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Abbott, David, Coleman-Fountain, Ned orcid.org/0000-0003-1622-7026 and Humphrey, Harvey (2024) Disabled People Negotiate Gender, Sexual Identity & Self-Directed Social Care Support in England:how does choice and control operate? Critical and Radical Social Work. ISSN 2049-8675

https://doi.org/10.1332/20498608Y2024D000000043

Critical and Radical Social Work • vol XX • no XX • 1–17 • © Authors 2024
Print ISSN 2049-8608 • Online ISSN 2049-8675 • https://doi.org/10.1332/20498608Y2024D000000043
Accepted for publication 18 July 2024 • First published online 02 September 2024

research article

Disabled people negotiate gender, sexual identity and self-directed social care support in England: how does choice and control operate?

David Abbott, D.Abbott@bristol.ac.uk
University of Bristol, UK

Edmund Coleman-Fountain, edmund.coleman-fountain@york.ac.uk
University of York, UK

Harvey Humphrey, harvey.humphrey@glasgow.ac.uk
University of Glasgow, UK

Putting disabled people in charge of their own support was a central component of the UK personalisation agenda. Austerity, staff recruitment difficulties and local authority retrenchment have meant that the experience for disabled people has not always lived up to the rhetorical promise. In this context, disabled people with marginalised sexual and/or gender identities face difficult choices in everyday interactions of support that trouble the idea that control routinely sits with them. In this article, we draw on two research studies with disabled people who use self-directed support in which they discuss navigating gender and sexual identity. In both studies, there are opportunities for disabled people to draw on support that is empowering, but we also hear about 'bad bargains' that they are sometimes forced to make. We argue that the hard-won goals of choice and control are being degraded and confronting LGBTQI+ and non-binary disabled people with sometimes impossible dilemmas.

Keywords disabled people • social care • personalisation • control • sexuality and gender

To cite this article: Abbott, D., Coleman-Fountain, E. and Humphrey, H. (2024) Disabled people negotiate gender, sexual identity and self-directed social care support in England: how does choice and control operate?, *Critical and Radical Social Work*, XX(XX): 1–17, DOI: 10.1332/20498608Y2024D000000043

Introduction

On the day we sit to organise this article, UK news outlets are reporting a story about a disabled man who has saved up his direct payment funds to go to Florida to 'have a bit of respite from the mundane reality of everyday life' (Rose, 2024). He had forgone trips to the cinema to save up, not for his own costs but for those of the two personal assistants (hereafter, PAs) he would need to take with him. (Witness the 'online pile-on' from many non-disabled people saying they would like the state to pay for them to go to Disneyland.) His local authority demanded the money back, saying they were not 'approved or eligible costs'. This example speaks to a central theme in this article: not only does the concept of 'approved costs' undermine the principle of choice and control within personal assistance, but it also conjures up the antonym of disapproval for money spent towards certain activities. Direct payments are funds allocated to disabled people to organise their own support in ways that sustain independence and promote choice and control, as compared with other models of support in which the disabled person is more a recipient of care/support organised by an external organisation.

There has been a strong policy imperative in the UK to deliver social care that maximises the choice and control of disabled people who are deemed eligible for social care services. The Community Care (Direct Payments) Act 1996 and the Care Act 2014 are clear about the kinds of personalised and high-quality support they want to realise for disabled people. The Care Act 2014, for example, focuses on well-being, defined as a broad concept that includes domestic, family and personal domains. The English government says it continues to be committed to improved and personalised services for users of social care services (PMSU, 2005; DH, 2006, 2010). Local authorities are expected to implement change in order to shift social care for disabled and older people towards: a less bureaucratic and more 'personalised' form of service 'which is on the side of the people needing services and their carers' (DH, 2007); a system that should 'empower citizens to shape their own lives and the services they receive' (PMSU, 2007); and a more preventative and less crisis-driven mode (DH, 2008).

