

# **‘I could have run away’: Women’s Experiences of Self-directed Support as Unpaid Carers**

## **Interim Report (July 2019)**

This interim report uses data from the ‘My Support, My Choice: User Experiences of Self-directed Support in Scotland’ project, run by the Health and Social Care Alliance Scotland (the ALLIANCE) and Self Directed Support Scotland (SDSS) and funded by the Scottish Government. Published with thanks to Naja Bergen Dale for her role in compiling the research.



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## Foreword

**Fiona Collie, Policy and Parliamentary Affairs Manager, Carers Scotland**

Carers Scotland believes that Self-directed Support (SDS) offers great potential to carers to support their caring role, their own health and wellbeing and personal aspirations. We have supported its implementation from the beginning for this very reason.

Implemented correctly, consistently **and** fully, it can provide the ability to organise the support the person they care for needs in a way that not only meets their loved one's needs and desired outcomes but also to support caring, family life and carers' own opportunities to work, take part in leisure and learning and spend time with family and friends.

But too often, as this report shows, SDS is not meeting these aspirations. For carers, it can instead add to the demands of caring, placing greater pressure on carers, adding the role of information gatherer, administrator, accountant and employer to an already heavy load.

And provision of SDS is not equal. We often hear from carers in remote and rural areas of the difficulties of recruiting personal assistants or indeed of choosing another service. Choice, flexibility and availability of SDS varies considerably between local areas across Scotland.

Moreover, in challenging financial times, fewer people are able to access support, as authorities tighten criteria to meet only those with critical or substantial need.

The impact of this on unpaid carers and the economy is hidden. In our most recent State of Caring survey, 14% of carers said they have experienced reductions in the support the person they care for receives.<sup>1</sup> This leaves carers to fill the gaps which reduces their choices around caring and other areas of their lives – most notably retaining employment. This is an important point to recognise. Reductions in social care impact on the 1 in 7 workers in the UK who are carers. Despite their efforts saving £10.8 billion each year, 1 in 5 carers have to give up work to care, with resulting individual personal and financial costs and an impact on the wider economy.

But even with these challenges, it is possible to create an environment where the intentions of SDS can be moved forward.

Having the right information at the right time is key. We know from carers that information from the very start of their caring journey is critical in both having a choice in whether or not they wish or are able to provide care **and** in enabling them (and the person they care for) to exercise their right to have choice and control over the support they need.

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<sup>1</sup> Carers UK, 2019. State of Caring: A snapshot of unpaid care in the UK, pp.21-22. Available at: [http://www.carersuk.org/images/News\\_campaigns/CUK\\_State\\_of\\_Caring\\_2019\\_Report.pdf](http://www.carersuk.org/images/News_campaigns/CUK_State_of_Caring_2019_Report.pdf)

It is also important to commission and develop the right services with carers and the people who use them, enabling risk and offering as much flexibility as possible and, above all, trusting and empowering individuals and carers to identify the right solutions to meet their own personal outcomes.

“I could have run away” explores the experiences of carers accessing SDS. It makes stark reading, yet the messages within can give greater understanding of the challenges that need to be addressed and bring an invaluable contribution to building the right environment for SDS to succeed. I would encourage anyone involved in the development and delivery of SDS to use this report to help build success in their local areas.

## Introduction

This interim report focuses on women's experiences of Self-directed Support (SDS) as unpaid carers and provides insights into the current application of SDS in Scotland. It is based on 15 semi-structured interviews that took place between November 2018 and May 2019 in five local authority areas. The 60-minute interviews are part of the first wave of 'My Support My Choice', a mixed-methods research project about people's experiences of SDS across Scotland. The project involves 80 interviews and six focus groups across eight local authority areas and a national survey. It is delivered by the Health and Social Care Alliance Scotland (the ALLIANCE) and Self Directed Support Scotland (SDSS), with funding from the Scottish Government.<sup>2</sup> This report contains interim findings that will be supplemented by subsequent analysis covering a broader area of Scotland and a larger pool of data, to be published later in 2019.

## Background

Introduced in the Social Care (Self-directed Support) (Scotland) Act 2013, Self-directed Support (SDS) aims to grant people greater choice and control over their social care. It is defined by the Scottish Government as 'the support individuals and families have after making an informed choice on how their Individual Budget is used to meet the outcome they have agreed'.<sup>3</sup> Support should be designed and delivered in equal partnership between people and professionals. Local authorities are legally obliged to offer four SDS options. Option 1 provides direct payments to the individual, or their carer, who can use the budget in accordance with an agreed support plan. Option 2 allows individuals to choose their preferred support provider/s, which is then managed by the local authority or a third-party provider. Under Option 3 support is managed and provided by the local authority. Option 4 combines some or all of the first three options.

The introduction of SDS in Scotland is a policy aimed at reinventing formal systems of care.<sup>4</sup> While in specific circumstances people may employ a family member as a personal assistant, this is not currently seen as a mainstream approach in most areas. Informal care is not consistently addressed by SDS policy, which is why it is important to see the unintended consequences reform has had for this group of people. Looking at lived experience, this report flags up some of the issues unpaid

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<sup>2</sup> The Health and Social Care Alliance Scotland, 2019. My Support My Choice: SDS Research Project. Available at: <https://www.alliance-scotland.org.uk/blog/news/my-support-my-choice-sds-research-project/#expanded>.

<sup>3</sup> Scottish Government, 2019. Self-directed Support: A National Strategy for Scotland. Available at: <https://www2.gov.scot/resource/doc/329971/0106962.pdf>.

<sup>4</sup> K. Rummery, 2009. A Comparative Discussion of the Gendered Implications of Cash-for-Care Schemes: markets, Independence and Social Citizenship in Crisis. *Social Care Policy and Administration*, 43(6), p.638.

carers have had with the process of accessing SDS with or for the people for whom they care. Although the SDS policy has not been designed to deal with informal systems of care, it may be possible for local authorities to make the system more accessible to unpaid carers. It is essential that the Scottish Government integrates the voices of unpaid carers into this and future plans for implementing SDS. The SDS Implementation Plan 2019-2021 has just been published (June 2019), and specifically highlights the importance of ensuring that people – supported people, unpaid carers, and families – are ‘fully involved in decisions about their support’,<sup>5</sup> but more explicit action plans showing how to support carers are needed. For example, while the Carers (Scotland) Act 2016 is discussed in the SDS Implementation Plan, initial findings from the ‘My Support My Choice’ project indicate that many carers still struggle to access services for their own support, and are more likely to prioritise needs assessments for the people for whom they care than their own assessment and health needs.

