Partnership and Personalisation in Personal Care: Conflicts and Compromises

Kirstein Rummery[1] , Julia Lawrence[1]* and Siabhainn Russell[2]

[1]Faculty of Social Science, University of Stirling, Stirling, UK
[2]Department of Social Care and Social Work, Manchester Metropolitan University, Manchester, UK
*E-mail: julia.lawrence@stir.ac.uk

Background: Personalisation in social care services has become a feature of the delivery of long-term care for disabled people in many developed welfare states. Aim: Scotland has used the devolution of health and social care powers to develop a personalisation scheme (known as 'Self-directed Support'). The authors apply a theoretical and empirical framework to understand the experience of contemporary disabled users of personalised services. Methods: The authors use a Scottish data set of six focus groups and a survey of 126 disabled people and family carers. Results: The data showed that flexible funding and the ability to provide services that cross agency boundaries were instrumental in moving towards equitable outcomes. Conclusions: Although there are clear policy and practice barriers to inter-agency working in personalised care services, the evidence suggests that it is worth investing in overcoming these barriers for disabled people and family carers.

Introduction

Historically disabled people needing care and support have always relied on a mix of family, private and state support to meet their needs (Barnes and Mercer, 2010). A growing demand for state services has revealed that these are not always user-centred or flexible enough to meet needs. In response to this, there has been an international shift towards 'personalisation': devolving the funding and therefore the responsibility for providing support from the state to individual service users (Slasberg *et al.*, 2012; Thill, 2015). At the same time developed welfare states have increasingly moved towards 'partnership' arrangements in the provision of support services for disabled people: trying to remove inter-agency and interprofessional barriers to provide more seamless and user-oriented support (Pearson *et al.*, 2017; Feeley, 2021). We explore these developments and examine the data from a Scottish study of what users of personalised services need to achieve personalised outcomes. We will also consider our work in the context of the COVID-19 pandemic and the Feeley (2021) Independent Review of Adult Social Care in Scotland.

Personalisation: what does the international evidence tell us about what works?

Internationally, the evidence shows: pressures emanating from an exponential rise in demand, many disabled people themselves becoming politically active, and the move away from formalised residential care arrangements. These have resulted in different 'cash-for-care' schemes worldwide (Manthorpe *et al.*, 2015; Pearson *et al.*, 2017; Pearson and Watson, 2018). Although these schemes vary considerably in their intentions, scope and how they function, they are essentially mechanisms whereby a disabled person receives a cash benefit in order to purchase services themselves, in lieu of receiving services or support directly. These schemes can be seen as a way of 'commodifying' care (Ungerson, 1997: 375) and several different models have emerged: tightly controlled personal care budgets allowing direct employment of formal care workers; care allowances paid directly to disabled people but not directly governed; income maintenance approaches (allowances are paid directly to carers to acknowledge or compensate for the loss of earned income, usually only available to low-income carers); and directly paying informal carers to replace publicly funded formal care (Galvin, 2004; Kreimer and Schiffbänker, 2005; Jackson, 2018).

The evidence on take-up of such schemes indicates that it is generally articulate, younger, well-educated disabled people who are disproportionately represented amongst users (Spandler, 2004). Take-up amongst older people, ethnic minorities and learning disabled adults remains comparatively low (Irvine *et al.*, 2017; Williams and Porter, 2017). Cash-for-care schemes are also likely to lead to a widening gulf between carers working in regulated, professionalised and protected formal care employment and those working in private, unregulated employment, whether this be for a family member, direct employer or through the grey/black labour market. Where cash-for-care schemes are used to route money to informal family carers, this can have the effect of creating, or reinforcing, dependency relationships both inter-generationally (for example, between learning disabled adult children and parents/carers, or between daughters/daughters-in-law and parents) and intra-generationally (for example, between spouses) (Larkin and Mitchell, 2016). Finally, the use of unregulated and unsupervised cash-for-care payments, both to pay family carers and directly employ unskilled care workers, has the result of commodifying intimate and sometimes unarticulated relationships and expectations, with the possibility of exploitation and abuse of vulnerable parties on both sides (Ungerson, 1997).

Partnership theory in disability provision: the role of trust and interdependence in inter-agency and interprofessional working

Partnership working in developed welfare states has emerged as a key way to deliver welfare that is neither centralised and reliant on bureaucratic state, unresponsive provision, nor entirely liberalised and in the hands of individuals and the free market (McCall and Rummery, 2017). Clearly, such partnerships have allowed policymakers and street-level bureaucrats to broadly define social inclusion and welfare such that it includes many sectors of the economy that would not traditionally be included, such as the cultural sector (McCall, 2009; McCall, 2010). Traditional state welfare provision has developed in agency silos, with each agency concerned about protecting their own boundaries and power rather than working collaboratively (Papadopoulos, 2003; Ranade and Hudson,

2003). Moreover, disabled people's needs do not fall neatly into agency boundaries: is help with bathing, health or social care? Is support to access education social care or education? Is support with transport an issue for transport, health, social care – or does it become an educational issue if the transport is to school or university? (Feeley, 2021).

Across and within agencies, different professionals work with different aims and theoretical models to provide care and support for disabled people, further complicating matters. Health professionals, while they increasingly work (and are educated to work) within more diverse theoretical models including social and biopsychosocial models, continue to be predominately embedded within a medical model in the approach to healthcare (Shakespeare *et al.*, 2009; Shakespeare and Kleine, 2013; Harris and McDade, 2018). The medical model frames people's illnesses and impairments as the causes of their disability. Therefore, the aim is to help disabled people overcome these illnesses and impairments to reduce their disability. Workers in social care agencies have tended to use (and be trained in) a social model of disability, perceiving people with impairments and illnesses as disabled by an inaccessible society (Oliver, 2009; Millar, 2016). Therefore, the aim is to support disabled people to live in an oppressive society and remove some of the barriers which disable them. Although joint working across health and social care has blurred these boundaries, the medical model approach to disability remains dominant in healthcare practice (Hogan, 2019; Cameron and Lingwood, 2020). Moreover, the biopsychosocial model (including the International Classification of Functioning, Disability and Health (ICF)), which examines the complex interactions between biology, psychology and social factors (Wenzel and Morfeld, 2016), has underpinned recent development of welfare provision across both sectors for disabled people, yet has been criticised by disabled people themselves (Shakespeare *et al.*, 2017; Clarke *et al.*, 2019). Whilst personalisation would indicate that the choice and control – and therefore the power – over services should lie with the service user; organisational, professional, and normative barriers may prevent that.

