

# What works in community-based adult social care in Scotland?

Research report

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Research conducted as part of the Glasgow Disability Alliance *Future Visions for Social Care* programme.



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## Executive summary

*'Well there's a policy called Getting It Right For Every Child. What about getting it right for every disabled person?'* (Judith, parent of Stevie)<sup>1</sup>

Self-directed support should be enacting independent living for everyone in Scotland that uses any of the four SDS options for social care. Independent living is defined as follows (Scottish Government, 2021, p.9):

Independent living means people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself, or fending for yourself. It means having rights to practical assistance and support to participate in society and live a full life.

Since 2011, the Scottish Government has funded GDA to run an initiative called *Future Visions for Social Care* (Brunner, Burke, Scobie & Lawson, 2023). Since its inception, *Future Visions* has evidenced that multiple barriers continue to be experienced by disabled adults living in the community who need good social care and seek to achieve independent living (e.g. Witcher and participants, 2014). To complement these findings, as part of the *Future Visions* programme, GDA initiated this *What works in community-based adult social care?* study, independently conducted by the Centre for Disability Research at University of Glasgow. The study has sought to find examples of how community-based adult social care should work in Scotland, enabling independent living, aiming to find out:

- what factors made disabled people's social care work well for them;
- the work that disabled people had to do to achieve and maintain good social care; and
- any support needs, wishes and ambitions that may still not be met by the good social care package.

Ten adults receiving self-defined good community-based social care were interviewed between January and March 2023, about their good experiences. The research findings foreground the voices of research participants and demonstrate that while achieving 'good social care' is not the same as achieving independent living, good social care is founded on independent living principles. The study indicates steps needed to consistently secure independent living for people using community-based social care across Scotland.

## What makes good community-based adult social care?

Peoples' good experiences of social care were underpinned by the four established independent living principles – **freedom, choice, dignity, and control**. However, to capture more accurately what makes for good experiences, a fifth principle of **reciprocity** needs to be added.

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<sup>1</sup> All names in this report are pseudonyms.

## **Six features helped people to gain and maintain good community-based adult social care:**

- i. Assertiveness or self-advocacy
- ii. Knowing how the social care system works and being supported to navigate it
- iii. The human qualities of care and support workers and PAs
- iv. Predictable personal care, flexible social care, and strong teamworking by care/support workers and PAs
- v. Proactive and determined social work teams
- vi. Having a secure social care package, sufficiently funded

## **Seven features would help to secure good community-based social care and enable independent living for disabled people across Scotland:**

- i. Care package certainty, long-termism, and funding that facilitates independent living
- ii. Care package portability to allow freedom of movement within Scotland
- iii. Stable access to care/support workers/PAs with the qualities to deliver independent living principles
- iv. Social care that is put in place quickly
- v. Consistent and accessible information on SDS options
- vi. Not needing to 'fight' to get and keep good social care
- vii. Removing structural barriers to independent living

Good social care must also consistently and specifically account for the needs of marginalised disabled people who face intersecting barriers.

## **Conclusion**

*'... social care's not just about social workers and that. It's about everything.'*  
(Judith, parent of Stevie)

How do these findings help us to think about what community-based adult social care in Scotland is currently like? And how do they help us think about what community-based adult social care should be like to consistently deliver independent living across all four SDS options, and in all parts of Scotland? The evidence shows that barriers and constraints to independent living existed for all participants. This shows that good social care cannot simply be explained as, for example, 'some exceptional/privileged/lucky people always have good SDS'. No participants 'always had it good', and all had been constrained from enjoying independent living. This reinforces what is known about disabled peoples' wider and historic marginalisation in society.

## **Concluding points**

- a) To achieve the National Care Service goal of achieving consistency and addressing inequalities (Scottish Government, 2022), all four SDS Options (1, 2, 3, and 4) need to consistently deliver the independent living principles -

choice, control, freedom, dignity - and reciprocity too, whichever local authority people choose to live in.

- b) The findings show that good experiences of community-based social care are beyond providing for functional and outdated Instrumental Activities of Daily Living and Activities of Daily Living<sup>2</sup>. Good social care is about how disabled people are supported to have control over choices about the kind of activities they want to do, and how they are then supported to do those things.
- c) The evidence suggests that in good social care, power in the carer/cared for relationship changes, enabling the disabled person to have choice, dignity and control over how their social care works, leading to greater freedom for them. This 'everyday' freedom is underpinned by people having 'meta' control over their SDS option. This can be empowered by a good social work team and access to a DPO and a Centre for Inclusive Living (CIL) in every local authority.
- d) To enable people with community-based social care to have *'the same freedom, choice, dignity and control as other citizens at home, at work, and in the community'* (Scottish Government, 2021, p.9) requires social care funding to be sufficient for them to be able to live this free and equal life, with support. Self-directed support funding needs to be anticipatory, rather than annual, so that disabled people can plan ahead in their lives, as other citizens can. A lifecourse 'mindset' and consideration of social care as being relational and about 'being human' will help.
- e) Self-directed support cannot enable independent living by being only about individual assessments. Many disabling barriers are outwith the remit of social care. Barriers to independent living include equal access to employment, leisure, education, holidays, social spaces, public transport, and much more. Wider public services and Scotland's wider social and economic policies need to take a far more proactive, strategic and intersectoral approach to removing physical, social, attitudinal and other barriers.

### **Further research**

The study is of a small sample of users of community-based social care that have self-selected as having had a good experience. Further research should include, among many potential themes:

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<sup>2</sup> ADLs are activities relating to personal care and mobility inside the home that are basic to daily living. They include activities related to personal hygiene, dressing, eating, maintaining continence and getting around indoors. IADLs are activities which, while not fundamental to functioning, are important aspects of living independently. They include basic communication skills, transportation, shopping for groceries and clothing, housework, meal preparation, managing medications, managing personal finances. (Ipsos MORI, 2017: 22). See also Zarkou and Brunner (2023).

- Marginalised disabled people who face intersecting barriers' good experiences of community-based social care, notably BAME people, young people, and LGBTQI+ disabled people
- Direct research with disabled people with multiple and complex impairments to understand their lived experiences of good social care
- Experiences of social care professionals that provide good community-based social care
- Good experiences of people on SDS living in care homes.

## Background to the study

*'Well there's a policy called Getting It Right For Every Child. What about getting it right for every disabled person?'* (Judith<sup>3</sup>, parent of Stevie)

*'You don't live life to working times, do you?'* (Natalie)

*'To be honest, I mean, using the phrase a good...it's not a good package, there are no' loads of hours or anything, but it works for me. If I could get a PA to come in and do loads more hours, I would.'* (Kayleigh, parent of Ben)

Interviewer: *'... if you know ... another person who might have had a good experience, you could tell me that, and I could perhaps approach them?'* Respondent: *'The scary thing is, I don't actually know anyone, that's the scary fact of it.'* (Larry)

Glasgow Disability Alliance (GDA) is a Disabled Person's Organisation (DPO)<sup>4</sup> with over 5,500 diverse disabled people as members, and a wide network of partners and allies who support its aims. GDA's accessible programmes remove barriers and build capacity, and its community development approach seeks to empower disabled people to be leaders in their own lives.

Since 2011, the Scottish Government has funded GDA to run an initiative called *Future Visions for Social Care* (Brunner, Burke, Scobie & Lawson, 2023). *Future Visions* is a programme that combines support for disabled people in the Glasgow region to find pathways to independent living, plus a Social Care Expert Group that seeks to influence social care policy and National Care Service (NCS) development at local and national levels in Scotland. These activities support Scottish Government aims to progressively support independent living, including through Self-directed support, and to sustain collaboration and co-design in developing and implementing NCS and social care policy, both locally and nationally. Since July 2022, the Centre for Disability Research at University of Glasgow has collaborated with GDA as part of *Future Visions*, working together to draw increasing evidence from the programme.<sup>5</sup>

Since its inception, *Future Visions* has evidenced that multiple barriers continue to be experienced by disabled adults living in the community who need good social care and seek to achieve independent living (e.g. Witcher and participants, 2014). To complement these findings, as part of the *Future Visions* programme, GDA initiated this *What works in community-based adult social care?* study, independently

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<sup>3</sup> All names in this report are pseudonyms. Sincere thanks to all those who participated, and to those who helped find participants. This research could not have been done without them.

<sup>4</sup> A DPO is an organisation led and controlled by disabled people. See: <https://www.disabilityaction.org/dpo-is-an-acronym-for-disabled-peoples-organisations>, sourced 17 August 2023.

<sup>5</sup> *Future Visions* collaborative research reports can be found at: <https://www.gla.ac.uk/research/az/centrefordisabilityresearch/work/collaborationwithglasgowdisabilityalliance/>, sourced 15 August 2023.

conducted by the Centre for Disability Research. The study has sought to find examples of how community-based adult social care should work in Scotland, enabling independent living, aiming to find out:

- what factors made disabled people's social care<sup>6</sup> work well for them;
- the work that disabled people had to do to achieve and maintain good social care; and
- any support needs, wishes and ambitions that may still not be met by the good social care package.