Good care is a pillar on the road to equal rights and citizenship. Care has been pivotal in the disabled people’s movement as an important tool to empower and facilitate independence. The introduction of SDS is in many ways emblematic of an attempt to integrate greater choice and control into the lives of disabled people across Scotland. However, women’s rights groups such as Engender have expressed concern that the SDS Act also marked a shift in caring responsibilities to within the family unit – which has intersectional significance, especially regarding gender.

As a policy, SDS has been critiqued for lacking robust equality assessments. Emma Trottier of Engender has stated that ‘in spite of overwhelming evidence that women face significant barriers to experiencing and accessing good mental and physical health, there was little consideration of gender at the time the changes came into force’.<sup>6</sup> Indeed, the 2012 Equality Impact Assessment of the Act reads: ‘There have been several reviews of SDS where the case study participants were of different genders. These reviews did not raise gender-based inequality as an issue indicating that it may not be a significant factor’.<sup>7</sup> SDS is built around a model of social care and human rights, but in practice and theory, little attention has been given to gender; and as such, it cannot be considered to fully engage with the principles of human rights policy work.

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<sup>5</sup> Scottish Government, 2019. Self-directed Support Implementation Plan 2019-2021, p.9. Available at: <https://www.gov.scot/publications/self-directed-support-strategy-2010-2020-implementation-plan-2019-21/>.

<sup>6</sup> The Health and Social Care Alliance Scotland, 2017. Women’s experiences of Self-directed Support Briefing Paper, p.2.

<sup>7</sup> Scottish Government, 2012. Social Care (Self-directed Support) Bill: Equality Impact Assessment, p.12. Available at: <https://www.gov.scot/publications/social-care-self-directed-support-bill-equality-impact-assessment/>.

The findings of this report raise similar questions around lived realities of women who care for family or friends, and how this contradicts the spirit of the SDS Act. Meanwhile, in some areas Integration Joint Boards are explicit in their statements that families should ‘plug the gap’ to reduce pressure on services<sup>8</sup> – a position that impacts disproportionately on women, given that women are more likely than men to take on caring roles.<sup>9</sup> Nor is this trend likely to change without substantial increased funding provision around SDS; the Care Inspectorate’s most recent thematic review of SDS stated that in the current fiscal climate most partnerships that they inspected ‘prioritised the allocation of resources to those assessed as being at critical or substantial risk’ and signposted the other to less formal services [...] for support’.<sup>10</sup>

More widely, concerns have been raised that ‘cash for care’ policies have revoked women’s rights by cutting traditionally female-dominated jobs and relying on women’s double burden of work to fill the void.<sup>11</sup> In this way, SDS has been claimed to have a significant role in moving the responsibility of caring away from the state and back into the hands of private citizens.

In accordance with its rights-based principles, SDS is intended to grant individuals greater choice and control over their social care. Nonetheless, international literature on similar care strategies raise concerns that cash for care policies (specifically comparable to Option 1) have had negative impacts on women, tasking more households with the care of relatives as well as diminishing the care industry as a source of attractive employment.<sup>12</sup> The effects of these policies have been profoundly gendered as women make up an estimated 60% of carers and professionals employed in the care industry in the UK.<sup>13</sup> Women are typically the primary carers for children, husbands, and elderly family members; as such, they often become the recipients of restricted state-subsidised social security once they reach old age.<sup>14</sup> The dismantling of social security provisions in this way has a twofold impact on women: by transferring greater caring responsibilities into their

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<sup>8</sup> Gareth Jones, 2018. Families should help out more with social care, say Edinburgh health bosses, *Third Force News*. Available at: <https://thirdforcenews.org.uk/tfn-news/social-care-plans-to-call-for-greater-reliance-from-families>.

<sup>9</sup> Office for National Statistics, 2017. Unpaid carers provide social care worth £57 billion. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/articles/unpaidcarersprovidesocialcareworth57billion/2017-07-10>. See also Carers UK, 2019. State of Caring: A snapshot of unpaid care in the UK. Available at: [http://www.carersuk.org/images/News\\_campaigns/CUK\\_State\\_of\\_Caring\\_2019\\_Report.pdf](http://www.carersuk.org/images/News_campaigns/CUK_State_of_Caring_2019_Report.pdf)

<sup>10</sup> Care Inspectorate, 2019. Thematic review of self-directed support in Scotland: Transforming lives, p.17. Available at: <http://www.careinspectorate.com/images/documents/5139/Thematic%20review%20of%20self-directed%20support%20in%20Scotland%20June%202019.pdf>.

<sup>11</sup> M. Evans, 2015. Feminism and the implications of austerity, *Feminist Review*, 109(1): 146-155.

<sup>12</sup> L. Boivin, 2016. Cash for care in Quebec, collective labour rights and gendered devaluation of work, *Journal of Industrial Relations*, 58(4): 491-509.

<sup>13</sup> C. Beckett, 2007. Women, disability, care: Good neighbours or uneasy bedfellows?, *Critical Social Policy*, 27(3): 360-80.

<sup>14</sup> Engender, 2019. Engender response to the Scottish Government consultation on disability assistance in Scotland. Available at: <https://www.engender.org.uk/content/publications/Engender-response-to-the-Scottish-Government-consultation-on-disability-assistance-in-Scotland.pdf>



hands, and by cutting down the social security provisions available should they need care. These critiques pose a concern that makes it imperative to examine women's experiences as carers under the new social care system in Scotland.

## Methodology

This research makes use of thematic analysis as defined and outlined in Clarke and Braun's pioneering 2006 paper titled 'Using Thematic Analysis in Psychology'. Thematic analysis is a method for identifying patterns and themes within and across qualitative data. Taking the data as its focal point, this research has used an inductive, bottom-up approach to identify gendered themes within women's experiences of SDS as unpaid carers.

As this report contains interim findings, it will lay the ground for subsequent analysis that will cover a broader area of Scotland and a larger pool of data. Themes and findings may not be generalizable to the full wave of research and should thus be taken as an initial attempt to create a 'thematic map of analysis'.<sup>15</sup>

## Participants

The unpaid carers interviewed in this sample were pooled from five local authority areas around the central belt of Scotland. It is noticeable that a significant proportion of respondents were carers for their children (79%) and a smaller proportion (21%) cared for others such as parents and spouses (see Figure 1). This finding may indicate wider links to the gendered nature of childcare. Mary Evans argues that the language of neoliberalism has co-opted feminist agendas of emancipation.<sup>16</sup> Hiding behind the fact that women have now been 'given' access to civil rights and employment, this development has failed to address the gendered division of unpaid work and domestic labour. Women still perform the majority of reproductive work, unpaid, which filters into women's caring experiences explored in section 4:4 of this report: 'Pressure to Care'.