Rummery (2002) developed a framework of partnership working that has been applied to diverse social policy fields such as childcare, migration, activation, and disability policies (see McLaughlin, 2004; Dwyer, 2005; Lindsay and McQuaid, 2008). Rummery argues that the two distinctive features of partnerships are interdependence (that the partners involved need the others to be able to achieve their own objectives) and trust (that the partners involved are engaged in trusting the others to deliver on jointly held objectives) (Rummery, 2002). Personalisation would suggest professionals should be working 'in partnership' with service users: helping to define their needs and appropriate agency responses, thus being dependent on disabled people being clear about their needs; and trusting disabled people to use agency resources to meet those needs appropriately. Disabled people are dependent on professionals to define their needs and identify resources to meet them. Consequently, disabled people must trust professionals to carry out an accurate and fair assessment of their needs.

Self-directed support: the Scottish model of personalisation

Although there have been large-scale changes, the debate around disability is still dominated by a medical way of thinking. This perpetuation of the medical model can be explained to some degree by a difference in thinking around particular issues such as independence, and societal participation (Bricher, 2000; Lee, 2002; Thomas, 2002a,

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2002b; Ghosh, 2012; Oliver and Barnes, 2012; Hogan, 2019). The consequent increased focus on societal participation and individualised services has led to the personalisation agenda, which began in the UK in the 1980s when some disabled people who were receiving adult social care were able to decide whether they wished to receive 'direct payments', either through third party trusts managing budgets for them, or through the Independent Living Fund for those with higher level needs (Rummery *et al.*, 2000). The process was subsequently advocated in the early 1990s before being introduced following extensive campaigning by disabled people. Significant powers were devolved to Scotland in 1999, including health and social care policy (Mitchell, 2003). The Scottish Executive (now called the Scottish Government) in 2006 openly supported the promotion of 'personalisation', and in so doing, advanced the expansion of direct payments. In spite of the campaign to increase direct payments uptake for the personalisation concept, service users must understand how to access what is available. To accomplish this, commissioners in the public, private, and third sectors, must fully understand how these processes affect the way that they organise services (Dickinson and Glasby, 2010).

Self-directed Support (SDS) is the Scottish Government's programme of personalisation and is enshrined in the *Social Care (Self-directed Support) (Scotland) Act 2013* (Scottish Government, 2010, 2018a). This legislation came into force on 1 April 2014 and imposes a legal duty on local authorities to offer four possible options to those who are eligible for social care:

Option 1: Taken as a Direct Payment.

Option 2: Allocated to an organisation that the person chooses and the person is in charge of how it is spent.

Option 3: The person chooses to allow the council to arrange and determine their services.

Option 4: The person can choose a mix of these options for different types of support.

(Scottish Government, 2018a: 3)

Figures from ISD (2019) indicate in 2017/18 that 75 per cent of people in Scotland were self-directing their care with the majority, 78,054 people, selecting Option 3, whereby the Local Authority selects and arranges the provision of support using the individual's assessed SDS budget. In addition, 8,390 people were using Option 1 (Direct Payments), 7,435 were covered under Option 2, and 4,257 people were using Option 4 services. It should be noted that in Scotland there is a mix of urban and rural geography with differing population sizes and deprivation levels. In more rural areas, where there has traditionally been a lack of suitable services, the uptake of Option 1 has been higher. For example, in 2017/18 the number of people who choose Direct Payments ranged from under 100 per 100,000 in more urban populations (e.g. Dundee, Falkirk and North Lanarkshire) to over 250 per 100,000 in some rural and island areas (e.g. Highland, Moray, Orkney and Scottish Borders).

SDS, in principle, is a useful and workable route for disabled people to live independently through personalised services. However, it is clear that for SDS to work as intended, a fully functioning partnership between service users, the council, and other bodies providing services must exist. The focus needs to be on person-centred planning, carried out in a way that is not simply seen as an increase in bureaucracy (Slasberg *et al.*, 2012).

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Duffy (2018) argued that SDS should herald a change in the social care system, allowing individuals who need support to be active, fully participatory citizens. However, SDS was put in place while the Scottish health and social care service was undergoing large-scale re-organisation. Therefore, it became something that was effectively secondary to those changes and thus, it was not fully implemented consistently across Scotland. Furthermore, limited resources have prevented staff from making full use of the potential of service user participation (Carey, 2009).

Having summarised the policy context in relation to SDS in Scotland we will now place it in the context of individual experiences using survey and focus group data.

Methods: eliciting the views and experiences of disabled people and family carers

Survey

The dataset was created via a self-administered electronic questionnaire. The survey was a mix of closed questions, in which respondents had to simply tick a box that applied to them, and written answers to more open questions meant that the survey could also collect more detailed qualitative information. Hartley and Muhit (2003) concur with the advantage of this type of survey in that qualitative questions may give an idea of how well certain policy processes within different areas or regions are functioning, and indicate changes which may be required, or indeed indicate areas which are not covered. The combination of open and closed questions gives room for any additional relevant details.