The drive for disabled people to have more control over their day-to-day support was in part shaped by opposition to established models of support organised by local authorities, the independent sector or for-profit organisations from which 'care packages' were purchased. Disabled people would routinely have no say about who came to their homes to 'do' support and little input into whether that person was older, younger or of a similar outlook, ethnicity, gender or sexuality. Activists and academics wrote, and continue to write, about the radical changes, located within the Independent Living Movement, needed to transform how support was imagined and delivered (Morris, 1997; Watson et al, 2004; Glasby, 2005; Williams and Porter, 2017; Shakespeare et al, 2018).

The policy agenda of personalisation has always been subject to critiques of the individualisation and marketisation of social care, despite the fact that a universal, national and free social care system has never existed in the UK. Pearson et al (2020: 288, citing Leadbetter, 2004) highlight that the more radical 'deep personalisation' was imagined by the disabled people's movement as involving 'bottom-up', co-produced and re-envisaged ways of delivering support that were empowering and liberating rather than a 'model of consumerism': 'There is undoubtedly an ideological tension at the heart of personalisation, with the consumerist ideals of freedom conflicting with the collective impulses of social justice.' There is a growing sense and some evidence that the less radical aspects of personalisation now shape how the policy works in practice. The number of people using direct payments in the UK continues to fall and is now lower than in 2015/16, having fallen for each of the past five years. Overall, just 26.7 per cent of people drawing on adult social care use direct payments, down from 28.1 per cent in 2015/16 (Kings Fund, 2023). Possible reasons for the fall in number include the absence/decline of support to manage a direct payment, an overall decrease in local services to 'purchase', rates of pay being relatively uncompetitive compared with other jobs (TLAP and LGA, 2022), a high vacancy and turnover rate for PAs (Skills for Care, 2023), and the impact of Brexit on the workforce (Paton, 2022). A 2022 survey of nearly 1,000 PA employers (TLAP and LGA, 2022) found that 77 per cent of people who had needed to recruit a PA had found it more difficult, 69 per cent said people were taking jobs with better pay rather than PA jobs and 59 per cent thought that it was harder to find PAs with the right skills, values or training.

Over the same period, spending on advocacy services for disabled people and other users of social care services sharply declined. Furthermore, in a climate of austerity, some advocacy services and disabled people's organisations who are still funded by local authorities have had – or feel that they have had – their ability to speak out hampered by a threat of cuts for doing so (Pearson et al, 2020: 292), leading to accusations of a loss of authentic and independent advocacy roles. The poverty of personalisation and the regression from the more radical ambitions for it were laid bare in a sobering report from the UK Parliament's Adult Social Care Committee (2022), which highlighted the sense that disabled people using self-directed social care support were entitled only to a minimal level of care and support to 'live a basic existence' rather than a 'meaningful life beyond personal care'.

The overarching sense of crisis and failure to deliver on the promise of personalisation resulted in a 2023 'summit meeting' organised by the organisation Think Local Act Personal (TLAP, 2023), which asked: 'What would it look like if self-directed support and Direct Payments were working amazingly well? Can Local Authorities be trusted to deliver on the promise of personalisation?'

Personalisation, sex and gender

Within this overall policy and real-world context, how do systems of self-directed support engage with the full range of other important intersecting identities and protected characteristics a disabled person may have: gender, ethnicity, sexuality, age and gender identity (Mohamed and Shefer, 2015; Toft et al, 2019; Bahner, 2019; Emerson et al, 2020; Shuttleworth and Mona, 2020)? In terms of this article's focus on sexual and gender identity, social care staff, including PAs: may well not have this on their 'radar'; may have assumptions about differences and the acceptability of being disabled and gay, lesbian, bisexual, transgender, non-binary and so on (identity labels that are not always treated with similar levels of awareness, respect or approval as each other); may consider support needs related to sexual or gender identity to be 'off-limits' or disagreeable; and may have physical and spoken interactions that oppress and discriminate (Dunk, 2007; Abbott et al, 2016; Stevens, 2022). Adult social care staff include social workers, care plan managers, assessors and reviewers (whether from user-led organisations or local authorities), and support workers (whether employed directly by the service user through a direct payment/personal budget or other staff employed by the local authority to offer support services). All of these interactions between disabled people and the range of social care professionals that they work with provide opportunities (missed or taken) to include specific support needs related to sexuality and gender identity. Not every aspect of life that disabled people want and need support with is related to their sexual or gender identity by any means, and they may require social care support to go out anywhere, to go to work, to go to medical appointments, to get dressed, to go to the shops and so on. Some needs may be more easily labelled as connected with sexual and gender identity. Gender and sexual identities are mapped onto bodies, and these can be a source of power or subjugation (McLaughlin and Coleman-Fountain, 2018).