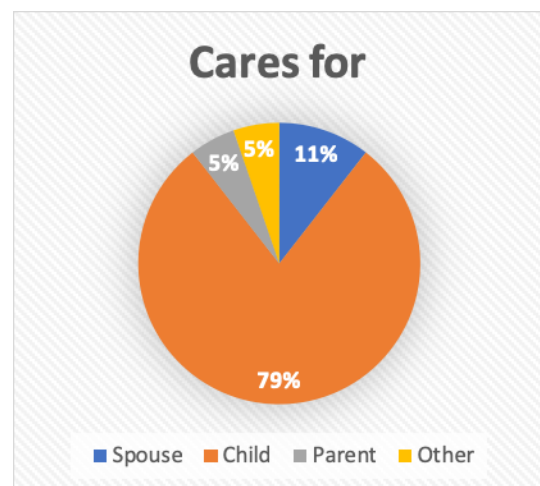


Figure 1

Of the carers we interviewed, the largest group (44%) were involved with Option 1 and managed a personal budget alongside or on behalf of the person for whom they

<sup>15</sup> V. Braun and V. Clarke, 2006. Using Thematic Analysis in Psychology, *Qualitative Research in Psychology*, 3(2), p.87.

<sup>16</sup> M. Evans, 2015. Feminism and the implications of austerity, *Feminist Review*, 109(1): 146-55.



cared. 17% of respondents were involved with Options 2 and 3 respectively, and a notable 17% of the carers interviewed cared for people with no social care support in place. Only 5% of the sample used Option 4 (see Figure 2).

Respondents lived in five local authority areas, across rural and urban Scotland. The largest body of respondents are from Dumfries and Galloway (33%), with 27% from Stirling, 20% from North Lanarkshire, 13% from South Lanarkshire, and 7% from Glasgow (see Figure 3).

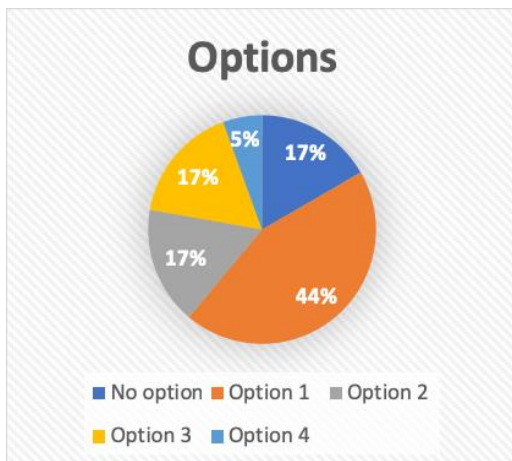


Figure 2

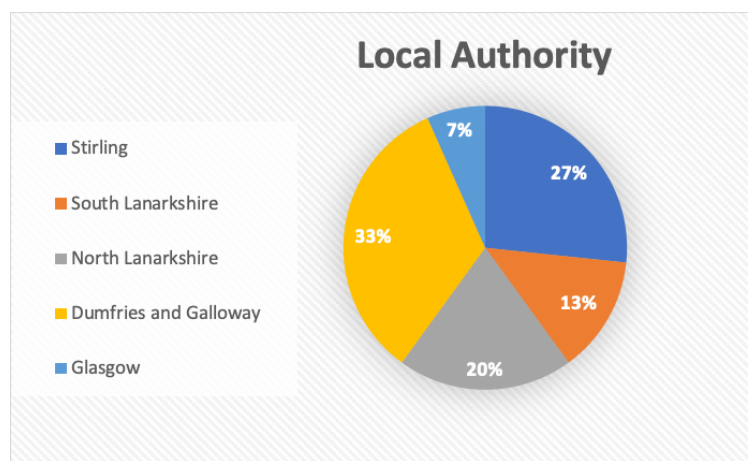


Figure 3

## Analysis

From the interviews, this report identifies four major themes. The quotes expressed in each section have been anonymised, with names and key details changed and alternative names allocated to each participant. All participants have granted consent for their experiences to be used. The four themes are as follows:

- carers' knowledge of SDS;
- how carers utilise informal channels of support;
- the impact of SDS on carer's mental health;
- the power relations ingrained in the process of accessing and applying for SDS.

# Chapter 1: Knowledge and Information

## 1.1. Information about SDS

Throughout the interviews, respondents emphasised lack of information about SDS as a hindrance to achieving good quality outcomes for the people they care for. Many of the carers we interviewed described difficulties in finding out that SDS existed, and rights to social care support. Many women did not receive information from social work, and instead were left to find out information about SDS via their own research or word of mouth. Respondents described problems in having no process to connect them to social workers who could offer them initial knowledge on SDS and the four options. Given the significance placed on practitioners and front-line workers as key communicators of SDS in the SDS Change Map and Implementation Plan 2019-2021,<sup>17</sup> and wider reports of stretched services,<sup>18</sup> this finding raises obvious problems for the implementation of SDS. Key descriptions of problems with information are as follows:

- 'If it wasn't for [third sector organisation] I wouldn't have known about SDS; nobody mentioned it to me, it was not accessible. When I did try to access it, it was a case of "Well, you're looking for it for yourself? Go to the Carer's Commission."'

Erin, North Lanarkshire

- 'At that point I never even realised social work existed. We didn't try these places because I never ever had any dealings with social work; I didn't know what they offered people.'

Amy, North Lanarkshire

- 'I just didn't seem to get any support from anyone, anywhere. I kept asking and I kept getting – for want of a better description – poo-pooed.'

Leah, South Lanarkshire

- 'It wasn't through social work [that I found out about SDS], I can tell you that. I think it was through the internet. [...] Nobody really helped me, so I've dug out things for myself.'

Eva, North Lanarkshire

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<sup>17</sup> Scottish Government, 2019. Self-directed Support Implementation Plan 2019-2021, p.9. Available at: [file:///C:/Users/hannah.tweed/Downloads/social-care-support-investment-scotlands-people-society-economy-self-directed-support-implementation-plan-2019-2021%20\(1\).pdf](file:///C:/Users/hannah.tweed/Downloads/social-care-support-investment-scotlands-people-society-economy-self-directed-support-implementation-plan-2019-2021%20(1).pdf).