The survey collected information about what people used their support for and what their experiences of using SDS were from three perspectives: those who were in receipt of SDS at the time; those who were potentially interested in SDS; and carers of those who received or were potentially interested in SDS. The survey also contained supplementary questions that were more qualitative, around what support allowed people to do and how it helped them, in line with robust measures such as the Adult Social Care Outcomes Toolkit (ASCOT) and adapted in co-production with disabled partners in respect of well-being (van Loon *et al.*, 2018). Potential participants for the survey were sought by contacting a range of disability and carer's organisations across Scotland. Social media was also used to share the survey and focus group details using a link to the project website. The survey was available online from September 2019 until the end of February 2020.

The survey was completed by 126 respondents, of whom 59 per cent (seventy-five) were currently receiving SDS, 24 per cent (thirty) were interested in SDS, and 17 per cent (twenty-one) cared for someone who was either in receipt of SDS or would like to receive SDS.

Focus groups

Focus group participants were recruited by contacting a range of disability and carer's organisations across Scotland and inviting them to share the study with people who might wish to participate. This led to a programme of six separate focus group meetings in locations across Scotland that took place over a period of eight months between May and December 2019. Research instruments were designed in co-production with a disability

rights organisation and a disabled researcher (who also co-facilitated the focus groups). Focus group questions asked about the experiences of applying for and receiving SDS. This was followed by a group exercise whereby participants were each asked if they could change three things about SDS to make it work better for them, what would they be. The facilitators then drew up a list and then asked the group as a whole to discuss these issues and decide upon the most important thing(s) that needed to change.

The focus groups had disabled people with mixed impairments and lasted up to an hour. Participants all either used, or would like to use SDS, or they cared for someone who used, or would like to use, SDS. Disabled participants chose whether to have a personal paid supporter or unpaid carer with them to assist in taking part: unpaid/family carers took part in a separate focus group (which also included unpaid/family carers who had undergone an assessment, or would like to undergo an assessment, in their own right for SDS) where they discussed their own views and experiences. Unpaid/family carers were also asked about the person they cared for, how long they had been getting support, and what they used it for. Pseudonyms chosen by the participants are used in place of focus group participants' real names. All participants were reimbursed for their travel and support costs but following their own preferences were not paid for taking part – this was so that participation was voluntary and did not feel like a 'paid' job with certain obligations.

Analysis of both the free-text survey answers and focus group answers was carried out inductively and thematically (Thomas, 2006) and the researchers worked with a disability rights organisation to check the reliability and validity of the emergent themes, as well as the accuracy of the quantitative data. Following that process those that corresponded most closely with the partnership framework of 'trust' and interdependence' developed by Rummery (2002) were included in this article to meet the purpose and length of this particular themed section – these were not the only themes that emerged but they were amongst the most valid. Ethical approval was granted by the General University Ethics Panel (GUEP) at the University of Stirling (Reference number – GUEP 438).

Findings: the importance of partnership working to transcend the inter-agency and interprofessional barriers to personalisation

What SDS is used for and what people would like to use SDS for

The survey asked respondents receiving SDS at the time, and those who were potentially interested in SDS, about activities that they currently do, or believed they could potentially do, with SDS as shown in Table 1.

Figure 1 and the discussion demonstrate similarities and differences between the survey participants who received SDS at the time and the survey participants who were interested in receiving SDS on what activities that they currently or potentially could do with SDS support.

Personal care

For support with bedtime, washing, dressing and toileting activities: 67 per cent of current SDS users said they used it to support this activity compared with 25 per cent of potential users who considered they would use it to support this activity. 50 per cent of potential users said they would use SDS for preparing meals and helping to eat compared to 58 per

Table 1   Range of activities that people use or would like to use SDS for

Preparing meals and helping you eat
Social, recreational leisure, sport
Community activities (including volunteering and politics)
Housework, gardening and other domestic tasks
Parenting or caring
Giving a carer a break (respite)
Physical health care
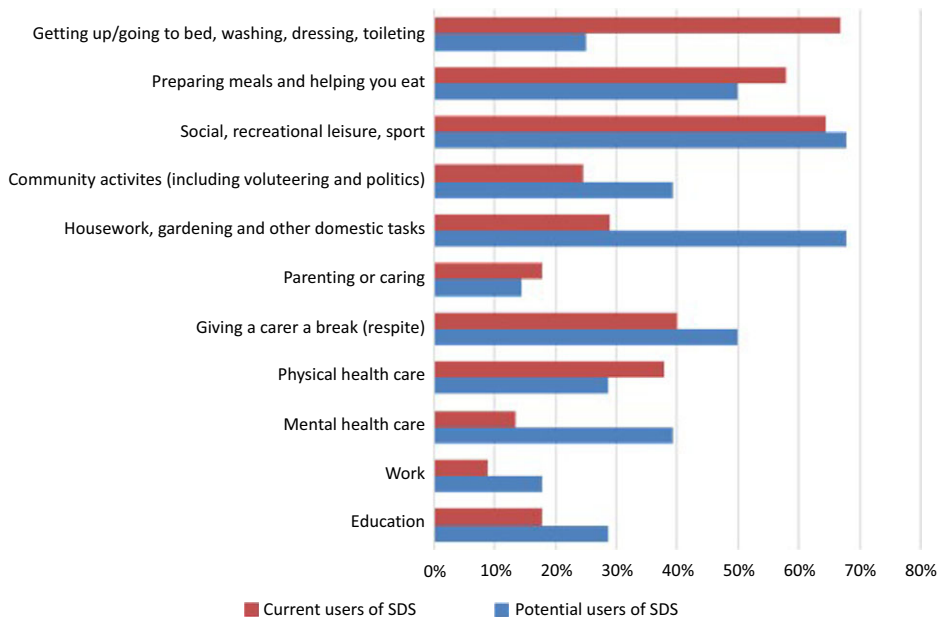Mental health care
Work
Education

Figure 1. What current users do with SDS v how potential users think they would use SDS

cent of current users who said they use SDS to support this activity. In Scotland, as personal care includes intimate care, this could be the responsibility of health or social care services (or both) (Scottish Government Health and Social Care Integration Directorate, 2018).