Disabled people can choose to employ PAs via personal budgets to allow them greater choice and control over many aspects of daily life, including sex, intimacy and relationships, than if care provided by a local authority is used. Sexual identity is of everyday importance to disabled people who recognise and want to explore this. At the same time, disabled people can feel under-skilled in managing PAs (Mitchell et al, 2017), something that may extend to negotiating support related to gender or sexual identity. That focus can also be silenced and stigmatised (Blyth and Carson, 2007; Liddiard, 2017). More broadly, the needs of disabled people from minoritised sexual and gender identities are largely unrecognised within social care provision (Hines, 2007; Schaub et al, 2023). Abbott et al (2017) point to the ongoing infantilisation of disabled people, which renders their sexual relationships platonic or abusive, with instances of lesbian, gay, bisexual, transgender, queer, intersex and others (LGBTQI+, the 'plus' representing other sexual identities, including pansexual or asexual) disabled people being refused the support they need to attend LGBTQI+ activities or to communicate and meet up with potential partners because they are either regarded as vulnerable or because there is resistance from social care staff based on discomfort or discriminatory attitudes.

We know very little empirically about the use and experiences of social care support by disabled people with gender and sexual identities that are not those considered 'normative'. We might assume that there may be some tricky negotiations with, for example, PAs, support workers, agency staff and so on when getting needs met that relate to sexual and gender identity. Apart from initial decisions to 'come out' about, for example, preferred pronouns, transitioning, dead names, sexual preferences and so on, users may well need support to access LGBTQI+ venues, take part in social activities with other LGBTQI+ people, facilitate other 'ordinary' daily aspects of being LGBTQI+ and require physical support with sex (alone or with others). LGBTQI+ people with learning disabilities may need particular support to assert and/or explain their needs as they pertain to sexual identity. Research with young disabled men (Abbott et al, 2016) suggested that in order to 'do' being gay and sexual, active support and consent from social care staff were crucial.

The Adult Social Care Outcomes Framework (ASCOF, 2015) LGBTQI+ companion document highlights the significant knowledge gaps in our understanding of how the general population of LGBTQI+ people access health and social access services. It also demonstrates that sexual orientation is rarely monitored by services and, where it is, that there is very little evidence that the data are actually used for anything. Finally, and unsurprisingly, it shows that discrimination has a direct impact on the perceived quality of care and support and affects outcomes for well-being.

Information about our research studies

We present data from two separate research studies, both of which were funded by the National Institute for Health & Care Research, School for Social Care Research. Study 1 was a collaborative project carried out by Abbott with: REGARD, a national disabled people's organisation of LGBTQI+ disabled people; Stonewall, a national campaigning organisation for LGBTQI+ equality; and the Social Care Institute for Excellence (SCIE), a national organisation with a remit to improve the lives of people who use care services by sharing knowledge about what works. The study took place between 2016 and 2018 and produced a range of practical outputs, including short films that are free to access online (SCIE, 2018), but that are presented here in an academic journal for the first time. The study received ethical approval from the National Social Care Research Ethics Committee. We adopted the acronym LGBTQI+ and defined it as referring to people who are lesbian, gay, bisexual, trans, queer, questioning and intersex or who hold such identities as non-binary.