<sup>18</sup> Care Inspectorate, 2019. Thematic review of self-directed support in Scotland: Transforming lives. Available at: <http://www.careinspectorate.com/images/documents/5139/Thematic%20review%20of%20self-directed%20support%20in%20Scotland%20June%202019.pdf>.

In several interviews, respondents highlighted support provisions for people after hospital discharge, to ensure appropriate care is in place. Collaboration between hospital staff and social work is an important factor in improving women's experiences of SDS as unpaid carers.

Many of the respondents had done their own research on SDS and expressed concern about other carers who might not have the energy to undertake independent research into SDS – particularly those who were stretched beyond capacity and at crisis point.

- 'I've just been learning as I go along, because you don't know the big picture. You don't know who to contact and where to go and who to contact, and so the information, as far as I'm concerned, wasn't really there. You had to go and find it.'

Sophie, Stirling

- 'I'm not sure what Self-directed Support actually covers, because when I signed the agreement, [I] had an appointment to sign it, and the person that was dealing with it was off sick that day. So, somebody else covered for them that didn't know anything about it when I was signing it [...] but [I] didn't want to delay it because the support started the day it was signed.'

Leah, South Lanarkshire

- 'I'm finding it very difficult to accept that there's no way that I can be helped. Not financially, I don't mean that, but [...] just help in the process, and there's been none.'

Anna, Stirling

An initial lack of information led more women to feel insecure about the administrative processes involved with Option 1. Although 44% of the women from the sample were involved with Option 1, the majority stated that they had major concerns with the amount of paperwork involved:

- 'We did paperwork, paperwork, paperwork, and a person went off sick; paperwork, paperwork, paperwork, got a new person; more paperwork, paperwork, paperwork, person left the post and nobody in post; paperwork, paperwork, paperwork for adult social care – and now we've changed the system. [...] I've just done paperwork for years which has resulted in absolutely nothing happening.'

Lily, Dumfries and Galloway

- 'Even for such short hours [SDS] was very challenging, because obviously it had to be done through an accountant and all the records kept.'

Mia, Stirling

- '[The social worker] left me paperwork and it was about HMRC and about employing somebody, and it was a whole book of rigmarole and I thought "that's not for me". I rang her up and I said, "I don't think I can do all that, that's too much for me."'

Emily, Dumfries and Galloway

- 'I'm getting this help to give me more time, but what I've found is it is more work because you have to organise it [...]. So, actually, if you ask me over the last two months, I've spent more time sorting it out than I have actually got the benefit of it.'

Leah, South Lanarkshire

Participants had mixed experiences with the process of SDS once it had started. Although a significant theme was painted around the complexity of paperwork involved with Option 1, some women acknowledged that their initial concerns about the process were not sustained:

- 'To me, taking and running an individual budget was straightforward, having had children and managing. I don't mean that in an adverse way, but just being able to do everything was straightforward. Having an SDS budget and employing people was a piece of cake because my skill set can deal with.'

Jessica, Dumfries and Galloway

- 'I was a wee bit apprehensive; I wasn't sure about the paperwork and stuff but I do have a few friends [...] that do Self-directed payments. I had a wee bit of advice from both of them (but not a lot) but when I did get it the paperwork was the thing that was bothering me most – but after I looked at it there wasn't very much.'

Eva, North Lanarkshire

- 'Making sure everything was all done right absolutely was quite overwhelming, but then [...] after a few meetings with [third sector organisation] things started to kind of... (Interviewer: Seem less daunting?) Yeah, paperwork and everything. It wasn't until I actually started doing it that I was like "This isn't too bad. This is ok."'

Eilidh, South Lanarkshire

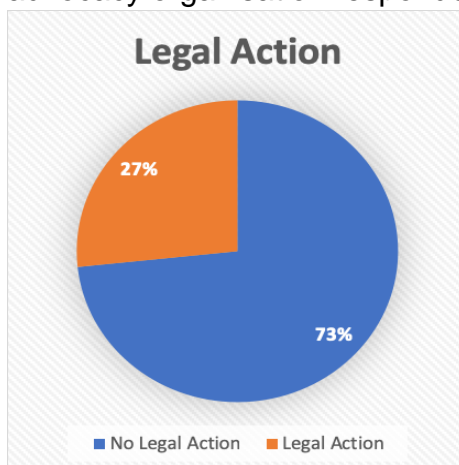
## 1.2. Knowledge of Rights

Many of the women interviewed stated that their level of knowledge of rights under SDS had a direct influence on the quality of outcomes. In the sample analysed, 27% of the respondents had taken legal action: either direct legal action against social

work or using formal complaint structures within the council (see Figure 4). A common theme for the women who had taken legal action was a concern for other people who might not have the means or knowledge to challenge assessments as they had done. This concern was confirmed amongst some of the women in the group that had not taken legal action.

Advocacy, particularly independent advocacy, was a recurring theme throughout the interviews in the project. Independent advocacy is a form of supported decision-making that can help maximise people’s involvement in and control over decision-making, including in relation to SDS. An independent advocate will not make decisions on behalf of the person or group they are supporting; they will help them to get any information needed for them to make informed choices, and then help the individuals in question to convey those choices to others.<sup>19</sup>

Heather Gibson’s 2018 report for the Scottish Independent Advocacy Alliance (SIAA), ‘Self-directed Support and Independent Advocacy’, highlights that 83% of advocacy organisation respondents thought that more could be done to promote the



role of independent advocacy around people’s experiences of SDS (15), and only 14% felt that the legislation had ‘achieved its aims to allow individuals more involvement and flexibility regarding their support’ (16). Given the inclusion of Item 7 on the SDS Change Map (‘People have access to good quality independent advocacy, if they feel it is required’), these findings and the relative paucity of information on people’s experiences of SDS and independent advocacy invites further research on this topic.

Figure 4

- ‘It’s as if, if you know how to get around these things, then it’s working. [...] I think those people who are really needing things, and they’re stuck at home, and they’re maybe not challenging things as much as what I do, it must be quite difficult for them.’

Emily, Dumfries and Galloway

- ‘I phoned the social work to ask them for SDS on the basis of Amanda, and the lady on the phone said, “Yes, you’ve applied for that before, but she didn’t make the criteria.” [...] And I went, “Right, OK”. So me being me, I thought that was all.’

Erin, North Lanarkshire

<sup>19</sup> Scottish Independent Advocacy Alliance, 2019. What is Independent Advocacy? Available at: <https://www.siaa.org.uk/us/independent-advocacy/>.