The findings seek to inform:

- Scottish Government policy in relation to the National Care Service
- Health and Social Care Partnerships
- Local authorities and Integration Joint Boards
- Public, private and third sector providers of social care
- Disabled People's Organisations, Centres for Inclusive Living,<sup>7</sup> and other organisations supporting disabled people
- Wider public services with duties to remove barriers for disabled people.<sup>8</sup>

### What is adult social care?

The 'Feeley review', or Independent Review of Adult Social Care (IRASC) (Scottish Government, 2021, p.19) described the goal of social care as follows:

'Social care support is the means to an end, not an end in itself. The end is human rights, wellbeing, independent living and equity, as well as people in communities and society who care for each other.'

In practical terms, community-based adult social care<sup>9</sup>:

'... covers a wide range of activities to help people who are older or living with disability or physical or mental illness live independently and stay well and safe. It can include 'personal care', such as support for washing, dressing and getting out of bed in the morning, as well as wider support to help people stay active and engaged in their communities.'

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<sup>6</sup> Through the report, 'social care' and 'adult social care' act as a shorthand for 'community-based adult social care'.

<sup>7</sup> CILs are organisations led and controlled by disabled people, which promote independent living and support disabled people to challenge and navigate barriers and make informed choices. See, for example: <https://www.gcil.org.uk/%2fabout-us%2faims-and-values.aspx>, sourced 17 August 2023.

<sup>8</sup> Many thanks to Prof. Nick Watson (University of Glasgow) and Tressa Burke (Glasgow Disability Alliance) for comments on drafts of this report. Thank you also to GDA staff, the team at the Centre for Disability Research, participants at the July 2023 Social Policy Association paper session 'What works in social care in Scotland?', and Scottish Government staff at the July 2023 GDA *Future Visions* event, who all provided kind and helpful feedback and comments on draft presentations of this research. Any errors are the responsibility of the author. This report was produced by the Centre for Disability Research, University of Glasgow, as part of the Glasgow Disability Alliance *Future Visions for Social Care* project 2022-23, funded by the Scottish Government.

<sup>9</sup> The King's Fund (2019) Key Facts and Figures about Adult Social Care, at:

<https://www.kingsfund.org.uk/audio-video/key-facts-figures-adult-social-care>, sourced 25 July 2023.



Behind these aims and activities lies a web of legislation and policy, commissioning and procurement activities, regulations, funding streams, a formal workforce and informal carers (Jepson, 2020). In 2020-21 in Scotland, £2.3bn was spent on social care for those aged over 65, and £1.5bn on those under 65 (Fraser of Allander, 2022, p.4).<sup>10</sup> In the same year, approximately 93,280 people received home care and 130,130 people had an active community alarm and/or telecare service (some in receipt of both). In contrast, as of 31<sup>st</sup> March 2021 there were approximately 33,353 residents in care homes (Fraser of Allander Institute, 2022).

### **Adult social care and independent living**

The goal of Scotland's principal social care legislation, the Social Care (Self-directed Support) (Scotland) Act 2013 (Scottish Government, 2014, p.4), is that:

Self-directed support, alongside many other policies, is intended to support, promote and protect the human rights and independent living of care and support users in Scotland. It aims to ensure that care and support is delivered in a way that supports choice and control over one's own life and which respects the person's right to participate in society.

So, self-directed support should be enacting independent living for everyone in Scotland that uses social care. IRASC (Scottish Government, 2021, p.9) defines independent living as follows:

Independent living means people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself, or fending for yourself. It means having rights to practical assistance and support to participate in society and live a full life.

IRASC notes that this definition has been adopted over many years by the Scottish Government, COSLA, the NHS, and the disabled people's independent living movement. The definition has also been agreed in Scotland's largest city, including with Glasgow's strategic Independent Living Programme Board (2012-2017).

Under self-directed support (SDS), all local authorities have a legal duty to offer four options to people who have been assessed as needing a community care service.

The four options for SDS are:

- option 1 – a direct payment, which is a payment to a person or third party to purchase their own support
- option 2 – the person directs the available support
- option 3 – the local council arranges the support
- option 4 – a mix of the above.

Whichever SDS option a person chooses, the principles of independent living should be enacted in how their social care is delivered.

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<sup>10</sup> The two largest areas of expenditure in 2020-21 were on care homes (£860m) and home care (just under £700m) (Fraser of Allander, 2022, p.4).

## Methodology and methods

In-depth qualitative research is useful for understanding the mechanisms behind how events occur, and for testing 'established' knowledge and assumptions. As such, it is strong at identifying new insights for policy makers, practitioners, and communities, and for drawing out themes for future research. An in-depth qualitative study does not seek population representativeness; it seeks to get '*a lot from a little*' (Silverman, 2001, p.5). The credibility and fitness for purpose of insights from qualitative research come from the rigour of analysis and transparency of reporting (Spencer et al, 2003). In disability studies, there is a long history of work to overcome the historic lack of 'voice' of disabled people in research about their lives (Goodley, 2011, pp. 22-27). This study foregrounds the voices of disabled people, as part of that emancipatory tradition (Stone and Priestley, 1996).

This in-depth qualitative study individually interviewed a self-selecting sample of ten disabled people living in the community who had a self-defined good experience of social care. The study did not seek people living in residential care or anyone self-funding their social care. Individual interviews enable clear personal narratives unmediated by group norms and allow participant anonymity and confidentiality. Prospective participants were sought through DPOs, CILs, and impairment-specific organisations. Participants maintained their anonymity by contacting the researcher directly. Interviews took place between January and March 2023. All interviews were conducted by telephone or on Zoom, were audio-recorded with consent, and were fully transcribed for analysis. Interviews lasted between 30 minutes and 75 minutes. All participants were offered a £20 voucher to compensate for their time. The study proposal was ethically reviewed by University of Glasgow.

Thematic analysis was informed by Ritchie and Lewis (2003) and combined seeking independent living concepts expressed by participants, alongside identifying dominant bottom-up themes emerging from the data. Analysis was aided by Nvivo12 software. Participants talked about good experiences of paid support, home care, personal care, respite, day services, self-directed support, provision of equipment and more. The vast bulk of the data was about good experiences of support by Personal Assistants (PAs), care workers and support workers, and good experiences of systems of assessment and funding. Significant amounts of data were about barriers and limits to good experiences.

## Sample

Six participants identified as female, three as male, and one as trans. Two participants were BAME disabled people. Two interviews were with parents describing the good social care received by their late-teenage and early-20s-aged children with multiple and complex impairments. The oldest participant was in their 70s. All participants had several impairments including lifelong and chronic conditions, visual impairments, psychosis and other mental health issues, learning difficulties, and mobility impairments. Several participants were wheelchair users.

Participants described good experiences in eight different local authority areas in Scotland. They lived in rural, town, suburban, and urban neighbourhoods. Good

experiences had lasted between four months and 14 years. All experiences were within the past 14 years. Most were ongoing. Participants had a variety of social care support packages: one SDS option 3, three SDS option 2, four SDS option 1, one ILF, and one informal care/DPO support only. Hours of support per week ranged from informal and DPO support only to 30+ hours of paid care per week. People described good experiences from a range of providers: four had self-employed PAs, two used private companies, one local authority support, two third sector organisations, and one informal/DPO support. Some participants had additional informal support from their family, and some had paid support only.

This data already indicates that it is not possible to generalise in a simple way about 'good' versus 'not good' in terms of, for example, SDS option, age, local authority, or geographical area. However, themes beyond these are discernible as seen below.

## Introduction to findings

*'... social care's not just about social workers and that. It's about everything.'*  
(Judith, parent of Stevie)

First, the findings describe what it feels like to experience good community-based social care. The report then describes how participants experienced the principles in the definition of independent living - freedom, choice, dignity, and control - being put into practice in good social care, adding an extra principle which was also persistently expressed: reciprocity (mutual agreement, exchange, trust, learning and regard). Next, the report discusses what helps disabled people to gain and maintain good community-based social care. The report then describes how gaining good social care is not the same as achieving independent living, and the additional elements that are needed to enable and secure independent living for disabled people across Scotland. Then the report sets out some specific themes that support good social care for more marginalised disabled people facing intersecting barriers such as racism, homophobia and other oppressions. Finally, some concluding themes are drawn. Each section includes several quotes from participants that capture the theme and sub-themes described, so foregrounding the lived experience of disabled people (Stone and Priestley, 1996).

