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## Promoting human rights or increasing expectations? Effects of Self-Directed Support on the realisation of human rights in Scotland

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### ABSTRACT

This research investigated Scottish practitioners' reflections on how local Self-Directed Support (SDS) implementations have affected the realisation of human rights. The findings indicate that SDS increased service users' awareness of their rights but often in rather abstract ways, with service users (and practitioners) not getting information about SDS-related systems, processes, and procedures needed to make informed choices that support their human rights. The practitioners participating in this study found SDS systems and processes overcomplicated and struggled with accessing information needed for guiding service users. Although there is evidence that some processes are gradually becoming simpler, a focus on controlling resources has created a gap between the human-right-based ethos of SDS and its local implementations, reducing the ability of SDS to promote human rights and, according to some practitioners, just increasing service users' expectations. This gap might be further widened by insufficient engagement with independent support and advocacy organisations.

### ARTICLE HISTORY

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### KEYWORDS

Self-directed support;  
personalisation;  
direct payments;  
human rights;  
personal budgets

### Points of interests:

- This article looks at whether Self-Directed Support in Scotland has achieved its aims to promote the rights of people with disabilities.
- Self-Directed Support is legislation that aims to promote human rights, such as dignity and self-determination, by giving people with disabilities more choice and control over the care they receive. Many practical obstacles make this challenging.
- This study found that people with disabilities have become more aware of their rights in general, but this often has not translated into getting care in a way that promotes their human rights.
- This study found that limited resources have meant in practice that local social work departments have focused on how to control their

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spending on meeting the needs of people with disabilities. This often has meant that the rights of people with disabilities have received less attention and have been neglected.

## Introduction

Self-Directed Support (SDS) is a social care arrangement that aims to provide choice and control for service users by involving them in identifying their support needs and offering various options to manage their support (Scottish Government 2014). SDS was introduced by the Social Care (Self-directed Support) (Scotland) Act 2013 and came into force on 1 April 2014. This legislation signifies the plans of the Scottish Government to transform the systems and culture of social care, resulting in a greater empowerment of service users and promoting their human rights (Scottish Government 2014).

The Scottish law states that SDS encompasses four options which are mechanisms for managing and arranging support (Scottish Government 2014). Option 1 is called Direct Payments and allows service users to manage their social care budget and to employ personal assistants. Option 2 is called an Individual Service Fund and gives service users choice and control over how their support is managed without the responsibility of managing the financial aspects (which are handled by a third party). Option 3 refers to a traditional service provision whereby a local authority makes decisions about and manages service users' care. Finally, Option 4 constitutes a combination of the three other options which gives even greater flexibility for people with disabilities regarding how they want to arrange their social care budget. Pearson, Ridley, and Hunter (2014) state that regardless of the option through which SDS is delivered, service users should have an opportunity to exercise choice and control and be treated as equal partners by professionals. This makes 'choice and control' defining features of SDS rather than a delivery mechanism (Pearson, Ridley, and Hunter 2014) which should be, however, offered to each person with disabilities eligible for social care support so their right to self-determination is respected.

The SDS Act is one of many pieces of legislation that have aimed to promote and protect human rights. Dalrymple, Macaskill, and Simmons (2017, 10) described the SDS Act as a unique piece of legislation in Europe that places 'a set of human rights principles at the very heart of a fundamental framework of delivering and accessing social care support'. The set of values (respect, independence, freedom, safety, fairness) and principles (participation, dignity, involvement, informed choice, collaboration) underlying SDS (Scottish Government 2014) have strong correspondences not only to human rights but also reflect social work values (Duffy 2010; Hugman 2007). The SDS legislation is also linked with the concept of 'independent living', meaning that people with disabilities have choice and control over their lives in the

same way as everyone else (Harris and White 2018). Independent living is 'the practical expression of disabled people's human and civil rights' (Elder-Woodward et al., 2015, 272) and is explicitly referred to in the official SDS guidelines of the Scottish Government (2014).