- ‘I don’t shout, I don’t ask, I don’t demand, I don’t say. And that’s my fault. Because I just think they’re busy, and I can do it, and that’s landed me here I’m afraid. She’s a good social worker, but we’re in the bottom of the pack right now.’

Anna, Stirling

Where women challenged assessments, they reported better quality outcomes. A common theme from many of these women was the suggestion that others should challenge initial assessments:

- ‘They say “How many hours a week?”, but if you know the legislation, [it] says you don’t have to break it down, you can go for a budget and use it flexibly. So every time [social work] try and get me to say “Oh, I’ll only use this many hours a week” I refuse, and I just say that it’s used flexibly – and because [my partner] is a lawyer they tend to listen.’

Chloe, Dumfries and Galloway

- ‘I’m a bit of a guinea pig now. I hate to say it, but this is why I shouted a bit, and got the lawyers involved. And now they seem to think “Oh, [a carer’s assessment] will help now”, and they thought that would cancel the case against Rania. But no, that’s not right. [...] It’s just a postcode lottery, and I think it’s ridiculous.’

Erin, North Lanarkshire

### 1.3. Transparency

57% of the women we spoke to highlighted lack of transparency in the council’s needs assessments processes as a problem. They linked this lack of transparency to hindering their understanding of the SDS process and creating difficulties in challenging assessments. The women expressed a desire to gain more insight into the process of assessments, to understand rights and options. Transparency was not an explicit theme explored in the research questions, yet it came up in 57% of the interviews (see Figure 5).

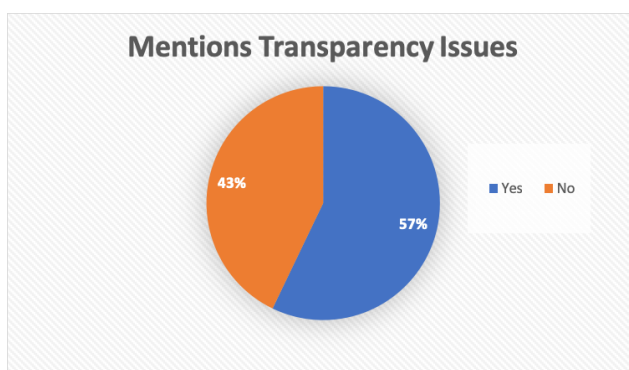


Figure 5

- 'I think the person at the centre of it [SDS] is lost and [...] that's who it's all about. The person at the centre should be supported and obviously they've been assessed so everybody knows the hours they are due to be supported what that support looks like [...]. They need to become more transparent for everybody so that people do have what we call choice - because right now I think it is just these words, they all talk the talk but nobody is delivering. That might be very broad, but certainly we've had some horrendous experiences.'

Mia, Stirling
- 'I find it challenging when the communication is not clear, and when written communication is unclear. I like things written down. And the lack of transparency, those would be the main challenges.'

Emma, Glasgow
- 'I think there's a lot of subjectivity there, getting budgets approved, so if you sat in this year's review it will be interesting to see what people think.'

Jessica, Dumfries and Galloway
- 'I was just told [my son] was to get [X] hours support [...]. But I wasn't told how they worked that out, how they came about that figure, anything. I got a report about it, but they didn't say how they then took that report to be quantifiable as anything. You know, I've no way of knowing how they came about that information.'

Leah, South Lanarkshire

## Chapter 2: Support

The women interviewed for the research all discussed the formal and informal routes of support they had used while being assessed for or accessing SDS. Linda McDowell talks about the shift of care from the state to the family unit, which was exacerbated following the 2008 financial crash, and how this created new relations amongst generations. McDowell argues that intergenerational care is now a developing norm in the UK, and one that is specifically gendered. As such, this report explores the importance of support networks to women who care for their friends or family members.<sup>20</sup>

### 2.1. Peer Support

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<sup>20</sup> L. McDowell, 2017. Youth, children and families in austere times: change, politics and a new gender contract, *Area*, 49: 311-16.



The women interviewed in the sample mentioned support networks as something they would like to expand on and had actively tried to find through informal channels of support (e.g. family, internet forums, local carer centres, word of mouth, etc.). The women who did not have access to a support network noted this as a difficulty in their day to day lives.

- 'I don't have family in the area, so I couldn't ask for help. So this way, even though it was a care agency that had to step in, I was able to give [my children] some of the support they needed for appointments.'

Olivia, Dumfries and Galloway

- 'I think [peer support] is where you get your wellbeing, isn't it?'

Amy, North Lanarkshire

- 'I think when you grow up with a child with a disability, they people are your friends; the people that have children the same as you. You sort of end up learning to be a support mechanism for them all. [...] I feel [support group meetings] are good for me because I get to speak to these women.'

Eva, North Lanarkshire

Women used their informal support networks in creative ways. Those who used peer support primarily used this to attain greater knowledge of the SDS pathways:

- 'I was part of [third sector organisation] as a Board Member, at one point, so I met a lot of parents that way – but also Facebook [...]. It was just reading other people's stories, that made you realise what you could use, so it was quite handy that way.'

Olivia, Dumfries and Galloway

- 'I questioned it [travel expenses for personal assistants] at the time, because I heard somebody else say that they'd got it included, they'd managed to wangle it, and they could get it included.'

Emily, Dumfries and Galloway

Additionally, a significant number of the women engaged with Option 1 had used their support network to recruit personal assistants:

- '[The personal assistant] knows me and she knows Katherine and that's where I had said to her, "Would you like some of my hours to do Katherine?" And that's how we got Katherine's PA. [...] [Katherine's friend] gets less hours. Katherine has a friend at probably does get the same budget, but she uses an agency – she only gets like three days a week.'

Eva, North Lanarkshire

- ‘We were lucky enough that where Tom was at with his respite, that’s where these two guys worked. They got in touch with me saying, “Hey! We’re looking for a folk to work with Tom”, so we employed them. They knew Tom from before, doing his respite and things, so they knew the good and the bad, the ups and the downs.’

Eilidh, South Lanarkshire

## 2.2. Third Sector Organisations

One of the recurring themes in the interviews was accounts of the process of accessing SDS being somewhat ‘overwhelming’ (Eilidh, South Lanarkshire). As explained in Chapter 1, this concern led some women or the people for whom they care to opt for Options 2 or 3. In many of the interviews, respondents explained that third sector organisations helped them understand SDS and feel more comfortable opting for pathways that were not Option 3 (council arranged support) – including some who now work for third sector organisations following their experiences of SDS and care:

- ‘The biggest problem I've got here working with Self-directed Support is trying to get families to believe that they are capable of being employers [...] They're terrified of the services, they're terrified. They don't know the four options and [...] they're scared a bit of employing somebody.’