Social, recreational leisure, and sport and community activities

64 per cent of those who currently receive SDS said it supported social, recreational leisure and sport activities and this was equitable to 68 per cent of potential SDS users who said they would like to use it to support this activity. For other community activities,

including participating in volunteering and political activities, 25 per cent said SDS supported with this activity, whereas 39 per cent of potential users said they would want to use SDS to support this activity. In Scotland responsibility for providing this support is split between social care, local authority leisure and sport facilities, and voluntary organisations (Play Scotland, 2011; Scottish Government, 2013, 2018b; Allcock, 2018).

Housework, gardening, and other domestic tasks

SDS supported housework, gardening and other domestic activities for 29 per cent of current SDS users, whereas 68 per cent of potential SDS users indicated they would want to use SDS to support this activity. The role of SDS in supporting parenting and caring activities was similar between groups with 18 per cent of current users and 14 per cent of potential users citing it to support this activity. Respite care was currently being used by 56 per cent of current SDS users, 44 per cent of potential users said they would like to use SDS to support them with this activity. In Scotland service cutbacks mean this is very rarely provided by social care, and is predominantly the responsibility of individuals, families and the voluntary sector (Manji, 2018).

Work and education

In terms of ability to work, 18 per cent of potential SDS users considered it would support this activity, and this contrasts with only 9 per cent of those who received SDS at the time using SDS to access work. Similarly, 29 per cent of potential SDS users considered it would support education activities compared with 18 per cent who currently receive SDS using it to support this activity. Access to work is the responsibility of the Department of Work and Pensions (at UK level – this is not devolved to Scotland), and education is the responsibility of local authorities and the Scottish Government (Cairney, 2011; Cairney and McGarvey, 2013). This crossover of responsibility can mean that users of SDS find it difficult to use SDS to access work and education in a way that people who potentially would like to use an SDS budget to access work and education are unaware of, which may offer some explanation for the difference in perception between current and potential users of SDS. This gap in perception and sense of crossover in responsibility may also explain differences between current and potential users of SDS with regard to other activities such as housework, gardening and other domestic activities.

Health care

The extent to which SDS was considered to support physical and mental health differed between current and potential SDS users. 38 per cent of those currently receiving SDS said it supported their physical health care needs being met, while only 29 per cent of potential users considered SDS would support their physical health care needs. However, this view was inversed for opportunities to improve mental health, where 39 per cent of potential users considered they would use SDS to support their mental health compared to 13 per cent of current users who use SDS to support this activity. These figures are important because they draw a clear distinction between the services that current users of SDS access, and those that potential users anticipate being supportive. Mental health services

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in Scotland are provided by a mix of health, social care, and education (for under eighteens) (Goldie *et al*., 2016).

Summary

Overall, those who currently receive SDS, and those who are interested in receiving it, consider that it will support many activities as part of their lives. However, the extent to which these two groups considered SDS to support some activities varied. A greater proportion of those who currently receive SDS used it to support personal care activities such as getting up/going to bed, washing, dressing, toileting, preparing meals and physical health care than is anticipated in those who are interested in receiving SDS. Conversely, a greater proportion of those who are interested in receiving SDS consider they would use it to support their mental health, ability to access work and education, community engagement and housework, gardening and other domestic tasks. The differences across these groups may be due to the differences in the anticipated versus actualised benefits of SDS. Alternatively, these differences may highlight what activities current users of SDS are able to access, and these diverge from what potential users anticipate as being supportive. It may also be that for some activities a financial contribution has to be paid by the person receiving SDS and potential users may be less aware of this than current users (Self Directed Support Scotland, 2020). Our recruitment strategy cast the net for participants as widely as possible and tried to ensure that our participants were a representative group of users and potential users of SDS. However, owing to the fact that we relied on social media and support organisations to recruit it is possible that needs were different between the two groups, and that our sample of non-users was skewed towards those already aware of support networks and organisations.

Positive experiences: personalisation overcoming inter-agency and interprofessional boundaries

Flexibility and social participation

Both survey respondents and focus group participants referred repeatedly to flexibility being the key element that made personalisation work for them: this included the flexibility to purchase services that were user-centred and did not necessarily reflect agency boundaries. This led to a much wider ability to participate in society:

> Can select right staff, lots more freedom and flexibility enabling me to be in the community and meet my needs and outcomes for a happy life. Problems are addressed quickly, reducing stress for everyone providing a healthy environment. Money is spent on service provision and there is no wastage, we know how much money there is and where the money is going. The service is tailor made for me, not managers and staff. (Survey respondent 2)

> Flexibility of work hours and choosing own carer. Therefore, only known, and trusted people caring. (Survey respondent 12)

> [SDS] allows me to meet other people and join in activities that my parents could not take me to. (Survey respondent 8)

> [SDS gives me] lots more freedom and flexibility enabling me to be in the community and meet my needs and outcomes for a happy life. (Survey respondent 11)

> Having personal Carers mean that my son feels supported and safe. He knows and trusts them. They enable him to access the community a little, and to maintain what independence he is capable of, despite his challenges. (Survey respondent 26)

> Can select right staff, lots more freedom and flexibility enabling me to be in the community and meet my needs and outcomes for a happy life. (Survey respondent 38)

> It's the flexibility and the innovation that you can use the Direct Payments for I think is brilliant. (Focus group participant Myra)

Negative experiences: agency boundaries preventing personalisation

Lack of flexibility and reduced social participation

Both survey respondents and focus group participants felt strongly that their funding was often not generous or flexible enough to enable full social participation, because it was very centred on core personal care needs rather than being about enabling personalised approaches to independence:

> Limited amount of funds means I do not have full flexibility of hours required for evening events. Not allowed to use any of the funding for expenses to allow evening work or go to events. (Survey respondent 7)