### **A. The lived experience of disabled people: what it feels like to have good community-based social care.**

People described the wonderful feeling of getting social care that works for them, for example Rachel: *'The right package, the right person, the right support, your life just transforms... This is what normal life should be like.'* As well as supporting people with personal care, tasks and activities within the home, good social care supported people to be able to do social activities outside the home, such as leisure activities, shopping, meeting friends, participating in events, pursuing their professional interests, and more. When asked what made her care and support good, Lucy said: *'The variety of staff that I get from, like, all over. And it's basically exploring new things that I've never done before and just being myself.'* Lucy described how her support workers had helped her apply for volunteer work that she was interested in:

*'... I applied for it with ...help with my support workers. They went up to the hospital and asked if ... the voluntary job was still going ahead. And they were like, yeah. And then they gave me all the stuff that I had to fill out.'*

Larry used his PAs to pursue his professional life:

*'If I didn't have a good PA team behind me, I wouldn't be able to go to conferences or go to things, because I need that support of somebody with me, and they are good at being flexible and working around that...'*

For younger people this included going to clubs and parties. Judith's strategy for recruiting PAs supported Stevie to do things that he enjoyed, as any other young person might:

'I stipulated that we wanted somebody round about Stevie's age ... They've taken Stevie out to nightclubs... birthday parties with all the friends of the two PAs. I think that's really important, you know, they're very young... [T]hey've taken him to an Outward Bound thing. And he's had a great time. They've been ... surfing with him... and they know him very, very, very well.'

At its best, good experiences enabled independent living – social care supporting disabled people *'to have the same freedom, choice, dignity and control as other citizens at home, at work, and in the community'*.

## **B. The principles that underpin independent living - freedom, choice, dignity, and control.**

When asked what good social care meant, people often gave examples that reflected the principles of independent living and the Scottish definition of social care. They talked about freedom, choice, dignity, and control, and the ways that these were put into practice, underpinning their good social care. What participants said also suggests that 'good experiences' of social care demand an additional principle to be considered: reciprocity.

- **Freedom:** participants described how their social care packages gave them the freedom to do things like go to gigs, attend conferences, and meet friends, for example Natalie: *'... just having that sociability of my second PA and it's made a big difference, I've been able to visit friends and family ... rather than them coming to visit me...'*

Freedom is also about being able to take risks - especially perhaps for young people, described by Kayleigh about her teenage son:

'I said, what I really want to do is... have wheelchair roller discos, where we get families to meet up together, in a non-competitive environment, and just have a rammy ... my hope is that eventually a PA will then go to, like, a Travelodge with him ... But [social worker] can see that journey, she can see that there's an element of risk, and we're weighing that risk and ...we're giving him a life with risks, you know, in his world, and allowing him to do all that. And she can see that it makes sense and she's not poo-pooing it.'

Freedom is also about being able to be spontaneous, captured by Rachel:

'...that's something that I can do now, like, 'let's just go and have lunch somewhere' ... And because it's the same PA the whole time, you can be a bit more spontaneous. We've done gardening, we've done cupboards, we've done trips to the skip ... go and get my nails done... it so improves your mental health when you've got nice nails.'

- **Choice:** implicit in choice are notions of empowerment and having personal agency. Participants described how good social care empowered them in everyday choices. This could be anything from what they wanted to do in their time with their care/support worker/PA (Judith: *'Stevie'll tell them where they want to go for lunch or what he wants to see at the cinema and that type of thing.'*), to the way they wanted their egg cooked in the morning, for example Harpreet: *'If I want something spicy, like a fried egg the way I want it, I just speak to them, 'can you make it like this?' and they say 'sure, no problem'.*

These everyday choices were underpinned by being able to make bigger, or 'meta' choices. This included people being enabled to make an informed choice over their preferred SDS Option, and then how they were able to use their chosen SDS Option. Kayleigh noted how her use of her care package was empowered by a Centre for Inclusive Living (CIL) working in harmony with the local authority. She summarised: *'... the only way that I think it works is because I have a magnificent social worker, I have magnificent support from [CIL]':*

*'... the minute we get our package, they [local authority] advise that we go to [local CIL worker] to then help us with what we need to do, what our legal expectations are, what our legal requirements are. And then, you know, if they want to then she'll obviously make a PA advert, guide us through...'*

'Meta' choices also included being able to actively choose a care/support worker/PA. For Natalie, directly employing a PA had enabled her to access the personal qualities that she needed:

*'... it means I get to find somebody that works with me personally ... you're able to tick so many boxes, be it personality, characteristics, dislikes, likes, how you work, how you gel, your sense of humour, your music... [I]f they're open to it, you're open to it as well, and it works for a good working relationship. And, you know, there's a friendly atmosphere to it, because you're both happy working with each other.'*

- **Dignity:** people gave examples of how their dignity was upheld by good social care. These ranged from the day-to-day attitudes and respectfulness of carers/support workers/PAs to how assessments were carried out. Gerry explained how he felt that his day-to-day social care helped give him equal dignity to non-disabled people:

*'... the care does, you know, give me dignity, the fact I can get up and dress myself before I speak to you for example ... I've had my breakfast ... those are things that people normally take for granted.'*

Larry, as a disabled trans male, described how social care assessments could maintain dignity, through respectfulness:

'It was a really good experience having assessment, I have to admit, very thorough, telling us like what we were entitled to ... before the assessment was sent to panel, [social worker] ... let me check through it and stuff, which was really good, because when I'd had a care assessment when I lived in [other authority], they got my pronouns wrong, simple things like that. So, it did feel good to know that he was being respectful and taking things seriously.'

For Daphne, her involvement in activities for BAME people run by a DPO contributed to her good social care:

Respondent: 'GDA, like, most of the new members at GDA they are so respectful. Yes, they are respectful and they, like, they don't discriminate.'

Interviewer: 'Yes, okay. So, these principles help you to feel...'

Respondent: 'At home.'

Sometimes participants could see their own social care experience as one of dignity because they had experienced others' dignity being breached, for example Rachel:

'I do often get a pang of guilt when I'm sitting in [DPO name] meetings and you just hear the horror stories ...one man sat in his own shite ... over the whole weekend. A doubly incontinent man who should have had proper care ... You come away thinking, oh my goodness, I really know I'm so fortunate in having what I do.'

- **Control:** Control can sometimes interact strongly with choice. If a person can make a choice, they have a sense of control, as seen above. However, sometimes participants described a sense of control that was distinctive, about gaining control over a situation. Many of these examples were in the domestic sphere, for example Natalie:

'... overall, you know, I'm happy where I'm at with social work, having the two PAs. I'm in control of who I invite into my home, which is really important to me, that private space...'

As might be expected, a sense of control was more overtly expressed by participants that directly employed a PA under SDS Option 1. However, care/support teams under other SDS options could also act in a way that gave participants a sense of control. Veronica felt in control of her support under a local authority support package:

'... although I was housebound at that point, I still felt in control. I was informed at every stage... I knew who was coming every day ... If they

needed to change the times of my visits, they would always phone and ask beforehand, and I always felt I could say no ...'

Participants described how CILs supported them to take control of their care packages. For example Kayleigh's local CIL supported her to be able to offer her son's PAs '*... the maximum amount that I can pay ... so that I'm employing the best people and my people feel the most valued that they can.*' However, some areas did not have CILs, as Kayleigh had witnessed in another local authority, so reducing the opportunity for disabled people to have control over their care package:

'... working in [other authority] ... there's nothing at all like [CIL name] in there. For the people of [other authority], once they get SDS then if they have any queries they have to go to the direct payments team who work for the council to get any understanding of what's going on... So, they're essentially shafted ...before they even get the money...'

## Summary

The evidence suggests that in good social care, power in the carer/cared for relationship changes, enabling the disabled person to have choice, control and dignity in their social care, leading to greater freedom for them. This 'everyday' freedom is underpinned by having 'meta' control over their SDS option. We can see that to achieve good social care, local authorities need to maximise realisation of the four principles in the independent living definition across all four SDS options (1, 2, 3 and 4). However, participants' good experiences suggested that there was a further principle that was important to independent living: reciprocity.

- **Reciprocity:** Meaning mutual agreement, exchange, trust, learning and regard. Reciprocity is a key concept in co-production of social care,<sup>11</sup> and was established in the landmark 1968 Seebohm report on social care.<sup>12</sup> Nine of the ten participants talked about how good experiences of social care involved reciprocal relations with care/support workers/PAs, and sometimes with social workers. Crystallising this, Gerry noted: '*... my mum always says to me, you know, in terms of my support workers, who did you help today?*' Natalie described mutual learning between her and a PA: '*She's learned from me as well about the mental health kind of thing, and I think every day's a school day for both of us ... we keep learning together...*' Several participants described a process of mutual agreement over care/support timetables and changing hours of care. For example, Rachel had a PA with a baby, and hours were mutually agreed, excepting health appointments:

'Like, the other day, her new baby is starting to teethe and so was like, 'Rachel, the baby's, like...you know.' 'Okay... don't come in until he's settled.' ... it's just all negotiated ... except for times she does hospital visits, doctor's visits.'

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<sup>11</sup> See for example, <https://www.scie.org.uk/co-production/what-how>, sourced 15 August 2023.

<sup>12</sup> Scottish Government, 2021, p.19, sourced 18 July 2023.



Mutual trust, leading to the prospect of the cared-for and carer having a human relationship that goes beyond formal boundaries of paid caring was also prominent. For example, Veronica's support workers in a rural town volunteered '*in their own time*' to come to a craft fair with her, '*there wasn't any barriers to that*'. She contrasted this with moving to a city, in which her support worker lived nearby, but was clear that she was not allowed to spend time with Veronica outwith her paid hours. However:

'... eventually we did start getting together for coffees and lunches ... I'm saying, 'well, you're not going out with one of your service users, I'm your neighbour, so today I'm your neighbour and we're going out for a coffee'. But it really is discouraged...'