Chloe, Dumfries and Galloway (Carer and TSO employee)

- ‘I wasn’t there [at the needs assessment] on my own, which I felt was helpful because I didn’t know anything about it. At least [third sector organisation employee] knew about [SDS] and, you know, kind of knew I suppose my circumstances. So, she could [...] alert that [X] hadn’t been covered.’

Leah, South Lanarkshire

- ‘I think I would have probably chosen another option [than Option 1] if I didn’t have the help [third sector organisation] to get it all set up. [...] I wouldn’t have done it half as easy or felt as confident doing it without them. [...] If you’ve got the right support behind you, you can do anything. You can make it [...] work.’

Eilidh, South Lanarkshire

## 2.3. SDS and Family Life

A key theme for many of the women interviewed was their concern for family members other than the individuals accessing social care and/or SDS. Mothers of children who did not require SDS as well as those who did reported using respite and personal assistants to make sure that they had quality time with all of their children, while ensuring those who needed more support received appropriate care:

- '[Nurses] watch Randy maybe between 12am and 4pm, and that means I've got that time to spend with my other children.'

Erin, North Lanarkshire

- 'I have time with Johan [son] when Linda [daughter] is away, and it's great. It's amazing.'

Anna, Stirling

- 'We can get more time with my daughter without holding her back. Because I need to sort [my son] out first. Now, we can just go and do our thing, our time.'

Eilidh, South Lanarkshire

Where women do not have access to appropriate social care, inadequate time with other children in the household was frequently introduced as a concern:

- 'I was a full-time carer; [...] I couldn't work. [...] My [other] children resented me for the care that I give Hilda. [...] They resented me and sometimes they still do. They say to me I give her more than I give them.'

Eva, North Lanarkshire

- 'I find I'm missing my daughter growing up, because she's the bottom of the pile. She shouldn't be, but she is. She's got asthma, but her needs are lower than my son or my father or arguably my husband. [...] She has to come... Well, that's not last in the pile, because mine are last in the pile, but you know what I mean. [...] I think I'm missing part of her growing up.'

Leah, South Lanarkshire

- 'I was up 24/7 looking after [my youngest daughter]. But my wee boy, there's problems there; my [oldest] wee girl, she had to see a counsellor, because the more time I spent with Rania the less time it was with they two.'

Erin, North Lanarkshire

When respondents were happy with the support received via SDS, they highlighted that SDS had had a positive influence on family relationships and overall quality of family life:

- 'You wouldn't believe the difference [SDS] has made to everybody in my household.'

Eva, North Lanarkshire

- '[SDS] gave Hilda a life and gave me and my husband a life. [...] Some of that money was ours; together [...] we went off to New York, and that was the first time in eight years that we... Actually we went ten years without a day's

break. And so I would say the positive side is in regards to changed lives for the better, it's changed my life for the better.'

Chloe, Dumfries and Galloway

- 'And the social worker saw the other side of it and thought, well, me and my husband needed a bit of time for ourselves too, so they thought that would help both sides.'

Emily, Dumfries and Galloway

## Chapter 3: Mental Health

While some women reported that SDS supported family life and wellbeing, respondents also highlighted the negative impact that caring and assessment processes had on their own health and wellbeing. Specifically, some respondents referenced involvement with managing and accessing SDS on behalf of people for whom they care as having a direct and powerful negative effect on their mental health. This finding is supported by wider research on care; 27% of carers responding to Carers UK's State of Caring Survey 2019 reported that their mental health was 'bad' or 'very bad', with 81% of respondents reporting having felt lonely or isolated as a result of their caring role.<sup>21</sup>

### 3.1. Needs Assessments and Carers' Anxiety

Most of the women in the sample expressed a concern that needs assessments were invasive and emotionally charged. This reaction was further exacerbated if there was a lack of transparency around processes (see Section 1.3.) or a feeling of being blamed for the health of the person for whom they cared:

- 'My interactions with social work were often very difficult and emotionally charged. Because obviously you're trying to get the best care for somebody you love – and I realised that the problem was financial, with the council, but that wasn't being said to me.'

Emma, Glasgow

- 'What as a family we found difficult to deal with was the sudden invasion of [Social Services]. That was, wow, we had always deal with our own affairs and having to give our information about the family I was like, "Why do you need to know that? What's it to do with?" So perhaps the process was harder than it needed to be if they had just given the information. [...] The problem with it for families is that by the time the process starts you're in battle mode, and that should not be the case for anything; and I think that makes the life for the SDS worker difficult, it makes my life difficult, because there's the invasion of privacy.'

Jessica, Dumfries and Galloway

- 'I don't know how I didn't go under, that's the honest truth. [...] Any dealings with them I felt like another number. It's not really nice to be honest with you, not nice at all.'

Erin, North Lanarkshire

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<sup>21</sup> Carers UK, 2019. State of Caring: A snapshot of unpaid care in the UK, pp.21-22. Available at: [http://www.carersuk.org/images/News\\_campaigns/CUK\\_State\\_of\\_Caring\\_2019\\_Report.pdf](http://www.carersuk.org/images/News_campaigns/CUK_State_of_Caring_2019_Report.pdf)

- ‘When we first started with SDS, when I had to go to the panel, that was hard – that was awful, to sit in front of folk and tell them your story.’

Olivia, Dumfries and Galloway

### 3.2. Carers’ Capacity and SDS

Several respondents reported that they tended to take on more than they could handle – in some cases due to a lack of other options – and that operating above and beyond their capacity had an impact on their mental health. As discussed earlier in this report, in many areas people are only deemed eligible for SDS if they meet ‘critical or substantial risk’ criteria – and until that threshold has been reached, they are signposted to informal or third sector support systems.<sup>22</sup> Such a pattern is likely to compound existing issues around carers’ capacity and health and wellbeing.

- ‘I was so tired; I was just working all the time. Finishing your work and in the end you have an hour to drive down to an old folks’ home, because that was an hour already coming from my work to my mum’s bit, and then another hour to drive to the home – and in the meantime she wasn’t letting anybody touch her so I had to go there and bath her and do all the showering things as well. So you get home at 10pm at night and it’s exhausting.’

Ava, Stirling

- ‘My wains were crying out for attention; I just had no time for all three of them. It was like I was doing a day shift and a night shift. And that’s impossible: something had to give.’