### ***Note on the language used***

The way language is used in both everyday life and academic literature is important as language can label, stigmatise, and reinforce discrimination against various groups and individuals. Also, changing the way we speak can support cultural change and can change the way disempowered groups and people are perceived and treated (Zola 1993). In the 1970s, the "People First" movement started to advocate using person-first language (i.e. using the term "a person with disabilities" instead of "a disabled person") and such language became with time commonly used in the academic literature (Crocker and Smith 2019). The preference for person-first language has its origins in the disabled people's movement (Ashcroft and Anthony 2006; cited in Jensen et al. 2013, 149). For this reason, in this article, person-first language will be used with the exception of very commonly used phrases like "the disabled people's movement" (e.g. see previous sentence) and instances when the term "disabled people/person" is used by others and quoted in this article. It is worth mentioning that the debate about language used in disability studies is far from being non-controversial and is the subject of much debate, with some authors arguing that the disability-first (i.e. a disabled person) or the identity-first language (e.g. an autistic person) also has its place and is preferred by some service users (e.g. see the discussion between Vivanti (2020) and Botha, Hanlon, and Williams (2021). Diving deeper into analysis of this issue is out of the scope for this article, despite its significance.

### ***Self-directed support – a historical context***

SDS is often viewed as resulting from activism by people with disabilities and is thereby considered a step towards promoting human rights (Beresford 2009; Kendall and Cameron 2014; Roulstone and Morgan 2009; Series and Clements 2013). Disability activism was crucial to the development of Direct Payments (DPs) in both England and Scotland in the 1990s, strongly suggesting that this might also be the case for the introduction of SDS in Scotland (Pearson, Ridley, and Hunter 2014). The disabled people's movement pioneered the idea of independent living (Harris and White 2018). Morris (2004) reported that the Independent Living Movement adopted postulates in the form of twelve "pillars" which are basic needs that are important for people with disabilities to achieve independent living, including access to

employment and adequate income. These “pillars” also focus on accessibility understood very broadly and including accessible and appropriate housing, transport, health and social care, accessible information, and access to advocacy (Disability Rights UK 2021). Within the Independent Living Movement, direct payments were considered to be one of the enablers of independent living. This movement proposed direct payments to each person with disability (a cash budget equivalent to the amount of money that would be spent on their institutional care) to allow them to employ their own support assistants (Hasler 2004). People with disabilities argued that direct payments would give them an opportunity for ‘independent living’ in tenancies in the community, thus supporting their human rights to dignity and self-determination (Hasler 2004). DPs, a major achievement of the disabled people’s movement, were incorporated into SDS as Option 1 and the Scottish Government borrowed the language of the activism of people with disabilities in its legislation and policy documents (Roulstone and Morgan 2009).

Although SDS was inspired by the Independent Living Movement (Pearson, Ridley, and Hunter 2014), the extent to which its development and implementation have happened with meaningful and effective involvement of service users has been controversial. For example, Elder-Woodward (2016) considers the Independent Living Movement to have a close relationship with the (central) Scottish Government which resulted in its involvement in the development and passing of the SDS legislation through the Scottish Government. In contrast, Pearson, Ridley, and Hunter (2014) question the extent to which service users were involved in the (local) development and implementation of SDS in Scotland. Also, the data collected for establishing the baseline for the SDS pilots in Scotland showed that some participants, including participants from service users’ organisations, perceived SDS as a ‘professionally driven’ agenda (Ridley et al. 2011) and Manji (2018) indicates that some service users experienced SDS as a ‘cost cutting agenda’ rather than a means to greater choice and control.

While these views seem to contradict each other, it seems that Elder-Woodward refers to the involvement of people with disabilities at the central government level, whereas Pearson, Ridley, and Hunter (2014) refer to such involvement at the local authority level. The Scottish political system works in such a way that the central government develops and passes legislation, whereas local authorities implement this legislation. While human rights are well expressed in the SDS legislation and the Independent Living Movement was involved in the development and passing of this legislation, the local implementations of the SDS Act and the involvement of people with disabilities and the Independent Living Movements in such implementations have differed significantly between local authorities. Most people with disabilities and most practitioners will have perceived the implementation of SDS as they experienced it directly via the way their local authority

implemented it rather than what was written in the SDS Act, which the Independent Living Movement may have influenced. This might be one reason behind a quite strong perception of SDS development and implementation taking place without meaningful and effective involvement of service users (Barnes and Mercer 2006; Beresford 2009; Lloyd 2010; Pearson, Ridley, and Hunter 2014).

Many conditions need to be met for any legislation to make a difference in terms of human rights in the context of health and social care, including service users having 'knowledge, power, and an appropriate occasion to exercise both' to become agents able to direct their own support rather than passive recipients of social care (Elder-Woodward 2014; 308). In many studies, practitioners have voiced concerns about whether service users are actually being meaningfully involved in SDS assessment and support planning, due to it being confusing, and for some service users (e.g. older people or people in crisis), challenging and overwhelming (Kendall and Cameron 2014; Velzke 2017). Note that in a similar situation, Leece and Leece (2011) and Foster et al. (2006) found that that professionals are still dominant during assessment and support planning in personal budgets in England.