The principles on which CILs and Disabled Person's Organisations (DPO) work also illustrated reciprocity to several participants, for example Kayleigh:

'I have magnificent support from [CIL] who treat us equally and valued ... So, for example, while [CIL worker] told me about [issue], I told her ... the new Sense Scotland's college is opening up. She had no knowledge of it, so I'm passing my knowledge on to her to then share with other people.'

## Summary

The four established independent living principles – freedom, choice, dignity, and control – underpinned participants' good experiences of social care. However, the evidence suggests that to capture more accurately what makes for good experiences of social care, a fifth principle of reciprocity needs to be added.

Participants explained in specific terms what helped them to gain and maintain good social care, as seen in the next section.

## C. What helps disabled people to gain and maintain good community-based social care?

*'I think one of the key things is getting the right support, the right person to help you with what you need, or whether it's an organisation or whether it's the social work, you know. And also getting the funds, and making sure the funds...are enough for that person.'* (Judith, parent of Stevie)

Seven features enabled participants to gain and maintain good social care:

- i. Assertiveness or self-advocacy
- ii. Knowing how the social care system works and being supported to navigate it
- iii. The human qualities of care and support workers and PAs
- iv. Predictable personal care, flexible social care, and strong teamworking by care/support workers and PAs
- v. Proactive and determined social work teams
- vi. Having a secure social care package, sufficiently funded

These are described in more detail below.

### **i. Assertiveness/self-advocacy**

Most participants talked about the need for assertiveness or self-advocacy to get good social care, commonly saying they had needed to 'fight' to get and keep good social care (Gerry: *'I've also been a fighter for support. It doesn't come easy.'* Judith: *'Everything is a fight. They won't spend money.'*). Kayleigh, talking about her adult son, demonstrated that there is an unfairness that will arise if good social care is contingent on self-advocacy: *'I'm not ashamed to admit I'm, you know, a sharp-elbowed parent of a disabled child...'* adding: *'you're doomed to fail if you're sitting waiting for Social Work...'*. That not all participants said that assertiveness was needed suggests that it is not always a necessary attribute among people who experience good social care – and why should it be? Good social care should not be only open to those able to articulate their needs - it should be literally the opposite.

### **ii. Knowing how the system works and being supported to navigate it**

Almost all participants said that knowing how the social care system worked and having support to navigate the system and their choices helped construct their good experience. Some learned about SDS options through DPOs (Harpreet: *'The whole thing was started from GDA, they gave us all the links'*), others through social work, for example Natalie:

*'Maybe eight or nine years I was under social work getting support, supported by other organisations, which was a terrible experience. And then when my social worker's boss got in touch with me to say about self-directed support and about PAs and stuff ... that actually opened up that avenue for me.'*

CILs support people to navigate the social care system, as seen for Kayleigh in the last section. But getting knowledge of the system and support to navigate it could drive inequalities, as Kayleigh added:

*'I spoke to someone the other day who was amazed at all the things that we get as ... positive outcomes... So, there's this, kind of, two tier...those in the know and those who aren't in the know. And potentially, it's those who are trusted and those who aren't trusted...'*

A prime argument for national standards and accountability and a National Care Service in Scotland has been to achieve consistency and address inequalities (Scottish Government, 2022). Lack of an accessible, locally-based CIL is likely to worsen the social gradient of awareness of social care rights and reduce informed choices, as seen later in the report.<sup>13</sup>

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<sup>13</sup>The argument for a disabled people-led organisation in every local authority is long-established, see for example Prime Minister's Strategy Unit (2005) *Improving the life chances of disabled people*, Recommendation 4.3: *'By 2010, each locality (defined as that area covered by a Council with social services responsibilities) should have a user-led organisation modelled on existing CILs.'* At <https://core.ac.uk/download/pdf/4156824.pdf>, sourced 25 July 2023.

### **iii. The human qualities of care and support workers and PAs**

For care to be good, people had to have confidence in their care/support workers, and PAs. Trust mattered, for example Rachel had medication going missing under a previous care package, and now had a PA: *'Well, I know her. I trust her. It's the same person all the time ... I don't need to worry who's coming through my house.'* Friendliness, and care and support feeling like a social relationship, also mattered. Gerry:

'... it's the social element. It's almost being able to allow care to be secondary, if that makes sense ... it should be seamless ... the carer might want to say that they fell out with their sister last week, and then they talk about that... And then in amongst that care takes place.

Carers could even feel like family. Kayleigh: *'I feel as if they're my own girls, do you know what I mean? For all...they work for me, I think I feel as if they're part of the family ...'* But participants were aware that a close relationship with care/support workers or PAs could create tensions, as Kayleigh also noted:

'... I do struggle enormously with the formal line of, 'I am your pal but I'm not your pal' ... I'm aware that I'm an employer. And she is my friend but I'm aware that there is a line there ...'

Sometimes written care/support plans were important to good experiences, particularly when there was a high turnover of support workers. However, strong informal communication and 'being human' epitomised good experiences.

The importance of human qualities in the caring relationship to good experiences reflects the independent living principles of dignity and reciprocity. They are allied to the disabled person having control over who their care/support workers/PAs are, and to not having a high turnover of carers. This has implications for recruitment in terms of the qualities, as well as quantity, of the care/support/PA workforce, and in considerations of the 'match' between disabled people and care/support workers/PAs.

### **iv. Predictable personal care, flexible social care, and strong teamworking by care/support workers and PAs**

Good social care combined predictability and flexibility while maximising the ability of the disabled person to be in control. In good social care, care/support workers or PAs worked well as a team. They were able to communicate directly with each other and the disabled person, and flexibly cover for each other when needed to maintain the disabled person's care package. The disabled person was always central to any changes, and people receiving good social care had strong control over negotiating timetabling changes directly with PAs and care/support workers. Larry's support workers were employed through a company:

'We kind of have a set rota ... that we stick to, unless anything else is coming up or it needs changed. So say my hours for Friday are like – I don't know – half ten to half 12, and say actually I want to go out and go shopping, ... say I've got [support worker] scheduled in that day, I would say, would you be able

to do these extra hours if I speak to [care agency manager] and get it changed? ... I check with them first, because it's easier than like three people communicating through each other.'

Having consistency of care/support worker really helped people, with stand-ins very much exceptions to the rule. More predictable timings (rather than wide 'windows') tended to improve peoples' experience of personal care. Harpreet described being '*in my nightie by 6.30 pm*' under a previous not-good care package. Veronica described how her current personal care timings limited her independent living:

'... it doesn't give me my independence, because I don't have enough time. By the time they're coming in the morning, my energy's already starting to waver again. I'm up early ... they're expected to make my lunch, they're not expecting to give me a shower and get me dressed because of the time... I don't know what time they're coming back, they could be back at half four, it could be half seven. Like I'm not here at half four when they come, then I won't get a visit that day, so it doesn't give me any time to get out at all.'

In contrast, being able to negotiate more flexible timings for social care allowed participants to be and do social activities, like any other citizen. Natalie this summed up:

'And Saturday, you know, it's just flexible, and she had agreed that she would be able to take me to concerts and gigs ... So, it needs to be somebody that's flexible ... because you're trying to live a life, and life isn't rigid ... You don't live life to working times, do you?'

However, only exceptionally did flexibility stretch as far as enabling people to go on holiday or overnight trips, placing limits on choice and independent living, as described later.

#### **v. Proactive and determined social work teams**

Social workers had the power to help people to choose different SDS options that suited them. People with good experiences had confidence in social work, and tended to experience social workers as being proactive, on their side, '*determined to help*' (Veronica). Good social workers would support people to use their budget flexibly, for example Kayleigh:

'... when I ask for permission to use it in a creative way, to make sure it meets my son's outcomes, I'll drop [social worker] a message every month to say, look, just to let you know what we're doing is X, Y, and Z, this is what I've spent. And then let [social worker] know what I'm planning...'

Good social workers did quick and holistic assessments, for example for Larry:

'... when the assessment was done, he really did look at every aspect of my life, and not just what was going on at the present, but goals I had for the future, things I wanted to work towards, and how my care package could support me to do those things.'

These assessments led to secure support packages, giving people reasonable security to just get on with their lives, with support from their PAs or care/support workers. For example Larry: *'... [social worker] said even if he wasn't retiring, I probably wouldn't have an allocated social worker because my budget was sorted, and we were set up and kind of ready to go.'* Similarly for Rachel:

*'... I don't have regular contact with social work, 'cause I don't need them. You know... a social worker's time I'm imagining is a lot more expensive than a PA's time. And ...since the package has been in place, I haven't needed to call social work.'*

Comments supported the need for prevention in maintaining wellbeing and reducing need for further intervention. In addition, people with good experiences tended to also have confidence if they needed to approach social work because of a change in circumstance, which some had done, as seen in (vi.) next.