> Sadly, it's so micromanaged by social work you don't have much flexibility *[in Scotland the local authority's Social Work Department carry out the eligibility assessment for Direct Payments]*. Also with budget cuts repeatedly and a limited amount of stuff to spend on. (Survey respondent 14)

> There is no flexibility up here, nobody talks to each other, and they go all happy dancy with shiny newspapers saying, 'aren't we good?' and I say you are missing the whole point. (Focus group participant Fiona)

In some instances, local authority employees were very inflexible in their interpretation of assessment criteria and what was relevant, and the changing nature of some conditions:

> But it is the incessant need to put everything in boxes. They love putting things in boxes. But I could quite easily say on Monday I am in box one and on Tuesday I am in box two and on Wednesday I might be across all five boxes. Oh no you can't do that – you have to pick one box. Take away the need to put things in boxes coz people don't fit in boxes. (Focus group participant Eric)

> They turned around to me and said, "you can't have Option 3 because you live rurally – there are no children's services so we can't help you. So, you can have Option 1 or nothing" (Focus group participant Fiona)

> I could enjoy more leisure time, all my funding just now just meets my basic support needs. I sometimes get tired, would like a few days hols but don't always have the funding to support this. (Survey respondent 3)

Given what previous research such as that by Malli et al. (2018) has suggested about the impact of reductions in levels of support, and what we know about the positive impact of community participation, the increased levels of support which allow people to do more such activities can only be positive, as highlighted by focus group participants:

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Michael: I would be more involved in getting out there and building up contacts and be able to employ maybe one or two other support workers depending on how much extra support I can get. And really experience – living a life rather than surviving.

Lack of trust mitigating against partnership

Survey respondents and focus group participants highlighted the distrust they felt for social care professionals and agencies as being a factor in their choice to control their own budgets (Option 1):

No choice, no variety, no flexibility. (Survey respondent 9)

To keep as much control for myself. I don't trust social work. (Survey respondent 15)

SDS is supposed to be person centred. This is most definitely not the case. You are given a budget and told if you use it for day service or evening support then you can't have respite. You are told to choose one or the other. (Survey respondent 27)

The whole trust thing with the service is when you challenge them, and you are trying to get the best support for the person you are caring for and for yourself because the healthier you are. (Focus group participant Myra)

Yes, and more trust on the money that is being spent. Local authorities won't trust you with a penny, never mind £500 a month as I'm getting. There is an inbuilt mistrust within SDS that is oppressive, very oppressive. (Focus group participant Jim)

Trust was also hindered by social services refusing to take responsibility for some areas of personalisation on the grounds that this was the remit of another agency:

... my son also can't do a range of activities as they have said DLA [welfare benefit] is for this etc. (Survey respondent 30)

The behaviour of agencies and individual workers mitigated against trust by refusing to allow users to decide their needs and services:

We have a broker who deals with things. We are Option 1 but [council] DICTATE what it can be used on. (Survey respondent 47)

Just now, I do not feel that I direct my own support. I was once assessed as ineligible for social work without being met with or informed of the outcome of this assessment. I waited two years to hear from social work before I found out that they had assessed me without informing me. (Survey respondent 56)

When I was eventually assessed for SDS, the worker arrived in my home and said after a few minutes that I was not eligible for social work – at this point we had not spoken, she made this decision based on how I looked and the condition of my home, this does not take into account ups and downs in people's conditions, invisible disabilities or the fact that many people with severe mental health problems can present an apparently healthy and happy facade. (Survey respondent 62)

Despite previous research such as that by Evans and Harris (2004); Finlay and Sandall (2009); Russell (2018), describing the importance of discretion, focus group participants

suggested that this space for interpretation is leading to a post code lottery rather than individualised personalised care. This type of discussion of local and national differences saw focus groups wanting better inter-agency working and perhaps a nationalised system of personalisation:

> Fiona: Why is this not good because on paper it should be brilliant? And time and time again it is about poor communication between different professional disciplines which is different to what SDS was meant to be about.

> Michael: It depends who you are speaking to whether it be social work or anybody else is that they are educated to give you the right advice when it comes to it because quite a lot of them just do the tick box exercise and there is no actual understanding or empathy towards your situation.

Some participants suggest that there is a low level of monitoring which could imply trust in service users to use their budget responsibly:

> Mirren: I've been dealing with my daughter's budget now for almost two years and not one person has looked at any of my finances.

Linked to this, one participant called for a wider national system of monitoring, by an independent body, around the consistency of what local authorities offer:

> Fiona: I wish someone would just go around all the local authorities and value check them, look at all the local authorities and just say what do you actually have because legally they have to have stuff in place.

This discussion around disparities in monitoring, set against the need for a more national, system-wide monitoring of availability, is something where several studies concur, i.e., Manthorpe *et al.* (2011); Eccles and Cunningham (2018); Feeley (2021).

The variability about what SDS can actually be used for also indicated a degree of trust in service users:

> Mirren: We just use ours for wages or training, we can do training as well.

> Sigourney: Yes, that's right there are a lot of things that you can use it for.

> Mirren: But nobody tells you what you can use it for though. We have been able to use some money for sensory equipment in my daughter's house.

> Sigourney: That's right – you can be quite imaginative with it, and you should get support for that from your social worker.

However, the high degree of discretion and variation between agencies and individuals was problematic. It was made clear by focus group participants that the way in which individual professionals interpreted national and local guidelines was an important factor in how much trust service users could place in practitioners making sure SDS was implemented correctly and fairly in their case:

> Peter: We were told by one social worker you can save up all your SDS and go on a big cruise once every three years and another one saying, 'no you've got to spend it every month and if you don't spend it every month, we will take it off you.'

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Caroline: We've heard word of personal comments made of, 'we don't think you should get that'.
Peter: 'I don't believe in SDS' was one of the comments.

Caroline: 'Why should you get that?' you know, as a carer.