Above all, resources, or more precisely, the lack of them, seem to be a defining issue. Exercising human rights depends on resources (Slasberg and Beresford 2017). As Elder-Woodward (2014, 307) put it: 'If the state, in the form of its professional practitioners forbids or withholds such resources, choice and human rights are inhibited ...'. Interviews with practitioners by Pearson, Watson, and Manji (2018) highlight austerity as a major reason why service users are offered limited choice rather than opportunities for independent living. Similarly, in the Community Care and Unison survey of personal budgets (2011: cited in Pearson, Ridley, and Hunter 2014, 37), 48% of social workers considered the sizes of personal budgets insufficient. According to the Association of Adult Social Services, since 2009 social care budgets for individuals decreased by between 25% and 30% (cited in Woolham et al. 2017, 977). Moran et al. (2013) indicate this allows only for meeting personal care needs, leaving other 'higher' needs, such as participating in the life of the community, unmet.

Despite controversies about the impact of SDS on service users' rights, the stated aims of SDS are still to promote human rights, especially the right to self-determination. All legislation is open to interpretation, and according to Dalrymple, Macaskill, and Simmons (2017), the human rights principles underlying the SDS Act have been considered by some to be merely aspirational — there only to inform and guide — which has significantly reduced the importance of the SDS principles and their potential to transform life in social care in Scotland. In contrast, some organisations, including the Minority Ethnic Carers of Older People Project (MECOPP; Haddow 2018) and Scottish Care (2017), have published guidelines promoting

service users' rights in SDS in their attempts to maximise the potential of SDS for human rights.

Against this backdrop, this research aimed to investigate the impacts that SDS has had on the realisation of human rights among people with disabilities to produce empirical evidence on the effects of SDS on human rights in Scotland.

## Research process

Drawing on qualitative research methods (Hardwick and Worsley 2011), semi-structured interviews were conducted to answer these research questions: (1) how practitioners perceive the effect of SDS on the realisation of human rights among service users and (2) which factors, from the practitioners' perspective, influence this realisation. Using semi-structured interviews helped investigate how practitioners conceptualise human rights in SDS by providing a space where they could express and explore their subjective experiences of working with people with disabilities (Goodman 2001). At the same time, semi-structured interviews as a research method allow using a prepared list of questions to bring the interviews back toward discussion that would contribute to answering the research questions. Using this research method allowed generating rich and relevant data that will be discussed in the remainder of this article.

This research was conducted in Spring 2019 as part of the requirements for the degree of Master of Social Work of the first author. This had significant implications for recruitment of participants because at the university where the degree programme took place, masters students were only allowed to interview practitioners, not service users. Ideally, service users' views of the impacts of SDS on human rights would be heard directly from them and future research should follow up on the results presented here with service users. Although service users' voices were not directly captured by this research process, it was still possible to get insight into how SDS impacted human rights realisation through considering professionals' reflections on that topic.

To include a wide range of views, participants were recruited from both third-sector organisations (in these areas: third-sector disability advisory, and advocacy) and local authority social work teams. Purposeful sampling was used: specifically, practitioners were recruited who have some experience (6 months or longer) of working with service users with SDS packages (Marshall 1996). Nine participants took part in this research: four from third-sector organisations (P1, P2, P3, and P5) and five statutory social workers (P4, P6, P7, P8, P9). Among third-sector organisations, one participant was from a centre for inclusive living providing support for people with disabilities in one large urban local authority and two rural local authorities,



two participants were from an organisation specialised in SDS advisory and policy work Scotland-wide, and one professional worked in a welfare rights organisation for people with disabilities. Most of the social workers were from a large urban local authority with the exception of one who worked in a rural local authority. While the sampling was purposeful in the sense of recruiting participants with at least 6 months of experience of direct work with people with disabilities, it was opportunistic in terms of geographic area. Most of the third-sector practitioners had a perspective of work with more than one local authority or even nation-wide experience, whereas the social workers had mostly experience of just one local authority each.