CILs could underpin the qualities of the best social teams (Kayleigh: *'... the only way that I think it works is because I have a magnificent social worker, I have magnificent support from [CIL]*). However, as seen in Section D, not every local authority has a CIL. DPOs could also offer support to people making SDS choices, but unevenness of access to DPOs was a barrier, as Gerry noted: *'...I don't live in Glasgow, so I don't always get access to everything that GDA in detail have to offer. So I would encourage other councils to have advocacy like that.'*

Proactive and determined social work teams that helped people to make SDS choices, and then supported them with getting secure packages in place, were fundamental to good experiences.

#### **vi. A secure social care package, sufficiently funded**

Almost all participants described these two elements working together to underpin good experiences. Larry typified this, having a budget that is sufficient for him to live independently with support: *'...I get like [£ Amount] every four weeks, which basically works out about 40 hours ... as well as getting respite as part of that, so it was really good for me. It worked really well.'* But he also had confidence if his needs changed that reviews did not feel like a threat: *'I do feel that if I felt I needed a review because maybe I needed more hours, I could contact them and they would do so...'*

Awareness of budgetary constraints facing local authorities meant that some people with good social care still had to live with 'fear of the review'. Lucy had a secure package, received for over a decade, and had not spoken to social work for 'years', but said that her father was still anxious that *'... if they know that you're okay, they'll take the hours off you ...'* Rachel had unexpectedly received more support hours than her social worker had initially applied for (*'I'm also getting a bigger package so that helps a lot.'*) yet she was still very conscious of the annual budget cycle: *'I don't know, I'm sure they will be making cuts at some point to some packages, but for as long as my social worker's involved...'*

However, only exceptionally did funding stretch as far as enabling the disabled person to go on holiday or overnight trips, placing limits on independent living.

Annual funding also detrimented peoples' ability to live well and plan ahead securely in their lives, as seen in Section D, below.

## Summary

Six features helped people to gain and maintain good community-based adult social care:

- i. Assertiveness or self-advocacy
- ii. Knowing how the social care system works and being supported to navigate it
- iii. The human qualities of care and support workers and PAs
- iv. Predictable personal care, flexible social care, and strong teamworking by care/support workers and PAs
- v. Proactive and determined social work teams
- vi. Having a secure social care package, sufficiently funded

However, good experiences were not a synonym for independent living. More is needed to enable consistent access to independent living for people with community-based social care wherever they live in Scotland, as seen in the next section.

## D. What is needed to secure good community-based social care and independent living across Scotland?

In describing good experiences of community-based social care, participants could often only describe good social care because they had previously experienced poor social care, and/or knew others with poor social care. People also continued to experience barriers to independent living. Kayleigh summed up the low expectations for what can makes 'good experiences:

'To be honest, I mean, using the phrase a good...it's not a good package, there are no' loads of hours or anything, but it works for me. If I could get a PA to come in and do loads more hours, I would.'

Rachel put it in further perspective:

'I know of people personally who have incredible personal care needs and who had their package cut in half. And mine doubled. I mean, I just have been really fortunate, blessed ... lucky, whatever. I had a really good experience.'

Gerry put it slightly differently:

'Care is not perfect but as long you recognise the limitations in amongst that you can have a good life and work toward something that you want, and you deserve, but you need to be quite vocal in getting your needs met.'

Seven features emerged that would consistently secure good social care and independent living for disabled people wherever they live Scotland:

- i. Care package certainty, long-termism, and funding that facilitates independent living
- ii. Care package portability to allow freedom of movement within Scotland

- iii. Stable access to care/support workers/PAs with the qualities to deliver independent living principles
- iv. Social care that is put in place quickly
- v. Consistent and accessible information on SDS options
- vi. Not needing to 'fight' to get and keep good social care
- vii. Removing structural barriers to independent living

These are described in more detail below.

### **i. Care package certainty, long-termism, and funding that facilitates independent living**

Even with good experiences, people usually still felt constrained by the budgets they received. Dominant themes were uncertainty over budgets covering changing circumstances, not having full control over how budgets could be spent, not having sufficient social care to be able to afford holidays, and having funds reduced or removed.

People experienced uncertainty over budgets covering changing circumstances. Judith wanted her son's package to allow him to live as any other person of his age group would:

'...what was agreed was that even when the college is shut, Stevie's going to get the college hours, so it means [PAs] can come ... they can get him up and they can take him out. So most days he's out. And that's the way it should be. Because any 21-year-old person would be out working five days a week. [Local authority] can't turn round and say, 'well because he's not at college for the three days, we're withdrawing that and we're only giving you 14 hours.' ...that'll never do. And that's where I'm going to have the fight, I think.'

Future funding uncertainties clouded her good experience of social care:

'...I've basically had everything that I have asked for... I've got my PAs taking him to college, he's got his social hours ... he's well looked after, and that is working just now. Social care at the moment has helped immensely. It's helped Stevie to speak ... develop friendships, develop a personality, he's getting to know people and do the things he wants to do. But what's going to happen? Is that going to be taken away when he's finishing college because...they're just going to say, 'oh well he's not going to work' ... I don't know.'

Not having control over how budgets could be spent was also a constraint to good experiences. Kayleigh wanted Jon to also experience the world equivalently to non-disabled young people, but again faced uncertainty:

'... I've applied for a boat trip ... to go out to see all the puffins... So, obviously for Jon that would be great to be on a RIB boat, to be ... getting hit with all that sensory madness...because ...you know ... he can't get driving lessons or go to college, whatever... So, I have spoken to [CIL] and said, do you think that my SDS budget, that's sitting there doing nothing, would be allowed to be

used for us to get accommodation, with a PA, for us to do these things ... They'll probably say no 'cause they'll go, 'then everybody'll want a holiday using their SDS'.

Not having sufficient social care to be able to afford holidays was a persistent limitation for people. Holidays are a reasonable expectation for any citizen, or as Rachel put it, '*...a wee holiday would be great. Even just here, as in Scotland. Just, kind of like, what normal people do.*' Lucy typified what makes this difficult:

'... if I took my staff, I would need to have, like, sleepovers and stuff, and that would cost me a hell of a lot more. And that's just going away for five days. And ... if I take ill and I come back, would I get the hours back? And that's when a social worker will need to get involved. And I'd rather avoid that.'

A further concern was about care package funds being reduced or removed. This happened to Natalie as this research was being done. She had been told that she could spend accrued money to go on a holiday with her PAs, but at the end of the financial year had received a letter rescinding this. Along with wider tightening of her care package, this redoubled her wider poverty:

'I just want a chance. I'm focusing in on my music and my art these days. And on my previous phone call with social work there, I asked if I could use the money for a craft table. He said ... there was other funding I could possibly get from [charity], but it's like, surely SDS should be able to pay for that, rather than a handout. When you're unsure about funding, you're unsure if you're able to... a craft table, a video doorbell, a fence to separate me and my neighbour, I'm scraping about for the gas and leccy at the moment, when the summer comes I don't know if I'll be able to pay for the garden to be done.'

These themes were brought together by Gerry. He highlighted how short-termism in social care packages meant that disabled people are not supported in anticipation of changes through the life cycle and acted against opportunities for promoting wellness and wellbeing, restricting disabled peoples' freedom to plan ahead and 'grow' as any other independently living citizen might:

'... that's the thing with care, it's not very flexible, so as you change or as you get older or maybe you want to move away or start a family or you need a bigger premises ...you need to sort of start from scratch again almost... Your care needs to be part of your life, your life cycle progression ... they have to see it in a holistic sense, and ... not think we're putting any extra demands on it. We're only putting extra demands on it because we want to be included in society and play a part in society... I'm a firm believer in doing exercise and helping to take pressure off the NHS, right, but for me to do that I would need to increase my care package and I know that seems... quite sort of, 'oh, God, what does he want to do that for?', but it means that you're taking pressure off the NHS in the long-term ... it's about being able to take that bigger life cycle view of care I think, rather than a short, sharp, budgetary one.'



This anticipatory, flexible notion of life, and supporting people to be able to plan futures and prevent impairment was missing from experiences of good social care. This contradicts the public health policy expectation for citizens towards healthy lifestyles and preventative health, and the wider preventative aims for public services of the Christie Commission (Scottish Government, 2011). Instead, for Gerry his care package, although good, had been pared back:

‘A couple of years ago I got three hours taken off me. So, I’ve had to learn to adapt to what’s left ... and that isn’t always easy. And I do have a lot of care needs because there’s a whole washing, dressing, physical aspects, getting out, but I also need people to read my mail, help me with my bills ... so that all takes time...’

## **ii. Care package portability to allow freedom of movement within Scotland**

Participants were essentially ‘trapped’ because they received good social care. To move would throw their situation into jeopardy. This had happened to some participants. Judith highlighted this, she had moved authorities because her home was no longer suitable:

‘Now we always had [SDS] in [authority 1], but they worked slightly different than [authority 2]. [Authority 1] give you a budget for a year and you can use that budget for lots of things. But in [authority 2], you can't. You can only use it for care... In [authority 1], if you needed a piece of equipment for Stevie, say that was going to benefit him, like say a computer and you had money within that budget ... they would allow you to use that... But in [authority 2], they're not interested in that. They're only interested in the care capacity, be it social care or be it care for, like, washing and drying, that type of thing.’