Peter: So, it is interesting because I remember one of our members when SDS first started up they were asked to sign a blank form, a blank assessment form and the care manager said I will fill that in for you – just sign it there.

Comments around what is bad often focussed on restrictions around what SDS budgets can and cannot be used for, the lack of space for spontaneity and change at short notice, and no dedicated single point of contact as advocated by Duncan-Turnbull (2010); Self Directed Support Scotland (2020); and Feeley (2021). Individual service users and carers did not feel they could trust the system:

Bob: See trying to contact the social work for anything to do with it, it is almost impossible because you don't have your own social worker anymore so you are speaking to a faceless person on the phone who will never get back to you because you don't have a point of contact in social work anymore.

Jason: It used to be that when you were given a percentage of money that technically belonged to the government then because of that you had a care manager on your back all the time.
Bob: I'm purely wages – purely to do that. I even tried to get money to go to the barbers and get a shave and put the receipt in and it was thrown back at me. I mean there is nobody in my house to do it. The same with my washing.

Lack of trust: overbearing bureaucracy

A number of participants indicated that the amount of paperwork and monitoring which was required of them, both prior to and after an award of SDS. This was particularly the case if they had chosen Option 1. This concurs with the work of others, such as Eccles and Cunningham (2018); Self Directed Support Scotland (2020) and Feeley (2021):

Colin: The bureaucracy that you go through is phenomenal

Peter: And that if you sit and fill this form in, two lots of forms, both forty pages – at the end of that you feel like a complete waste of space and what am I doing here and what am I worth . . .

Mirren: The only thing I say, is like is there is a lot to think about – staff, budgets, HMRC, pensions – that's the overwhelming bit for me.

The impact of COVID-19 and the role of personalisation and partnership going forward

Previous research, including Manji (2018), has argued that SDS was a way of reducing social care costs. This was mentioned during focus groups and continues to be a concern in the context of COVID-19. Disabled people are concerned that their social care provision will be reduced further or stopped and that regulations such as those relating to social distancing have made it difficult for their care to be provided as it would normally be and that the sense of isolation that they feel has increased (Dickinson *et al.*, 2020; Inclusion Scotland, 2020; Scottish Human Rights Commission, 2020; Feeley, 2021). In response to the recommendations in the Independent Review of Adult Social Care in Scotland (Feeley, 2021), the development of a National Care

Service in Scotland looks likely in the next Parliamentary session (Scottish Government, 2021).

Conclusions

The rationale of inter-agency and interprofessional partnerships has always been to remove agency silos and barriers, and to enable more flexible, user-centred and therefore more responsive and effective support to be delivered. Our evidence shows clearly that perceptions from those using the system indicate this is not working very well. Those receiving personalised services found that their allocations of support were very narrowly defined and focussed on intimate personal care.

Our participants indicated a range of needs that were unmet through SDS, including transport, access to work, leisure, community, housework, mental health support and education. These are the responsibilities of a wide range of service providers in Scotland that go beyond social work, including UK level non-devolved services such as support for access to work and benefits, and Scotland-devolved services such as education, transport, leisure and the voluntary sector. It is clear that these organisations need to be involved in the planning and delivery of SDS to make the support being delivered truly personalised.

The evidence presented here also clearly indicates that there is much work to be done to engender a sense of partnership work between service users and social work agencies. This is a vital component of personalisation: service users need to be trusted to manage their own support, but in turn they also need to trust that the welfare agencies responsible for providing and funding that support are fair and competent in assessing their needs and allocating the level of support they are entitled to. The thirty-two different local authorities in Scotland results in thirty-two different systems of accessing eligibility for personalised social care services. Within each local authority there are four options available under SDS for how that support can be delivered once needs have been assessed. This leads to huge variability across different local authorities, different agencies within local authorities, and between different professionals within and across agencies. This is demonstrably unfair and leads to an undermining of trust between service users, carers and the state responsible for meeting their support needs.

There are solutions to this: all our participants were very clear that more time and more resources could dramatically increase the flexibility of their support and thus their social participation. However, time and resources in social care are currently in short supply, and post COVID-19 likely to become more so. Systematic reform to increase choice, control and personalisation would also need to be coupled with a national system of eligibility and entitlement. It is no accident that at the time of writing Scotland is debating substantial reform to social care to make it affordable and more consistent.

However, it is our view, based on this evidence, that some caution should be exercised in enthusiasm for a National Care Service. This looks like a National Health Service, and we have indicated earlier that a health-dominated system with health professionals using a medical model of disability is at odds with the aims of a personalised social care service. A highly desirable but impossible goal seems to be a system that is based on national entitlements, that is fair and engenders trust in its users, and at the same time that enables choice, control and flexibility to be exercised by disabled people and carers to lead independent lives and participate fully in society.

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Acknowledgements

References

Allcock, A. (2018) *ESSS Outline: Disability and Access to Leisure*, Glasgow: Iriss.

Barnes, C. and Mercer, G. (2010) *Exploring Disability: A Sociological Introduction*, Cambridge: Polity Press.

Bricher, G. (2000) 'Disabled people, health professionals and the social model of disability: can there be a research relationship?', *Disability and Society*, 15, 5, 781–93.

Cairney, P. (2011) *The Scottish Political System Since Devolution: From New Politics to the New Scottish Government*, Exeter: Imprint Academic.

Cairney, P. and McGarvey, N. (2013) *Scottish Politics*, 2nd edn, Basingstoke: Palgrave Macmillan.

Cameron, C. and Lingwood, L. (2020) 'What's wrong with 'seeing the person first?', *British Journal of Nursing*, 29, 5, 314–7.

Carey, M. (2009) 'Critical commentary: happy shopper? The problem with service user and carer participation', *British Journal of Social Work*, 39, 1, 179–88.

Clarke, H., Carmichael, F. and Al-Janabi, H. (2019) 'Adverse effects of social security on disabled people and their families in the UK: iatrogenic outcomes of quasi-clinical administration', *Scandinavian Journal of Disability Research*, 21, 1, 218–27.