The participants were approached either face-to-face or via email. Access protocols of their places of work were followed in the cases where there were such protocols. It was left up to the participants whether or not they wanted to speak with their employer or manager about their participation in this project. For example, most employers were aware that their employees might be given an opportunity to take part in the research but would not necessarily know who was approached or agreed to participate. Participants were also asked where they wanted the interviews to take place. Some participants were concerned about being identifiable from information about them in this report and therefore a strict approach to sharing their details has been applied and details such as their genders, ages, and the names of their organisations are not included. Also, each quotation needed to be carefully considered to ensure no one is identifiable from the information in this article. Participants agreed that they could be quoted after being assured that any personally identifying information would be excluded.

The interviews aimed to capture the way people express their subjective experiences through language and observations (Carey 2009; Goodman 2001). With prior consent, interviews were recorded and transcribed. Thematic analysis, framed mostly through an inductive approach helped identify themes based on Braun and Clarke's model (2006; cited in Hardwick and Worsley 2011; 13) with the exception of the theme 'Independent SDS support and advocacy in promoting service users' rights' which was pre-selected prior to the interviews because the literature indicated it as a likely factor for promoting human rights. The model of Braun and Clarke proposes the following steps for conducting thematic analysis: knowing, coding, theming, selecting, and committing. The model was applied by first transcribing and then reading the interviews multiple times (knowing), second, by categorising the data into meaningful and interconnected pieces (coding), third, by identifying over-arching themes (theming), fourth by selecting pieces of data that best represent themes (selecting), fifth, by writing these themes down in the dissertation (committing) and then into this article (Hardwick and Worsley 2011; 14-15).

The study was informed by a robust consideration of ethical principles and received ethical approval from the University of Edinburgh. While the

study involved no service users, as the focus was to gauge practitioner perspectives, nonetheless the rights of the participants were respected. The study was underpinned by a strong commitment to informed consent, confidentiality, and voluntary participation and appropriate ethical approval was secured before commencing data collection. Anonymity of the study sample was a crucial ethical consideration and identifying information has been removed from the paper to ensure that no data can be ascribed to any individual.

## Findings

Data analysis identified a number of key themes from the findings and this article reports these themes: (1) awareness of rights and accessibility of information; (2) independent SDS support and advocacy in promoting service users' rights; (3) the effects of systems, procedures, and processes. These themes have been explored below with appropriate narratives from the interviews.

### *Theme 1: Awareness of rights and accessibility of information*

Service users seem to have greater awareness of SDS, since its introduction in 2014, and people seem to have a greater sense of their rights and how to access information. Most of the statutory practitioners expressed the view that service users' rights are much more visible due to the introduction of SDS. Although 'a lack of public awareness of the rights and options for increased choice and control' was identified by Dalrymple, Macaskill, and Simmons (2017, 20) as a barrier to the implementation of SDS, some participants felt that, at least to some extent, this barrier has been challenged. In reflecting on this issue, P4 recalled that: 'They're more aware of their choices and rights and things', since the introduction of SDS. P6 said: 'SDS is just putting much more in the public domain and the people are actually saying you should be able to get some support through SDS...'

However, third-sector practitioners were of the view that the awareness of rights among service users is inconsistent and often insufficient for service users to make informed choices. This is because information and awareness of service users' rights and options in SDS can be very abstract and dissociated from the practicalities of specific SDS options. This has been expressed in the following way by P5, a third-sector practitioner:

'I think direct payments can be sold in a very positive way because: 'it's your budget', 'you're in control'... but the reality is — Are you telling them about managing that money? Are you telling them how difficult it might be to get care at that rate?'

According to the 'nature and effect' duty expressed in the SDS Act 2013, social workers should 'explain the implications of the support options

available to the person' to support the SDS principle of informed choice (Scottish Government 2014, 25–26). The Health and Social Care Alliance survey (2017) shows that 22.2% of service users learned about SDS from social workers. However, the quality of information shared with service users varies significantly between individual social workers depending on their own understanding of and confidence about SDS. In this context, P3 recalled:

'I suppose my experience of that is some of that information that people might receive could be very good and very detailed... And then you get the other extreme where there's none of the information that should be shared hasn't happened, some of the information that was shared is completely incorrect. Not just in terms of legislation but in terms of their own local policies and procedures that are in place.'

Many aspects of the SDS process and options are confusing and difficult for practitioners. Many participants admitted that they have problems with accessing and understanding information. Complexities and lack of accessibility of information about systems and processes were identified by participants as a barrier to service users exercising their rights in SDS. P9, who worked within a local authority, said:

'It should be a lot of easier for individuals and for the council. Currently, the whole paperwork, which I don't even get my head around, so I have no idea how some people who struggle with like literacy can get their head around it.'