Veronica had also moved authorities to be nearer her family:

‘... when I moved there, in the first instance, the social worker in [good experience authority] had said to me that it would be easy ... the two social work departments would speak to each other, and my care package would just transfer over. It didn't ...’

Gerry highlighted the lottery of social care that mitigates against disabled people being free to move:

‘... when you're looking at a national care service, it needs to be a national care service. It can't be 32 councils delivering care differently which is what's happening at the moment, and if I wanted to move to a different council ... I would need to start from scratch again. That's really limiting.’

Good social care could even trap people from moving within the same local authority. Larry:

‘I don't want to move, I don't want to rock the boat. I've got a good package... I trust [sub-local authority] social work department... I know what it's been like in a different council area, and it was horrific, honestly, so yeah, I don't even want to move within [authority] and be under a different social work team.’

This was even though Larry's house was far from ideal:

'...the bathroom's ... so small, you can't get a hoist in it, so I have to do very precarious self-transfers that have resulted in falls ... it's not perfect here, but it's better than everywhere else has been, and because social work is so good, it's now like, we'll make do, we'll manage...'

Several participants used the phrase 'postcode lottery' in relation to differences in good social care provision. However, some participants argued that this was not a lottery, but an inequality issue. Kayleigh lived in one authority and worked in another:

'... the Carers Centre here and [CIL] are probably dealing with people who are suffering from less social deprivations than they are where I work ... Where I think here they may just be dealing with a carer who is a carer, you know, and may have one or two issues. Whereas in [other authority], we're dealing with carers who will have ... alcohol issues, who'll be in poverty, who'll be in debt, who'll be in poor housing, who won't be well educated.'

The unpredictability of moving away from a good social work team and a good care package means that disabled people do not have equal freedom of movement as other citizens and are effectively trapped. It means that they have barriers to making major life decisions that are open to non-disabled people, such as moving house, seeking employment or education elsewhere, or finding life partners that live in other areas. To end this inequality, disabled people need to know that social care packages are guaranteed as portable. To underpin this, disabled people also need to be able to have consistent confidence in being able to access good social work teams and care/support workers/PAs wherever they choose to live in Scotland.

### **iii. Stable access to care/support workers/PAs with the qualities to deliver independent living principles**

Several participants had struggled to recruit and retain PAs to support them in the way they needed. This could lead to long delays in achieving good social care, such as for Natalie:

'I've always had the hours for the second PA, just nobody came forward with the full qualifications for me ... I had somebody start with me at one point, and I didn't gel with her, and ... she couldn't actually do the social hours that I was asking her to do ... I've been waiting another full year for another PA, and I've finally got this one.'

Several participants felt that higher pay for care/support/PAs would help, but their packages did not allow this. Natalie expressed the paradox that this leads to:

Interviewer: 'You can't offer higher pay to get a better quality of PA?'

Respondent: 'I could, but it would cut my hours ... I would get the same amount of money. So, I could pay more, but it would mean less hours.'

Interviewer: 'Right. Have you thought about doing that?'

Respondent: 'No, 'cause I need the time.'

Some participants were able to pay their PAs more because they had the opportunity to use their budgets flexibly. For example, Rachel was able to pay her PAs £13 an hour. But this flexibility wasn't consistent across authorities, restricting control for disabled people and undervaluing PA skills, as Natalie expressed:

'... I wasn't allowed to set the budget for her pay, I was told that's what she was to be getting ... she's worth well more than she's getting paid and I know some PAs are able pay more than I'm allowed, I don't know why.'

Natalie had really struggled to get PAs, and previously care/support workers, that had experience of working with both physical and mental health:

'It doesn't seem to be a marrying up of people with mental health and physical health problems... [Y]ou're either under the bracket of mental health, or you're under the bracket of physical health problems. You don't seem to get the crossover.'

Given the known correlation between physical impairment and mental distress, this is patently an area in which there is a high need for increasing knowledge, skills and capacity to improve assessment and support for those with both experiences.

Staffing wasn't only a constraint for participants that used PAs. Some had insufficient care and support workers through other SDS options, with unpredictability of who would be supporting them (Natalie: '*Just too many people coming in to my house. You know, constantly different people coming to my house*').

Some participants had experiences of care and support workers that did not care for them well. Harpreet: '*15 minutes wasn't enough for me. I found them really abrupt. So we had to stop that package. We had to stop the council coming in.*' Her husband elaborated:

'... the way they dried my wife's back after the shower, it was not like a very friendly way of doing it, it was just really rough sometimes and a couple of times I thought my wife is going to fall on her face because she was pushing more than wiping. One of the girls, I said 'don't send her', they said 'we have a shortage' which is another side of it, but I said 'if you have a shortage, just don't send her because I fear the safety of my wife.'

However, Harpreet noted that some care/support workers could make a difference in 15 minutes: '*they were homely, they will speak, even those 15 minutes they will make a difference.*' suggesting that it is sometimes possible for good social care to be provided in brief visits.

Rachel explained the emotional burden that was placed on care/support workers and disabled people by the stress of how care work is sometimes organised and managed:

'... [local authority care] did not meet my needs in as much as the staff themselves were fabulous, the management setup and system just was not.'

[T]here were ... people coming in here and I had spent half an hour just trying to talk them down because they were so up to high doh. They were crying. I had people just like, 'I can't keep doing this.' And I'm not letting somebody go out my house totally stressed like that when I know that they're going to somebody's else who's maybe as vulnerable or more vulnerable than I am.'

Rachel had a similar experience when using a private care company. She contrasted these with the flexibility, relationship-building and human qualities experienced with her current PA:

... she's been good at saying, 'come on, get out of bed ... I need somebody to sit and have a cuppa with me.' And she did that when I was really feeling quite depressed ... so the relationship there ... she seems to be aware of when to just leave me ... you know...'get up and shower and then you can go back to bed.' And they wouldn't have been allowed to do it [under her previous packages] 'cause ... everything was recorded, total minute detail.

For people using social care to have consistently good experiences across Scotland there needs to be an ample supply of care/support workers and PAs with the qualities to deliver independent living principles and with the diversity of skills needed to support Scotland's diverse population of disabled people.

#### **iv. Social care that is put in place quickly**

Some participants had lived for years without good social care, for example Natalie: *'Thirteen years ago I lost that job, and that's when I fell extremely ill, and I'm still struggling to get the care...'* She eventually phoned social work:

'... just to say how exasperated I was with the situation ... Maybe eight or nine years I was under social work getting support, supported by other organisations, you know, which was a terrible experience. And then when my social worker's boss got in touch with me to say about self-directed support and about PAs and stuff ... I knew straight away that's what I needed, and I probably needed that all my life to keep me safe... I believed that I would never have my needs met, basically. And now I believe I do have my needs met.'

The financial cost to the NHS and other public services due to the inadequate social care that Natalie received for all those years is incalculable – aside from the impact on her own health, wellbeing and life chances.

For Larry the 12 months that it took for his SDS assessment to be completed led to specific problems, undermining his dignity:

I was with their homecare team for one year until my SDS assessment was complete, and in that year I had 36 carers, which is obviously a lot of carers for anyone, but as a trans man who cannot have gender affirming surgery and someone with anxiety, it was horrific having that.

There is a need for timely assessments and a fast response from local authorities to minimise time waiting for assessments. Alongside a far bigger supply of high-quality

care/support workers and PAs, this will minimise the time people spend living with inadequate social care and without the prospect of independent living.

#### **v. Consistent and accessible information on SDS options**

Several people said that they found out about SDS through a Disabled Person's Organisation. However, access to good social care should not come down to the networks that people happen to be in, or down to 'luck' that they happen to live in an area with a DPO or CIL. Some participants had good information on SDS options from their social workers. Some people found SDS options confusing, Harpreet's husband noting:

'... if you start telling Option 1, Option 2, Option 3 – even I was confused, what's the meaning of Option 1 and Option 2? People are not interested in numbers, they need to be told in simple words 'the same carers will come to you and you won't handle the money.'

Natalie summed up the need for clearer, accessible information on SDS:

'... I find it difficult to get my head round... I've read some of the booklets that [CIL] gave me, but I don't feel there's enough information about how much power I have over my money ... I'm not given that information freely, you know. You've got to, kind of, feel your way and just ask questions.'

Kayleigh described how a positive change on SDS in her authority still favoured those 'in the know':

'... there was a point until very recently where we could only use our SDS budget for PAs. And obviously, in other regions that wasn't the case. So ... [CIL] and In Control<sup>14</sup> then begin to niggle the council a wee bit to say, wait a minute, all these folk are sitting here with budgets, doing nothing, what is that doing, it's benefiting nobody. And because of the situation then...the word isn't out there with everybody that you can use your budget creatively ... loads of people ... aren't aware of that.

To assure consistently good social care in Scotland, information on SDS options need to be accessible and clear to all people considering and using community-based social care, regardless of local authority. Consistency on achieving this, including outreach to intersectional and marginalised disabled people, would be aided by accessible CILs and DPOs in every local authority. This would complement information provided by statutory services.