Dickinson, H., Carey, G. and Kavanagh, A. M. (2020) 'Personalisation and pandemic: an unforeseen collision course?', *Disability and Society*, 35, 6, 1012–7.

Dickinson, H. and Glasby, J. (2010) *The Personalisation Agenda: Implications for the Third Sector*, Birmingham: University of Birmingham.

Duffy, S. (2018) *Self-Directed Support: If It's So Good Then Why Is It So Hard*, Sheffield: Centre for Welfare Reform.

Duncan-Turnbull, H. (2010) 'It's your life, take control: evaluating self-directed support in Hertfordshire', *Journal of Care Services Management*, 4, 3, 250–8.

Dwyer, P. (2005) 'Governance, forced migration and welfare', *Social Policy and Administration*, 39, 6, 622–39.

Eccles, A. and Cunningham, I. (2018) *The Enablers and Barriers to Voluntary Sector Organisations Providing Personalised Support Through Delivery of Self Directed Support Part Two: The Experience of SDS Implementation in Local Authorities*, Glasgow: University of Strathclyde.

Evans, T. and Harris, J. (2004) 'Street-level bureaucracy, social work and the (exaggerated) death of discretion', *British Journal of Social Work*, 34, 6, 871–95.

Feeley, D. (2021) *Independent Review of Adult Social Care in Scotland*, Edinburgh: Scottish Government.

Finlay, S. and Sandall, J. (2009) '"Someone's rooting for you": continuity, advocacy and street-level bureaucracy in UK maternal healthcare', *Social Science and Medicine*, 69, 8, 1228–35.

Galvin, R. (2004) 'Challenging the need for gratitude: comparisons between paid and unpaid care for disabled people', *Journal of Sociology*, 40, 2, 137–55.

Ghosh, N. (2012) *Disabled Definitions, Impaired Policies: Reflections on Limits of Dominant Concepts of Disability*, Kolkata: Institute of Development Studies.

Goldie, I., McLean, J., Woodhouse, A., Shields, J., Cameron, J., Biggs, H. and Knifton, L. (2016) *A Review of Mental Health Services in Scotland: Perspectives and Experiences of Service Users, Carers and Professionals*, London: The Scottish Government.

Harris, K. M. and McDade, T. W. (2018) 'The biosocial approach to human development, behavior, and health across the life course', *The Russel Sage Foundation Journal of the Social Sciences*, 4, 4, 2–26.

Hartley, S. and Muhit, M. (2003) 'Using qualitative methods for disability research in majority world countries', *Asia Pacific Journal of Disability and Rehabilitation*, 14, 103–14.

Hogan, A. J. (2019) 'Social and medical models of disability and mental health: evolution and renewal', *Canadian Medical Association Journal*, 191, 1, E16–E18.

Inclusion Scotland (2020) *Rights at Risk Covid-19, Disabled People and Emergency Planning in Scotland*, Edinburgh: Inclusion Scotland.

Information Service Division (ISD) (2019) *Insights into Social Care in Scotland 2017/18*, Experimental Statistics Publication, NHS National Services Scotland, https://www.isdsscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2019-06-11/2019-06-11-Social-Care-Report.pdf?5109804869 [accessed 09.05.2022].

Irvine, F., Wah Yeung, E. Y., Partridge, M. and Simcock, P. (2017) 'The impact of personalisation on people from Chinese backgrounds: qualitative accounts of social care experience', *Health and Social Care in the Community*, 25, 3, 878–87.

Jackson, R. (2018) *Reforming Social Care: Time for Radical Change*, Sheffield: Centre for Welfare Reform.

Kreimer, M. and Schiffbänker, H. (2005) 'Informal family-based care work in the Austrian care arrangement', in B. Pfau-Effinger and B. Geissler (eds.), *Care and Social Integration in European Societies*, Bristol: Policy Press, 173–92.

Larkin, M. and Mitchell, W. (2016) 'Carers, choice and personalisation: what do we know?', *Social Policy and Society*, 15, 2, 189–205.

Lee, P. (2002) 'Shooting for the moon: politics and disability at the beginning of the twenty-first century', in C. Barnes, M. Oliver and L. Barton (eds.), *Disability Studies Today*, Cambridge: Polity Press, 139–61.

Lindsay, C. and McQuaid, R. W. (2008) 'Inter-agency co-operation in activation: comparing experiences in three vanguard 'active' welfare states', *Social Policy and Society*, 7, 3, 353–65.

Malli, M., Sams, L., Forrester-Jones, R., Murphy, G. and Henwood, M. (2018) 'Austerity and the lives of people with learning disabilities. A thematic synthesis of current literature', *Disability and Society*, 33, 9, 1412–35.

Manji, K. (2018) "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', *Disability and Society,* 33, 9, 1391–1411.

Manthorpe, J., Hindes, J., Martineau, S., Cornes, M., Ridley, J., Spandler, H., Rosengard, A., Hunter, S., Little, S. and Gray, B. (2011) *Self-Directed Support: A Review of the Barriers and Facilitators*, Edinburgh: Scottish Government Social Research.

Manthorpe, J., Martineau, S., Ridley, J., Cornes, M., Rosengard, A. and Hunter, S. (2015) 'Embarking on self-directed support in Scotland: a focused scoping review of the literature', *European Journal of Social Work*, 18, 1, 36–50.

McCall, V. (2009) 'Social policy and cultural services: a study of Scottish border museums as implementers of social inclusion', *Social Policy and Society*, 8, 3, 319–31.

McCall, V. (2010) 'Cultural services and social policy: exploring policy makers' perceptions of culture and social inclusion', *Journal of Poverty and Social Justice*, 18, 2, 169–83.

McCall, V. and Rummery, K. (2017) 'The theory and practice of welfare partnerships: the case of the cultural sector', *Social Policy and Administration*, 51, 1, 56–75.