P5 was more vocal about some of the challenges, saying:

'A lot of it seems to be done behind, I don't think it's deliberate, behind closed door where you think I don't know what's happening and I think if I'm not absolutely clear about the process then it must be very difficult for clients. If you don't have the information, it's very difficult to make the choices that would support your human rights and if it's complicated information then you've got a whole load of vulnerability there...'

In conclusion, although participants reported that service users are more aware of their rights, this knowledge might not be what the service users need to make informed choices that support their rights to dignity and self-determination. This is due to the information being very abstract and lacking in detail about processes and implications of choosing specific options.

### ***Theme 2: Independent SDS support and advocacy in promoting service users' rights***

Research has shown that advocacy and service users' organisations were crucial for the successful implementation of DPs which might imply they are also needed for SDS to be successful (Barnes and Mercer 2006; Pearson 2006). The Scottish Government runs the "Support in the Right Direction Programme" which funds some organisations to provide independent support for SDS as part of the SDS implementation plan for 2019–2021 (Scottish

Government 2019). Also, a statutory duty was introduced to provide service users with support (e.g. to handle payroll in employing a personal assistant) to direct their own support especially with DPs (Scottish Government 2014). Overall, participants emphasised the usefulness of such support for service users but at the same time acknowledged that it is not used as much as it could be. For example, P1 said:

'Sometimes it feels a bit like... They fund the service so there is a service in order to fulfil their statutory responsibilities. They fund us but they don't use us the best way that they could use us as well.'

A statutory practitioner echoed this point by saying:

'So one thing we're trying to get better at in [local authority name] is to use advocacy more instead of being totally reliant on the individual to be able to drive that decision if they're unable to because of their circumstance and we need to get better... I think organisation like advocacy I think they help challenge that sort of views we're getting into because of financial pressures I think they help us to think about "Oh wait a minute, why aren't we considering this?". (P9)'

While reflecting on the role of independent support and advocacy, some statutory and third-sector practitioners observed that the increased awareness among service users of their rights can lead to increased expectations of services. This can create a tension between service users using advocacy to get their voice heard (which also might cause delays and increase stress) and their short-term interest in getting support urgently to address crises in their lives. This was expressed by P6, a social worker, in the following way:

'I worry that some of them give unrealistic expectations of SDS. I'm not sure that's always helpful for families in crisis. I think they need somebody who is quite sensible and reasonable, and some advocacy groups would be more... [pause] They just keep advocating.'

Most practitioners acknowledged that the increase in service users' awareness of their rights has led to greater expectations and to service users asking more questions about what they are entitled to through SDS. Especially statutory practitioners found it challenging to meet these expectation due to many obstacles present and already mentioned in this article. It is worth mentioning that the perception that unrealistic expectations of SDS sometimes have been created can undermine entitlements of people with disabilities. A third sector practitioner, P2, reflected on this in the following way:

'So we hear a lot of talk of like raised expectations whether that's about the options or whether that's about the amount that they would get in a package but again that kind of like so because you don't want to deal with people thinking that they're gonna get something that they're not, but actually what that means is that people won't be necessarily told what they're legally entitled to because ultimately authorities aren't always delivering on what people are legally entitled to...'

Third-sector participants expressed the opinion that most service users accept what they are offered by their social worker and very rarely challenge

SDS practices. P3 explained that this is partly because of the difficult and long process service users need to get through to challenge a decision and also because, unlike other social work legislation (e.g. the Mental Health (Care and Treatment) (Scotland) Act 2003), SDS is not very specific about many aspects of the SDS process (e.g. waiting time for assessment and eligibility, appeal process) which makes upholding rights of service users difficult. Participant P7 gave the following example:

'I asked her support to be increased and it wasn't and so she said to appeal. And at that point the appeal process was the service manager made the decisions about all of packages and she also made decisions about the appeals as well. So basically you were just appealing back to the same person who made the original decision...'

Overall, this theme suggests that advocacy and independent SDS support organisations are perceived as important in enabling service users to get their voices heard and to direct their support. However, services offered by these organisations are not always used to their full advantage. The results of this research suggests that local authorities are not only reluctant to fund service users' organisations to provide services other than support with financial and practical aspects of DPs (Pearson 2006) but also to engage the services which have already been funded to involve people with disabilities in social policy implementation (Johnston et al. 2009). Some participants suggest that this might be due to statutory practitioners' fear that such organisations might increase expectations, and the limitations of the SDS legislation that make it difficult to uphold rights of people with disabilities.