#### **vi. Not needing to 'fight' to get and keep good social care**

It was alarming to hear the accounts of the exhausting work that people had to do to get and keep good social care. Judith: *'I've had to fight for every single thing. Everything is a fight. They won't spend money.'* The work needed to get SDS in the first instance was contingent on the approach of social workers, as for Kayleigh:

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<sup>14</sup> <https://www.in-controlscotland.org/about-us>, sources 18 July 2023.

'... a number of years ago Jon had a social worker that I didn't get on with. And I struggled with ... the way that she spoke to me, and whenever I went to challenge it then I was always, kind of, made to look ... as if I was a troublemaker... [E]ventually I just walked away from the whole concept of self-directed support and having any relationship with Social Work.

Larry had had a similarly difficult experience when first approaching social work for support:

'I had such a negative experience in [poor experience local authority] with social work themselves ... it was probably as bad as it could get, to be quite honest. I think anything could have been better than how they treated us, basically. So for me it's the assessment process itself and the attitudes of how I'm treated...'

Gerry summarised the toughness that can be needed to get and keep good social care:

'I've also been a fighter for support. It doesn't come easy ... you have to know the system and you need to know how ... to not get nervous about the system and know when to shout to get your needs met.'

Consistently good social care will only be achieved across Scotland when people have easy access to it, wherever they live, and have confidence in keeping it once it meets their needs. If getting and keeping good social care relies on a 'fight' this will inevitably result in unjust access to SDS.

#### **vii. Removing structural barriers to independent living**

It is striking that participants described good experiences of social care predominantly in relation to getting support to live well within the home. Only to a limited extent did they describe good social care as enabling them to take part in social and cultural activities, volunteering, education and employment. However, independent living is about disabled people being able to live with the same opportunity for choice, control, dignity and freedom in every domain of life – including the workplace, political participation, and more (GDA 2018; Brunner and Glasgow DPO Network, 2022a, 2022b).

Gerry noted that, for example, DPOs '*have quite a really positive environment for everybody*', and indeed several participants did take part in DPO activities, and valued these. He added: '*but ... the world outside is cruel, so when you try and move in the outside world then that becomes even harder.*' His experience of trying to get and keep a job, even using Access to Work<sup>15</sup> grants, had not been good:

'There's a few jobs that ... I've had to leave just because of the amount of work, or I can't... do it quickly because of my lack of eyesight, so I've had to leave roles as well that I thought were quite good... I've also had a lot of

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<sup>15</sup> <https://www.gov.uk/government/publications/access-to-work-factsheet/access-to-work-factsheet-for-customers>, sourced 25 July 2023.

bullying and discrimination in jobs as well, because of the whole glass ceiling thing, and, 'oh, what are you doing here?'

Larry had considered returning to education but faced barriers:

'I did look at going back to college, then uni ... as part of the assessment, but I can't financially afford it ... [L]ike they've got kind of additional things you can apply for, but there's no guarantee for that. And because there's no guarantee, there's no guarantee I would be able to afford the flat ... And the college weren't very communicative ... about like supporting things for like dyslexia and that, so we just decided that maybe it wasn't for me...'

The paradox of social care is that it is assessed individually. This misses collective barriers that if removed would really unlock everyday participation and equal opportunities for disabled people - including those using social care. To make the shift from 'good social care' to full independent living requires good social care packages to be reinforced by inclusive employment and educational practices and policies, by accessible environments, houses and transport, and by the social security system. Removing disabling barriers in these systems will fully support disabled people to have an equal opportunity to contribute in every domain of life, consistently across Scotland. Social care cannot achieve independent living alone – wider public policy has a role too.

### **Summary**

Participants were not able to have the same choice, control and freedom as for every other citizen – even while receiving good social care. Seven features would help to secure good community-based social care and enable independent living for disabled people across Scotland:

- i. Care package certainty, long-termism, and funding that facilitates independent living
- ii. Care package portability to allow freedom of movement within Scotland
- iii. Stable access to care/support workers/PAs with the qualities to deliver independent living principles
- iv. Social care that is put in place quickly
- v. Consistent and accessible information on SDS options
- vi. Not needing to 'fight' to get and keep good social care
- vii. Removing structural barriers to independent living

The inequities in social care across authorities, being 'trapped' by having found a good local social work team and PAs/carers/support workers, and the sheer uncertainty of what would happen if people had to re-apply for social care, strongly constrained good social care experiences. More than this, social care support was not sufficient to enable people to plan ahead in life or to overcome structural barriers that still constrained experiences of independent living, which Scottish policy says that every person receiving SDS should experience.

## **E. Marginalised disabled people who face intersecting barriers' good experiences of community-based social care**

The small number of disabled participants who face intersecting barriers offered experiences of the types of things that helped them get good social care. Although the sample is very small, the need for more understanding of barriers to social care for LGBTQI+ disabled people in particular has been recently highlighted.<sup>16</sup>

Daphne, a BAME participant, felt that the values and practices of a DPO gave her respect:

‘Respondent: GDA, like, most of the new members at GDA they are so respectful. Yes, they are respectful and they, like, they don't discriminate.

Interviewer: Yes, okay. So, these principles help you to feel...

Respondent: At home.’

Larry already noted above how correct use of pronouns upheld his dignity. Larry described further the significance of dignity and respect as a disabled trans male receiving social care:

‘...I wear something called a binder [and] a prosthetic packer ... just being respectful around stuff like that. It's never been an issue, they will help me get my binder on and stuff, because I can't get it on myself. There's never been any disrespect around that, any question around that, any, 'oh, it's a bit of a pain to get on because it's so tight' ... Like sometimes they'll respectfully ask stuff, and I'm fine answering it. It's if they don't know, then how are they going to know if nobody educates them? So like I've not had a bad experience around my gender and stuff with that at all.’

Larry also highlighted that more formal ethics of care such as confidentiality and respectfulness could be particularly important for LGBTQI+ disabled people to be able to have a full social life:

‘But also the people that work with me being a queer trans man, obviously my identity's very important to me, there's a big safety aspect around that as well, being transgender. And part of what my PAs support me in could be going to social groups for people who are LGBTQ, and they really need to be aware as well that to be respectful in those space, not just to meet other people, but also that confidentiality in spaces like that is super important...

Larry emphasised the importance of good social care being able to support disabled peoples' diverse identity characteristics and intersecting barriers:

‘... there is going to be a lot of LGBTQ disabled people out there who will struggle with social work, have really bad experiences and stuff ... it's a minefield, basically, and it's not an easy one to cross, but it's a really, really important thing to highlight, because at the end of the day, it's part of who you

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<sup>16</sup> For example, <http://www.bristol.ac.uk/sps/news/2016/lgbtselfdirectedcare.html>, sourced 18 July 2023.



are, and it's a huge part of your identity, as much as my religion's part of my identity as well, so it's such a big thing that needs to be considered.'

The parents of the two young disabled participants had both worked hard to recruit young PAs. However, they experienced age-related intersecting barriers. Judith's son Stevie was at college: *'I don't think there's any expectations for him ... I have had countless meetings with them and asked them, you know, what would his next steps mean...? And they can't really tell me.'* However, *'... my biggest worry actually is what he's going to do after college, because there is nothing out there for him to do. I don't want him sitting in a day centre with 40-year-old people.'* This then drove uncertainty about his social care budget: *'And the worrying thing is when he leaves college what's going to happen to the budget, 'cause that's a problem because there's nowhere for him to go.'* This impacted in practical terms on their social care stability: *'I worry because if they withdraw the budget, my PAs will ...possibly look for another job, because 14 hours isn't enough, you know...'* Judith was seeking meaningful activities for Stevie in her authority:

*'... all too often these young people are getting wheeled about into Primark and all these shops with people because ... the carers, that's all they're doing ... I don't want that for Stevie. I want Stevie to be able to go to something he wants to go to. You know, I want them to go to help at the theatre or ... cinema ...you know, as a volunteer... something that he wants to do. He's not interested in arts and crafts 'cause he can't use his hands very well ... that's all you tend to get now.'*

Limited confidence over future funding of the care package, combined with very limited options for young people with multiple impairments, restricted the ability of Stevie to experience independent living.

Good social care must consistently and specifically account for the needs of marginalised disabled people who face intersecting barriers. This is a necessary dimension to enable every single disabled person using social care in Scotland to have choice, control, dignity and freedom, equal to any other citizen.

## F. Conclusion

*'... social care's not just about social workers and that. It's about everything.'*  
(Judith, parent of Stevie)

How do these findings help us to think about what community-based adult social care in Scotland is currently like? And how do they help us think about what community-based adult social care should be like to consistently deliver independent living across all four SDS options, and in all parts of Scotland? The evidence shows that barriers and constraints to independent living existed for all participants with good experiences. This shows that good social care cannot simply be explained as, for example, 'some exceptional/privileged/lucky people always have good SDS'. No participants 'always had it good', and all had been constrained from enjoying independent living. This reinforces what is known about disabled peoples' wider and historic marginalisation in society and the evidence of *Future Visions* programmes since 2011 that multiple barriers continue to be experienced by disabled adults living in the community who need good social care and seek to achieve independent living (e.g. Witcher and participants, 2014).

