degrading, it’s inhuman... I’m fearful for the next review coz

you are meant to get one every year... even though my needs probably won't change. The problem is that their eligibility criteria will probably change. So we could get even less next year. (Dennis 35)

The regularity of assessments was intended to ensure that service users' needs were being fully met. However, the wider context of welfare reforms at this time (Beatty and Fothergill 2015), as well as changing eligibility criteria meant that regular re-assessments were being met with considerable anxiety. The pressure on existing packages of support was not unique to Susan, Dennis and Vanessa's local authority. Sheila, lived in a different council area and had viewed her SDS assessment as an opportunity to request an increase in her allocated hours of support. She had been using a DPs for nine years, and not had her needs reassessed during this time despite experiencing a degenerative impairment. When she had asked her social worker for an increase in hours of support she was told *'they didn't have the money.'* Sheila was involved in her local SDS user group forum and had raised her experience with the council there:

I put the question 'what happens if someone's condition has worsened and they need more help', and I was told, 'if you have a crisis you will get help, but there's no more money. We're told that we have to implement SDS and part of SDS is the direct payment, but we're not getting any more money.' (Sheila, 62)

Sheila was therefore drawing on her Independent Living Fund (ILF), payments made to those with the highest support needs, to enable independent living, in order to cover the deficit.

I shouldn't have to use my ILF money for personal care. That should be over and above, and it's not happening like that... My ILF money's supposed to be for my support rather than supplementing the council. (Sheila, 62)

Sheila was also acutely aware at the time that the future of her ILF was also under threat following the decision by the Coalition Government to close the fund and devolve it to local authorities in England and to the Scottish Government in Scotland. While the Scottish Government has since preserved the fund for existing users (Scottish Government 2014b), this decision was yet to be announced at the time of Sheila's interview. Losing her ILF would have significantly reduced her independence, leaving her even more reliant on the limited personal care package she received from the local authority. The experience of these participants suggests that despite the outcomes focused approach of the legislation, budgetary considerations were still taking primacy in some local authorities.

Community care charges: passing on the costs of care

A further consequence of austerity highlighted by those involved in this study was an intensification of local authority community care charges. These are determined at a local level meaning the charges applied varied considerably across, and sometimes even within council areas. Four participants were living in local authorities that had abolished care charges for all age groups, so were not having to pay towards the cost of their social care. Another participant was over the age of 65 and so did not have to pay a charge on his personal care, but was still charged for domiciliary care (cooking, cleaning, etc.). One

participant paid her contribution directly to the ILF, and this was deducted from the care component of her DLA. She was therefore exempt from local authority charges.

Five were fully liable for charges, but again their experience varied considerably across local authority area as well as according to the benefits they received. Dennis' council expected him to contribute 50% of any income he earned over the threshold (£120 per week) because he was in full time employment. Susan had retired for health reasons, but because she was under 65 she still faced charges of £560 per month for her care:

It's changed again this year, ... because I'm under 65 I pay for all of my care so [I] pay for personal care, and anything that's counted as domestic support, housing support or personal support. So I basically pay for all the care I get from the council.... When I hit 65 if that is still the current policy, my contribution will be reduced slightly. (Susan, 62)

She used her £324 DLA care component to cover part of the charge but still had to meet the additional £236 out of her pension.

Decisions on who was liable for charging varied across local authorities as well, with some exempting those in receipt of the lower or middle rate care component of DLA, but not the higher rate. Often this was a rather arbitrary decision that bore little relation to the amount of care actually used by the individual. Lewis and Peter both attended the same day centre. Lewis attended the centre on two days per week, and also had someone from a homecare service for three hours per week to help him with his cleaning. Peter did not receive any

home care, but also attended the day centre for two days per week. However, because Peter received the higher rate of DLA and Lewis the middle rate, Peter was expected to pay £57.10 per week towards the cost of his attendance at the day centre, while Lewis was not required to pay anything. Peter's local authority had changed their charging policy at the same time as they introduced SDS:

I don't think I'll be able to continue at the centre, because of the Self-directed Support that's kicking in with the contributions, which are quite heavy. When I arrived at the centre in 2005, I was totally in that wheelchair and I was getting physiotherapy to get me back up on my feet. [...] and it took a while, but I managed to get back up on my feet for most of the time. (Peter, 50)

The timing of this change meant that Peter viewed SDS and the change in charging policy as two sides of the same coin. Attending the centre had been an important part of Peter's life, and he had been active in the management of the centre through his role as a trustee. The introduction of charges meant that he would no longer be able to contribute to his community in this way, as well as risking him becoming more socially isolated as a result. This is a growing consequence of austerity, with similar impacts for disabled people documented elsewhere in the UK (Hamilton et al 2017). COSLA's guidance on community care charges for 2013/14 (COSLA 2013) encouraged local authorities to give cognisance to the broader context of UK government welfare reforms, and the introduction of SDS. The experiences of participants in this study suggest that this this was not being reflected in local authority charging policies at this time.

Discussion

The findings presented here indicate that participants who used traditional services were not seeing significant changes in the organisation of their care following the introduction of SDS. These respondents also exhibited scepticism at the policy's potential to make a difference to their lives, and hesitancy at the additional work that would be involved for example in taking on a direct payment. This suggests that service users were not being given adequate information and support to explore opportunities to exercise greater choice and control. This was compounded by the lack of interim support to enable the transition from traditional services to option 1 or 2. Though based on a small study conducted early on in the implementation of SDS, these findings support research into cash for care schemes internationally (Alakeson 2010; Needham and Dickinson 2017), as well as at a UK level (Hart 2014; Manthorpe et al 2015; Fleming, McGilloway and Barry 2016). SDS was still a relatively new approach at the time of interviews for this study, and further research is required to establish whether this is likely to be an ongoing challenge.

Furthermore, the experiences of existing direct payments users suggests that the impact of the financial crisis and ongoing austerity on local government has been a reduction in choice and control for this group. While the most articulate individuals have been able to mobilise assets and social capital to challenge this in some cases, they have not always been successful in doing so. This is an important observation which goes against much of the wider research on personalisation, in which the most articulate service users and those using DPs have been able to achieve significantly better outcomes (Hart 2014; Beresford 2014a; Slasfberg and Beresford 2017). Again, further research is needed to establish whether this is a more widespread phenomenon.

The financial climate has also seen local authorities increasingly passing on the costs of care to individuals in the form of community care charges, which has impacted negatively on both new and existing service users. This underlines wider unresolved challenges around the funding and organisation of social care (Slasberg and Beresford 2016a). The impact at an individual level can be particularly acute when this affects not only on personal care, but also activities supporting social networks as with Peter and Lewis above. While increased risk of social isolation has been identified as a consequence of the confluence of personalisation and austerity (Hamilton et al 2017), further work is needed to explore the role of charging policies in this broader context.

Conclusion

This article has examined the introduction of SDS from the perspective of social care users in Scotland during the early stages of implementation. It began by examining some of the challenges of expanding choice and control to those using traditional services, as well as some of the structural barriers to expansion arising from the funding and organisation of social care in the UK (Slasberg and Beresford 2016a and 2016b). SDS was presented as a possible solution to some of these challenges (Needham and Glasby 2015), however its implementation at a time of significant financial hardship for local government has raised doubts over this potential (Pearson and Ridley 2017). The findings presented in this article suggest that, from this early snapshot at least, SDS has not been implemented with sufficient support to enable opportunities to exercise choice and control to be expanded to new user groups. Furthermore, the experiences of participants in this study have suggested that the timing of implementation has resulted in a rolling back of gains made by existing DP users.

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