### ***Theme 3: The effects of systems, procedures, and processes***

All participants talked about the role of systems, procedures, and processes in enacting the principles and values of SDS. Some participants acknowledged that some processes have been gradually improving. For example, P9 considered the plan to introduce 'Allpay' cards (a payment system used to manage DPs) to be a potential improvement in P9's local authority. (We must note that in contrast, P2 discussed Allpay cards as possibly being either supportive or detrimental for service users' choice and control depending how such cards get set up.) Other statutory participants also talked about improvements in SDS processes, for example, progress made by moving away from rigid points-based systems for allocating SDS funds. P8 said:

'So they definitely changed some of the processes, so you don't have to put in the scoring. There used to be a scoring sheet which felt like it was dehumanising process when you had to score something so quite subjective. So I might score her like this and someone else could score her in another way but you're talking about a child. So I think that wasn't really... fair or a social work approach. It didn't fit with my values, I suppose.'

All participants talked about systems, procedures, and processes that often do not work and are very confusing for all. P2 expressed it in the following

way: 'They've got a system that does not make it easier for them [the social workers] — it makes it harder every step of the way. So even when they've [the social workers] got the positive attitude to rights actually for people to realise these rights can be very difficult.' A social worker, P9, reflected on the role of processes by saying: 'I think we've gotten it too such as way of a process or process-driven, we maybe don't always explain the options properly to people.' Many practitioners attributed the difficulties with the SDS processes to their focus on controlling money. For example, P3 said:

'I think that local authorities spent so much time on trying to set up a system to manage the money to make sure that they didn't spend more than a certain budget that got allocated. It got completely focused on that rather than focus on the actually the real change that you could make to individuals' lives...'

Participants gave various examples of systems and processes which do not make it easier for service users to enact their rights. One example relates to eligibility criteria which has been discussed in the literature (Pearson, Ridley, and Hunter 2014; Series and Clements 2013; Slasberg and Beresford 2016). A third-sector practitioner, P2, gave the following example of how eligibility criteria affect service users' rights to social care:

'...often the first kind of set of criteria is often written for kind of physical impairment approach rather than from somebody with Alzheimer's or dementia or someone with mental health need where that need was not obvious and it's not necessarily physical ... And you have to kind of show that your needs are related for criteria that might not be fit for the purpose in a way. You have to challenge the policy or procedure often in order to get your need recognised and make use of the system really.'

The message was that many systems, procedures, and process as were designed to control how resources are allocated and spent. This theme provides empirical support to the points made by many commentaries expressing concerns about ongoing financial crises and how this reduces the potential of SDS to promote human rights and introduce cultural change in health and social care (Ferguson 2007; Lloyd 2010; Slasberg and Beresford 2016). Managing resources seems to be in sharp conflict with service users' rights to self-determination and to dignity.

## Discussion

The practitioners believed that SDS increased service users' awareness of their rights and made them more likely to inquire about them, and occasionally to take steps to uphold these rights when they see this to be the only way to access support they need. Several studies have shown that a lack of knowledge and awareness of DPs among service users is a significant obstacle to their successful implementation (Arksey and Kemp 2008; Maglajlic,

Brandon, and Given 2000; Manthorpe et al. 2011; Ridley and Jones 2002). Knowing that SDS incorporated the earlier DPs, the pre-SDS analysis of barriers and facilitators of the SDS in Scotland concluded that the lack of awareness might be a barrier to its implementation. This research suggests that this barrier has been overcome at least to some extent.

However, practitioners believed service users' heightened awareness and knowledge of SDS was not always enough for making informed choices about their packages of care in a way that supports their human rights. Furthermore, practitioners often feel they don't have enough understanding of frequently changing local and departmental SDS processes to guide service users. This echoes the evaluation of SDS test sites in Scotland done by Ridley et al. (2012) who identified that even though SDS training increased practitioners' understanding of SDS, they still did not feel prepared for dealing with practicalities of SDS, e.g. how to put an SDS support package together, complete assessments, and carry out costings of support packages. Several years after the introduction of SDS, participants in this study reported obscure systems, processes, and procedures and problems with getting information about SDS. The difficulty in obtaining such information made most of the practitioners empathise with service users by saying that if accessing and understanding information about SDS is difficult for social workers, then it is likely very challenging for service users in crisis and/or with disabilities (Velzke 2017). This research suggests that service users who need accessible information to make decisions about their care might still be disadvantaged, as they were in relation to DPs (McMullen 2003; SENSE 2008).