The goal of Scotland's principal social care legislation, the Social Care (Self-directed Support) (Scotland) Act 2013 (Scottish Government, 2014, p.4), is that:

Self-directed support<sup>17</sup>, alongside many other policies, is intended to support, promote and protect the human rights and independent living of care and support users in Scotland. It aims to ensure that care and support is delivered in a way that supports choice and control over one's own life and which respects the person's right to participate in society.

Self-directed support should be enacting independent living for everyone in Scotland that uses any of the four SDS options for social care. Independent living is defined as follows (Scottish Government, 2021, p.9):

Independent living means people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself, or fending for yourself. It means having rights to practical assistance and support to participate in society and live a full life.

The research findings demonstrate that while achieving 'good social care' is not the same as achieving independent living, good social care is founded on independent living principles. The study indicates steps needed to secure good community-based social care and to enable independent living for disabled people across Scotland.

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<sup>17</sup> Under self-directed support, all local authorities have a legal duty offer four options to people who have been assessed as needing a community care service. The four options for SDS are:

option 1 – a direct payment, which is a payment to a person or third party to purchase their own support

option 2 – the person directs the available support

option 3 – the local council arranges the support

option 4 – a mix of the above

Source: <https://careinfoscotland.scot/>, 03 July 2023.

## What makes good social care?

Peoples' good experiences of social care were underpinned by the four established independent living principles – **freedom, choice, dignity, and control**. However, to capture more accurately what makes for good experiences of social care, a fifth principle of **reciprocity** (mutual agreement, exchange, trust, learning and regard) needs to be added.

### **Six features helped people to gain and maintain good community-based social care:**

- i. Assertiveness or self-advocacy
- ii. Knowing how the social care system works and being supported to navigate it
- iii. The human qualities of care and support workers and PAs
- iv. Predictable personal care, flexible social care, and strong teamworking by care/support workers and PAs
- v. Proactive and determined social work teams
- vi. Having a secure social care package, sufficiently funded

### **Seven features would help to secure good community-based social care and enable independent living for disabled people across Scotland:**

- i. Care package certainty, long-termism, and funding that facilitates independent living
- ii. Care package portability to allow freedom of movement within Scotland
- iii. Stable access to care/support workers/PAs with the qualities to deliver independent living principles
- iv. Social care that is put in place quickly
- v. Consistent and accessible information on SDS options
- vi. Not needing to 'fight' to get and keep good social care
- vii. Removing structural barriers to independent living

Good social care must also consistently and specifically account for the needs of marginalised disabled people who face intersecting barriers.

These themes, drawn from analysis of good experiences, help us to think about what community-based social care in Scotland is like, and what it should be like to consistently deliver independent living across the four SDS options.

## Concluding points

- a) The accounts of good experiences suggest that the Scottish definition of independent living is too rarely the lived experience of people on SDS living in the community. The evidence showed that moving house could jeopardise a good care package, leading to the paradox of good social care 'trapping' disabled people. To realise the National Care Service goal of achieving consistency and addressing inequalities (Scottish Government, 2022), all four SDS Options (1, 2, 3, and 4) need to consistently deliver the independent living principles - choice, control, freedom, dignity - and reciprocity too, whichever local authority people choose to live in.

- b) The findings show that good experiences of community-based social care are beyond providing for functional and outdated Instrumental Activities of Daily Living and Activities of Daily Living (I/ADL).<sup>18</sup> Good social care is about how disabled people are supported to have control over choices about the kind of activities they want to do, and how they are then supported to do those things.
- c) The evidence suggests that in good social care, power in the carer/cared for relationship changes, enabling the disabled person to have choice, dignity and control over how their social care works, leading to greater freedom for them. This 'everyday' freedom is underpinned by people having 'meta' control over their SDS option. This can be empowered by a good social work team and access to a DPO and a CIL. Together these can transform historic power imbalances that have not helped disabled people to achieve equal outcomes in health and social care (Tronto, 1998). Effective social work teams can open up SDS options for people by assessing for needs-defined-as-independent living. A CIL and a DPO in every local authority can support disabled people to navigate the social care system, including marginalised and intersectional disabled people. This, in turn, will help the National Care Service goal to achieve consistency and address inequalities in social care in every area of Scotland.
- d) To enable people with community-based social care to have '*the same freedom, choice, dignity and control as other citizens at home, at work, and in the community*' (Scottish Government, 2021, p.9) requires social care funding to be sufficient for them to be able to live this free and equal life, with support. Self-directed support funding needs to be anticipatory, rather than annual, so that disabled people can plan ahead in their lives, as other citizens can. A lifecourse 'mindset' and consideration of social care as being relational and about 'being human' will help.
- e) Self-directed support cannot enable independent living by being only about individual assessments. Many disabling barriers are outwith the remit of social care. Barriers to independent living include equal access to employment, leisure, education, holidays, social spaces, public transport, participation and much more. Wider public services and Scotland's wider social and economic policies need to take a far more proactive, strategic and intersectoral approach to removing physical, social, attitudinal and other barriers to disabled peoples' opportunities to have '*the same freedom, choice, dignity*

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<sup>18</sup> ADLs are activities relating to personal care and mobility inside the home that are basic to daily living. They include activities related to personal hygiene, dressing, eating, maintaining continence and getting around indoors. IADLs are activities which, while not fundamental to functioning, are important aspects of living independently. They include basic communication skills, transportation, shopping for groceries and clothing, housework, meal preparation, managing medications, managing personal finances. (Ipsos MORI, 2017: 22). See also Zarkou and Brunner (2023).

*and control as other citizens at home, at work, and in the community.*  
(Scottish Government, 2021, p.9).

- f) How should Scotland measure the attainment of independent living, in contrast to overly-simplified and out-dated 'measures' of I/ADL (Zarkou and Brunner, 2023)? How can it track progress over time? Approaches might include:
- Quantitative and qualitative progress on maximising the number of long-termist care packages, sufficiently funded to facilitate independent living, comparing this by local authority
  - Quantitative and qualitative progress on equal access to CILs and DPOs across Scotland
  - Qualitative experiences of people using community-based social care and how this translates into independent living outcomes
  - Progress by public services and public policy outwith the formal social care system on removing structural barriers to disabled peoples' independent living
  - Measuring experiences of social care and independent living outcomes for people with different types of impairment.

Social care users, DPOs, CILs, and social care organisations need to be fully involved in co-design of any monitoring process.

### **Summary**

Good social care is not the same as independent living. But it is a necessary constituent. On a local level, people approaching social care services for support need to feel attitudes at every stage that convey that the local social care system is as reliable and consistent as any other in terms of its ability to enable independent living. On a Scotland-wide level, disabled people need to feel that the Scottish Government and public services have 'got their back' and are removing structural barriers to independent living. Alongside the other recommendations in this report, these would enable far more disabled people to have *'the same freedom, choice, dignity and control as other citizens at home, at work, and in the community'*.

### **Limitations of the research**

The study is of a small sample of users of community-based social care that have self-selected as having had a good experience. There are potential biases found through self-selection, including bias towards those that are particularly empowered, resilient and determined, and with the capacity to take part in a research interview.

Recruitment was through DPOs and CILs, and some impairment-specific organisations. This means that people that took part in the study may be exceptionally well networked.

The study did not include people self-funding their care packages, so the sample did not hold a prima facie socio-economic bias.<sup>19</sup>

The accounts of good experiences were, by definition, subjective, a further potential bias. However, good experiences were often contrasted to poor experiences, and to the poor experiences of others. This suggests that the good experiences were comparative, not 'in a vacuum'.

The sample may have held a skew toward those with social workers and care/support workers/PAs that were particularly confident in releasing power, and in working with independent living principles, hence the good experiences. While likely, this does not invalidate the study whose aim was to foreground the voices of social care users. Rather, it suggests a need for wider research to gather perspectives of social care professionals doing good work to support independent living.

Two parents were interviewed on behalf of their young adult disabled children with multiple and complex impairments, their experiences acting as a 'proxy' for their children's good experiences of social care. It was beyond the capacity of this study to facilitate direct responses from the young people. While parents' voices are significant, they are distinctive from the views of their children. There are approaches to successfully involving people with multiple and complex needs in studies (e.g. Dee-Price et al, 2021), again demanding further applied research.

Intersecting barriers did emerge as a theme for young people and LGBTQI+ people. These need to be treated with caution as these are tiny sub-samples. Although participants included two BAME people, no strong themes emerged in relation to these communities. These suggest a further gap for applied research.

### **Further research**

Further research should include, among many potential themes:

- Marginalised disabled people who face intersecting barriers' good experiences of community-based social care, notably BAME people, young people, and LGBTQI+ disabled people
- Direct research with disabled people with multiple and complex impairments to understand their lived experiences of good social care
- Experiences of social care professionals that provide good community-based social care
- Good experiences of people on SDS living in care homes.

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<sup>19</sup> Self-funders are important for local authorities, the Scottish Government and others to consider, notably in relation to fully understanding the demand for care/support workers and PAs (Henwood et al, 2022).

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