Erin, North Lanarkshire

- ‘I was hitting my head off a brick wall, basically, feeling quite put upon because I have no life. I’ve lost my friends because I’ve no time for them.’

Leah, South Lanarkshire

As part of this experience, the women who were interviewed reported that the needs of the people for whom they cared took precedence over their own needs:

- ‘I still think it’s terrible I have to use my [carer’s] budget on [my son]. Don’t get me wrong, it was still my choice to use it on him – because he didn’t have a budget.’

Erin North Lanarkshire

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<sup>22</sup> Care Inspectorate, 2019. Thematic review of self-directed support in Scotland: Transforming lives, p.17. Available at: <http://www.careinspectorate.com/images/documents/5139/Thematic%20review%20of%20self-directed%20support%20in%20Scotland%20June%202019.pdf>.

- [On benefits of SDS to respondent] 'Basically, being able to attend appointments that I need for my own health, even though sometimes still I struggle to get to some of them. But it gives me that flexibility, whereas before I couldn't do any of that.'

Olivia, Dumfries and Galloway

- 'I have health conditions as well, but they always take second place, because I'm so busy running about after everybody else.'

Leah, South Lanarkshire



## Chapter 4: Power Relations

Several carers explicitly talked about the unequal power relations involved in the process of managing and accessing SDS on behalf of the people for whom they care.

### 4.1. Pressure to Care

In accordance with women's historical role in the care industry and the fact that in 2016 women made up 59% of unpaid carers in the UK,<sup>23</sup> many participants described a lack of choice as characterising their role as carers:

- 'Because [the council] withdrew the carers I had nothing. I had to give up my job and a social worker came out and she did like an assessment, and she said, "You've got ten hours of care."

Ava, Stirling

- 'It's not my fault; I didn't choose to be a carer. I didn't have the choice. I don't mind, I would do my best for anybody, but I didn't deliberately pick it. It's not a job if you get what I mean. It's not a paid job, it's a voluntary thing, but it's not voluntary because it's necessity.'

Leah, South Lanarkshire

- '[The social worker] told me "No", she says, "Basically he'd need to be neglected to apply for SDS." I think [the council] think it's the family's responsibility, I think they feel as though the health needs are being met because it's the family's responsibility for them. But who's meeting the family then?'

Erin, North Lanarkshire

- 'It's the transport that's the biggest gap in everything, it's the transport. Paul's got a mobility car, so they think that he's got transport. Well he does and that's his car but he needs someone to drive him places – and surprise, that's his parents.'

Lily, Dumfries and Galloway

Some carers further highlighted that, as guardians, they could not be paid to look after their relatives, and the problems this caused their families. Other respondents highlighted that local authorities had ruled that family members could not be

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<sup>23</sup> Office for National Statistics, 2017. Unpaid carers provide social care worth £57 billion. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/articles/unpaidcarersprovidesocialcareworth57billion/2017-07-10>. See also Carers UK, 2019. State of Caring: A snapshot of unpaid care in the UK. Available at: [http://www.carersuk.org/images/News\\_campaigns/CUK\\_State\\_of\\_Caring\\_2019\\_Report.pdf](http://www.carersuk.org/images/News_campaigns/CUK_State_of_Caring_2019_Report.pdf).

employed as personal assistants (even in instances where the carer was not a guardian):

- 'I'm the one who's had all the experience, and as a backstop could provide some level of care to [my daughter] – but because of my guardianship status I can't be paid to look after her.'

Mia, Stirling

- 'Family can't do it [be a personal assistant]. I don't understand that, when I'm family and I'm already doing the care. There're so many silly rules. What they should have do is pay me as a job, that's what I said. Why do they pay the carers so little? [...] What gets me is that the council or the government doesn't mind that: "Oh, you can go and care for 24 hours, that's fine. You can go and do it unpaid."

Ava, Stirling

## 4.2. Perceptions of Social Work

One disturbing finding is that several of the respondents stated – unprompted – that they were afraid to challenge needs assessments out of fear that their budgets would be cut. These reported experiences link to wider questions of power imbalances in the system and indicate that SDS is not being implemented in accordance with its rights-based principles.

- 'You feel like you're having to protect what you've got at the moment.'
- Amy, North Lanarkshire
- 'I remember seeing the first social worker's face when I said, "Now what about Self-directed Support?". She didn't want to answer – it was not a welcome addition to the conversation.'

Emma, Glasgow

Several respondents reported negative consequences after requesting larger care packages for the people for whom they care:

- 'For 18 months I got no respite – and that happens to a lot of families who challenge the support agencies [...]. They will close ranks.'

Chloe, Dumfries and Galloway

- 'I'm saying to [social work] that we need a rise, I'm suggesting that [my daughter] is due for a rise. And they weren't buying it, and saying that we had to go down by £1500 and then she has to contribute.'

Jessica, Dumfries and Galloway

One respondent linked power imbalances in reviews to a lack of communication between social work and herself:

- I couldn't remember everything back then, and [the social worker] was always in a hurry. She would come in with stuff at the end of the day, and say, "Oh sorry, you know, I haven't had time to get to you before now. I've got this, can you quickly read through it and sign it? [...] I need to get it back in?"

Emily, Dumfries and Galloway

In the latter example, these problems with communication meant that the respondent did not get her points across during meetings with social work:

- 'You know, like a meeting's been set up, and you're sitting at the meeting. And maybe the head teacher will come up with something, and the social worker says, "Yes, I think that would be the way forward, I think we've all agreed that" – like the professionals. And you think, "Oh, they must have been talking about this, you know, before bringing it, ken, to me. And I'm maybe just the final one just to say that's OK!" [...] Sometimes they would start talking about something and you wanted to say something, and then they would be onto something else and you hadn't got your point over.'

Emily, Dumfries and Galloway

There were also recurring themes throughout the interviews around women feeling shame and fear in relation to asking for help and during needs assessments with social work:

- 'I felt that at times I was being judged as well.'

Jessica, Dumfries and Galloway

- 'I was frightened to approach [social work], I was frightened. [...] It's as though you put the person in front, that's it, you know what I mean, as though you're telling lies or something. [...] We had to justify that we were still involved in Lukas' care.'

Amy, North Lanarkshire

- [On needs assessments] 'It makes you feel like you are going to do something – it makes you feel like you're going to use the money in an inappropriate way.'

Anna, Stirling

- ‘The families I do know that know somebody’s coming [to do a needs assessment], and it’s not the full year, will be getting anxious. They’ll say, “We’re wondering if they’ll come to cut my budget.”’