Similarly to the findings of Manthorpe et al. (2011), the results of this research indicate that systems, processes, and procedures can be both barriers and facilitators for the implementation of SDS. Although participants gave a few instances of positive changes in such systems, most examples illustrated how SDS systems make it harder to implement the human-rights principles of the legislation. The practitioners viewed the focus of SDS systems, processes, and procedures on controlling resources to be interfering with the potential of SDS to promote human rights. This research also provides empirical evidence for claims in the literature that the SDS implementation has been resource-driven (Pearson, Ridley, and Hunter 2014). An example of this dominance of the issue of resources given by one practitioner was the way local authorities rigidly predefined eligibility criteria and needs rather than allowing them to be responsive to unique needs of individual service users (Series and Clements 2013; Slasberg and Beresford 2016).

This research indicates that support systems for empowering service users to make informed decisions about their care remain underdeveloped and underused. There is a wealth of evidence suggesting such systems in the form of advocacy, and activism by service users and service-user-led organisations

are crucial for the development and implementation of human rights legislation (Rosenberg 2004; Shakespeare 1993). Service user organisations have not been significantly involved in policy-making processes (Ridley et al. 2011; Johnston et al. 2009) and have increasingly struggled for funding (Barnes and Mercer 2006). Moreover, many people with disabilities have limited or no contact with service user and/or advocacy organisations (PMSU 2005) and this research suggests that SDS has not significantly changed this.

Although the Scottish Government has put in place additional funding for independent SDS support organisations, the results of this research suggest that such organisations have not been involved significantly in the SDS implementations and in empowering service users due to, at least in part, statutory practitioners' fears that such organisations increase expectations and they might not be able to meet these expectations possibly due to insufficient resources and unclear processes. It seems this may have been a significant obstacle in the way of the SDS legislation promoting human rights as, according to Pearson, Ridley, and Hunter (2014), the lack of significant involvement of such organisations is likely to increase the existing inequalities in health and social care.

The third-sector practitioners show understanding of the difficult position statutory professionals are in, but at the same time they emphasise that just because the local authorities don't always deliver what people are legally entitled to, this does not mean people with disabilities should not be informed about their rights. On the contrary, they still need to know their rights. Knowing one's rights is important for making informed decisions. Service users need to know whether their rights are being met in order to decide whether to accept what they are offered or to challenge it.

This research indicates that it is significant that the SDS Act (2013) did not put in place any new processes for challenging local authorities' decisions about SDS packages of care, and that the previously existing processes suffer from a lack of independent evaluation early in the complaint process. Also, unlike other legislation such as the Mental Health (Care and Treatment) (Scotland) Act 2003 (Scottish Government 2003), the SDS Act is not precise about many aspects of the SDS process (e.g. time scales) including the processes for upholding service users' rights. This means that in the first instance service users complain to the institution that made the decision about their package and in some cases the complaint may be handled by the same person who made the decision that the complaint is about (e.g. see the example quoted earlier). Moreover, the SDS Act (Scottish Government 2013; section 9 on page 8) did not introduce an unambiguous right to independent advocacy specific to SDS which in practice means a lack of additional funds to support advocacy services for SDS (Pearson, Ridley, and Hunter 2014). This is a limitation of the legislation itself, which emphasised the importance of human rights without putting in place mechanisms to support service users with upholding these rights.



Professionals' fears that advocacy and SDS support organisations might increase service users' expectations might stem from practitioners' doubts about what is achievable by SDS in the context of neo-liberalism and austerity (Needham 2011). As Lloyd (2010) points out, service users' rights to choice and control often remain unfulfilled 'because in the day-to-day reality of service organisation and provision the political agenda of resources always takes precedence' (192). According to this research, the day-to-day reality for practitioners consists of figuring out how their own local SDS processes work and how to meet service users' needs in the context of shrinking resources. The social workers' reluctance to engage SDS support and advocacy organisations to avoid raising service users' expectations suggests that social workers struggle to utilise SDS to support service users' rights in the current context.

Thus, this research shows a dissociation between the moral imperatives of SDS with its human rights ethos and the problem that fulfilling service users' rights requires funds which are reduced due to ongoing demographic and economic challenges. The enactors of the SDS Act expressed the belief that SDS would reduce spending in social care, but the evidence base for this claim was always very limited (Zarb and Nadash 1994; cited in Pearson, Ridley, and Hunter 2014, 60). According to Pearson, Ridley, and Hunter (2014), many commentaries just prior to the SDS Act (e.g. Leadbeater 2008; Duffy 2010) linked personalisation with savings as high as 45% in health and social care. For the social policy makers introducing SDS, this might have seemed like killing two birds with one stone: improving realisation of human rights (such as the right to self-determination) and making savings. This approach treated the highly complex relationship between human rights and resources as unproblematic without spelling out what needs to happen on the practical level of SDS for personalisation to result in savings without compromising human rights. The lack of such considerations led to SDS practices, systems, and processes being extensively focused on resources, in some cases at the expense of service users' human rights.