McLaughlin, H. (2004) 'Partnerships: panacea or pretence?', *Journal of Interprofessional Care*, 18, 2, 103–13.

Millar, J. (2016) 'Disability: a question of perception', in J. Bolger and S. Hothersall (eds.), *Social Policy for Social Work, Social Care and the Caring Professions: Scottish Perspectives*, London: Routledge, 271–92.

Mitchell, J. (2003) 'Devolution and the future of the union', in J. Fisher, D. T. Denver and J. Benyon (eds.), *Central Debates in British Politics*, Harlow: Longman, 33–47.

Oliver, M. (2009) *Understanding Disability: From Theory to Practice*, Basingstoke: Palgrave Macmillan.

Oliver, M. and Barnes, C. (2012) *The New Politics of Disablement*, London: Palgrave MacMillan.

Papadopoulos, Y. (2003) 'Cooperative forms of governance: problems of democratic accountability in complex environments', *European Journal of Political Research*, 42, 4, 473–501.

Pearson, C. and Watson, N. (2018) 'Implementing health and social care integration in Scotland: renegotiating new partnerships in changing cultures of care', *Health and Social Care in the Community*, 26, 3, e396–e403.

Pearson, C., Watson, N. and Manji, K. (2017) 'Changing the culture of social care in Scotland: has a shift to personalization brought about transformative change?', *Social Policy and Administration*, 52, 3, 662–76.

Play Scotland (2011) *Getting it Right for Play Children's Play in Scotland: The Policy Context*, Midlothian: Play Scotland.

Ranade, W. and Hudson, B. (2003) 'Conceptual issues in inter-agency collaboration', *Local Government Studies*, 29, 3, 32–50.

Rummery, K. (2002) *Disability, Citizenship and Community Care: A Case for Welfare Rights?*, London: Routledge.

Rummery, K., Glendinning, C., Halliwell, S., Jacobs, S. and Tyrer, J. (2000) *Buying Independence: Using Direct Payments to Integrate Health and Social Services*, Bristol: Policy Press.

Russell, S. (2018) *From Coherence to Fragmentation: 'Transition Policy' Affecting Young People with Cerebral Palsy in Scotland*, University of Aberdeen: ProQuest Dissertations Publishing.

Scottish Government (2010) *Self-Directed Support: A National Strategy for Scotland*, Edinburgh: Scottish Government.

Scottish Government (2013) *The Keys to Life Improving Quality of Life for People with Learning Disabilities*, Edinburgh: Scottish Government.

Scottish Government (2018a) *Health and Social Care: Self Directed Support Scotland, 2016–2017*, Edinburgh: Scottish Government.

Scottish Government (2018b) *A More Active Scotland: Scotland's Physical Activity Delivery Plan*, Edinburgh: Scottish Government.

Scottish Government (2021) *A National Care Service for Scotland: Consultation*, Edinburgh: Scottish Government.

Scottish Government Health and Social Care Integration Directorate (2018) *Circular No. CCD3/2018, Free Personal Care Guidance*, Edinburgh: Scottish Government.

Scottish Human Rights Commission (2020) *COVID-19, Social Care and Human Rights: Impact Monitoring Report*, Edinburgh: Scottish Human Rights Commision.

Self Directed Support Scotland (2020) *My Support My Choice: People's Experiences of Self-directed Support and Social Care in Scotland*, Edinburgh: Self Directed Support Scotland.

Shakespeare, T., Iezzoni, L. I. and Grace, N.E. (2009) 'Disability and the training of health professionals', *The Lancet*, 374, 28, 1815–6.

Shakespeare, T. and Kleine, I. (2013) 'Educating health professionals about disability: a review of interventions', *Health and Social Care Education*, 2, 2, 20–37.

Shakespeare, T., Watson, N. and Alghaib, O. A. (2017) 'Blaming the victim, all over again: Waddell and Aylward's biopsychosocial (BPS) model of disability', *Critical Social Policy*, 37, 1, 22–41.

Slasberg, C., Beresford, P. and Schofield, P. (2012) 'How self-directed support is failing to deliver personal budgets and personalisation', *Research, Policy and Planning*, 29, 3, 161–77.

Spandler, H. (2004) 'Friend or foe? Towards a critical assessment of Direct Payments', *Critical Social Policy*, 24, 2, 187–209.

Thill, C. (2015) 'Listening for policy change: how the voices of disabled people shaped Australia's National Disability Insurance Scheme', *Disability and Society*, 30, 1, 15–28.

Thomas, C. (2002a) 'Disability theory: key ideas, and thinkers', in C. Barnes, M. Oliver and L. Barton (eds.), *Disability Studies Today*, Cambridge: Polity Press, 38–57.

Thomas, C. (2002b) 'The 'disabled' body', in M. Evans and E. Lee (eds.), *Real Bodies*, London: Macmillan, 64–78.

Thomas, D. R. (2006) 'A general inductive approach for analyzing qualitative evaluation data', *American Journal of Evaluation*, 27, 2, 237–46.

Ungerson, C. (1997) 'Social politics and the commodification of care', *Social Politics: International Studies in Gender, State and Society*, 4, 3, 362–81.

van Loon, M. S., van Leeuwen, K. M., Ostelo, R. W. J. G., Bosmans, J. E. and Widdershoven, G. A. M. (2018) 'Quality of life in a broader perspective: does ASCOT reflect the capability approach?', *Quality of Life Research*, 27, 5, 1181–9.

Wenzel, T. R. and Morfeld, M. (2016) 'The bio-psycho-social model and the international classification of functioning, disability and health: examples of using the model, its parts and the items', *Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz*, 59, 9, 1125–32.

Williams, V. and Porter, S. (2017) 'The meaning of 'choice and control' for people with intellectual disabilities who are planning their social care and support', *Journal of Applied Research in Intellectual Disabilities*, 30, 1, 97–108.