Chloe, Dumfries and Galloway

### 4.3. Rhetorics of Care: Austerity and Charity

When asked about their experiences of social care assessments, some respondents formed claims to social care around an explicit recognition of a ‘council cash draught’. Respondents frequently referred to being supplicants when claiming care, with feelings of gratefulness for what was allocated to them – even when it was not enough to meet the needs of the person being assessed:

- ‘It [transport costs] is a lot of money to be out of pocket. Which sounds ungrateful, because somebody’s giving you money, do you know? I don’t want to sound ungrateful.’

Leah, South Lanarkshire

- ‘I would also say that I completely understand it when money is so tight. This isn’t a witch hunt: I don’t think that I and my family deserve anything extra.’

Emma, Glasgow

In some cases, women indicated that their awareness of the local authority’s financial constraints led directly to them claiming fewer hours of care. One respondent, Sophie, stated that she considered herself ‘mindful of the fact that the council had a cash draught’, and later linked this awareness to her role as a carer:

- ‘I am effectively working for nothing, because I am not claiming the full amount. But even with the increase that I’ve asked for it does not come close to the visits I make and what I do for my daughter.’

Sophie, Stirling

Rhetoric around dependency has long been recognised as having a significant and direct impact on people who access social care. Researchers argue that rhetorics of care affect identity formation. Beckett states that ‘for many women to be seen to be a carer and to care can be the single most important plank of their identity claim’.<sup>24</sup> However, women in the interviews demonstrated awareness of the impact rhetoric had on their engagement with social care. Several respondents reflected on popular understandings of social care in popular culture, and challenged rhetoric that supported cuts to social care:

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<sup>24</sup> C. Beckett, 2007. Women, disability, care: Good neighbours or uneasy bedfellows?, *Critical Social Policy*, 27(3), p.366.

- 'I think it's an ideological push to get rid of public services, and I think that's how they are doing it. They try to justify that you have your money and you provide your cares in whatever set up, but that the overall goal is to close down things like the [activity and resource centre] which are amazing services and a life-line to families like us. [...] Times are different now. That's how it feels.'

Lily, Dumfries and Galloway

- 'Speech and language [around SDS] are like, "I'll do a wee bit with you for five minutes", and just everything's all about money, and it's all about the budget. And if you can't access the service, you can't grow as a family.'

Erin, North Lanarkshire

- 'It got to the point I wrote to my MSP at three in the morning because I was so exacerbated about it all, and she got somebody from social work to come out because they'd got a moany letter.'

Leah, South Lanarkshire

One of the unexpected findings was the variability of rhetoric women used around claims to support even within the space of a single interview. Respondents would use language of 'luck' and 'being grateful', and displayed consciousness of 'not wanting to claim too much'. Later, the same respondents would reflect and challenge the language they had used earlier, correcting themselves to say that they had the 'right' to access SDS.

The complexity of respondents' approaches to their rights to access care can be pinned to a long developing discourse around social security provisions and dependence. As early as 1994, Linda Fraser and Nancy Gordon argued that a new moral register had developed to understand 'dependency' in a negative view.<sup>25</sup> They argued that dependency should be seen as an ideological term and one that came to produce a particular political subject. Fraser and Gordon pinned this subject to be 'the welfare mother'; an unmarried woman who often had an intersecting identity as a black minority and/or a young teenager.<sup>26</sup> Today, such discourses resonate within ideal ways of being a mother seen through cultural studies. Austerity policies have created specific positions for women who are expected to act the role of 'Do-It-All-Mums', regardless of any social or economic restrictions.<sup>27</sup> The implications of austerity have come to have a profound influence on maternity, femininity and family life, which have been culturally redefined in ways that protect the heterosexual

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<sup>25</sup> L. Fraser and N. Gordon, 1994. A Genealogy of Dependency: tracing a Keyword of the U.S. Welfare State, *Signs: Journal of Women in Culture and Society*, 19(1), p.324.

<sup>26</sup> *Ibid.*, p.311.

<sup>27</sup> K. Allen et al., 2015. Welfare Queens, Thrifty Housewives and Do-it-all Mums: Celebrity Motherhood and the Cultural Politics of Austerity, *Feminist Media Studies*, 15(6): 907-25.

nuclear family.<sup>28</sup> It is therefore not surprising that the majority (79%) of respondents stated that they engaged in unpaid care for their children.

Furthermore, SDS is supposed to drive discourse away from the medical and charitable models of disability and towards the social and human rights models of disability and personhood. The former focuses on what is ‘wrong’ with people, rather than their capabilities, and is surrounded by a wider rhetoric of expected gratefulness from people who use social care. The latter model frames society as creating barriers, rather than people’s conditions, and presents these barriers as infringements of people’s rights (which include the right to independent living and to be a part of their communities). The respondents discussed in this report still clearly engage with both the medical model and charitable concepts of social care – even as they challenge their own use of those rhetorics.

## Conclusion

The findings of this interim report point towards the fact that some women who are unpaid carers have particular difficulties in accessing SDS with or on behalf of the people for whom they care. This report has highlighted themes surrounding knowledge and information, support, mental health, and power imbalances, demonstrating that there is a pressing need for more work to map the intersections between the expectations around women carrying out emotional labour and gendered experiences of unpaid care. While there has been excellent work done in Scotland to analyse and push for change in relation to women’s unpaid labour (Engender) and carer’s experiences (Carer’s UK), it is imperative that the Scottish Government, local authorities, and the third sector consider gender imbalances in the intersections of care and gender when developing policies and approaches to SDS – and the language they use.

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<sup>28</sup> E. Gutiérrez-Rodríguez, 2014. The Precarity of Feminisation: On Domestic Work, Heteronormativity and the Coloniality of Labour, *International Journal of Politics, Culture, and Society*, 27(2), p.193.

## **About the ALLIANCE**

The ALLIANCE is the national third sector intermediary for a range of health and social care organisations. The ALLIANCE has over 2,700 members including a large network of national and local third sector organisations, associates in the statutory and private sectors and individuals. Many NHS Boards and Health and Social Care Partnerships are associate members.

Our vision is for a Scotland where people who are disabled or living with long term conditions and unpaid carers have a strong voice and enjoy their right to live well.

## **About Self Directed Support Scotland**

Self Directed Support Scotland represents organisations run by and for disabled people, our members support thousands of people across Scotland with their social care choices. Together we work to ensure that SDS is implemented successfully so that people have full choice and control over their lives.



Please contact the ALLIANCE or Self Directed Support Scotland to request this publication in a different format.

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