### ***Limitations***

Due to the small number of participants, the research should be seen as providing a starting point for further studies involving more participants and a greater diversity of agencies. For example, none of the participants represented a social care provider organisation. Another limitation of this study, which has already been discussed, is that it did not interview service users.

### ***Implications***

This research indicates that to empower service users to exercise their rights, practitioners need to be empowered themselves. One of the necessary

(although not sufficient) conditions for that to happen is timely access to reliable information about local and departmental SDS processes. Practitioners need this information not only for their own understanding but also to share it with service users, enabling them to make informed choices. The practitioners perceive access to such information as difficult due to a lack of transparency of processes and procedures for various SDS options. This seems to have a cascading effect on service users who might form their views based on incomplete information obtained from professionals and might as a result make decisions that do not support their human rights. Transparency was identified very early as one of the conditions necessary for enabling service users to make informed decisions (Duffy 2010b). Yet this research together with observations by others (Series and Clements 2013; Slasberg and Beresford 2017) shows a lack of transparency that presents a significant obstacle for SDS to promote human rights.

SDS has intensified the tension in the day-to-day practice of social workers who must help service users get support which is both (1) timely and available and (2) what they need to fulfil their human rights, where the latter might require involving advocacy or an independent organisation which might take time and possibly raise expectations. Therefore, it might be useful for statutory practitioners to partner more with such organisations. Even if this is limited to just referring service users for independent SDS support or advocacy, it can have an important role in challenging some SDS practices and making systems in health and social care more transparent, especially in terms of the problematic relationship between human rights and resources (Slasberg and Beresford 2017).

Human rights and limited resources do not sit comfortably next to each other. As Slasberg, Beresford, and Schofield (2013) and Elder-Woodward (2014) indicate, resources are crucial for service users' human rights to be realised and for SDS packages to bring about positive outcomes in their lives. This research suggests that the implementation of SDS has suffered from a lack of acknowledgement of the practical issue of human rights being dependent on resources (Lloyd 2010). Slasberg and Beresford (2017) note the long-standing 'funding [discussion] taboo' in health and social care and suggest honesty about the relationship between needs and resources as a way forward. Otherwise, SDS risks following further in the steps of similar system changes such as community care reforms of the 1990s where the idea of 'tailor made' services was also present but implemented in a limited way because of lack of resources (Lloyd 2010).

## Conclusions

This research investigated some of the effects of SDS on the realisation of human rights in Scotland. The research provided empirical evidence for SDS increasing

the awareness of human rights in health and social care and the limited influence of this awareness on the realisation of such rights through SDS. A dissociation was identified between the human rights rhetoric of SDS and day-to-day practices using SDS to put care packages in place. Several years after the introduction of SDS, this dissociation has not been addressed, leaving practitioners wondering whether SDS made a difference in the realisation of service user's human rights or just increased expectations without putting in place resources for meeting these expectations. Such doubts stem from systemic difficulties (e.g. resource-driven processes and insufficient access to and usage of support systems) and contextual factors (e.g. economic crises and neoliberalism).

The tension between the roots of SDS in neoliberalism and the roots of SDS in the Independent Living Movement has long been discussed (Pearson, Ridley, and Hunter 2014). This research shows how this tension affects every-day SDS practices and how the SDS implementation suffers due to not directly addressing the details of the difficult relationship between human rights and resources. This research suggests that local resource management and tinkering with SDS processes is unlikely to make a significant difference in SDS promoting human rights. What seems to be needed instead is first to empower practitioners with proper knowledge of local implementations of SDS and resources necessary to manage that information and second an acknowledgement at the societal level that sufficient resources are needed so that social work departments can focus on human rights needs rather than devoting too much time and energy to carefully staying within limited budgets.

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No potential conflict of interest was reported by the authors.

### **Data deposition**

The data is confidential interview transcripts and is not currently deposited anywhere.

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## Data availability statement

The data (interview transcripts) that support the findings of this study are available from the corresponding author, DB, upon reasonable request.

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