We conducted a survey of people who self-identified as being LGBTQI+, disabled and in receipt of a direct payment or personal budget. We then conducted follow-up, qualitative interviews with a subset of the survey respondents. Finally, we held a focus group with support workers who were employed by LGBTQI+ disabled people. This article focuses on our first set of data: the survey responses and the unexpectedly large amount of data collected from the free-text response options. We not only made the survey available online but also (aware of the digital exclusion faced by many disabled people) sent a postal survey with a stamped address envelope to anyone who requested it. We also offered to collect responses via a telephone interview. We promoted the survey via all of our contact lists, membership lists and social media contacts. When we realised that our survey respondents were predominantly young and overwhelmingly white, we resent information to community groups, with a particular focus on older disabled people and Black and minority ethnic disabled people. This slightly improved the uptake from older people but did little to increase the responses from Black and minority ethnic disabled people – a particular limitation of the study.

There were 56 survey respondents: 53 per cent of respondents identified as female and 30 per cent as male; 15 per cent of respondents identified as non-binary; 2 per cent of respondents preferred to not specify their gender; 34 per cent of respondents identified as a lesbian/gay woman; 26 per cent identified as a gay man; 32 per cent identified as bisexual; 9 per cent of respondents preferred to not specify their sexual identity; and 20 per cent replied that they identified as trans. It is not possible to establish how many LGBTQI+ disabled people might be in receipt of direct payments or personal budgets, so we cannot say what percentage of the whole possible population we have reached. The headlines from the closed survey questions were that: more than half of those surveyed said that they never or only sometimes disclosed their sexual orientation or gender identity to the PAs who they paid to support them; more than a third of those surveyed said that they had experienced discrimination or received poor treatment from their PAs because of their sexual orientation or gender identity; and more than 90 per cent of those surveyed said that their needs as a LGBTQI+ disabled person were either not considered at all or were only given some consideration when their needs were assessed or reviewed.

Study 2 was also a collaborative project led by Edmund Coleman-Fountain, with Harvey Humphrey, Disability North (a disabled people's organisation) and, in its later stages, Pathfinders Neuromuscular Alliance, a user-led organisation of people affected by neuromuscular conditions. It took place between 2020 and 2023 and received ethical approval from the National Social Care Research Ethics Committee. The focus of this research was: to explore young disabled adults' views about managing issues of sexual and gender identity with their PAs; to think about how or if these issues arose in day-to-day support arrangements; and to explore ways to make PAs and social care services and support more inclusive of young disabled adults with the full range of different genders and sexualities. The project was inclusive of young disabled adults who were lesbian, gay, bisexual and/or transgender, as well as heterosexual young disabled adults. The study involved: interviews with 12 young disabled adults' experiences around seeking support from their PA; interviews/focus groups with 11 PAs about their experiences and their advice and needs around support; and the production of training and information resources for young disabled adults, adult social care services, PA support organisations and individual PAs. For this article, we draw on the interviews with young disabled people. An advisory group of young disabled adults was involved in the decision making about all aspects of the project (Humphrey and Coleman-Fountain, 2024). The 12 participants included cis women, trans men, non-binary people and a trans woman. All but two identified as white.

In both studies, we did not define 'disability' and produced easy-read versions of all of our materials, being conscious that people with learning disabilities can be excluded from research that takes place under the broader heading of 'disability'. We pull these two studies together here because they speak so centrally to the call of this special edition and, combined, offer powerful insights into the interactions between sexuality and gender in social care personalisation that are missing from the academic literature. Both studies adopted broadly similar thematic approaches to data analysis. Both studies worked in partnership with their academic and non-academic partners at the data-analysis stage to support shared sensemaking of the data and to give time and space to discuss such issues as how to 'frame' messages, how to ensure they remained ethical and mindful of the sensitivity of people's accounts, and how to avoid any danger of identifying participants. In order to write the article, we looked specifically at the data across both studies that had been coded as speaking to the intersection of control and sexual and/or gender identity, as well as mismatches between the rhetoric of personalisation and the reality. We stress – and describe – the preference for this approach to accessing social care support, with its roots in liberating models of choice and control for disabled people. A practical challenge in writing this article was that each study had very different descriptors to give information about who is speaking in quotations, and we have not been able to make this consistent. While the quotations used are illustrative rather than representative, we have attempted to include quotes and examples from the full range of participants across gender and sexual identities as described by people taking part, namely gay, lesbian, bisexual, queer, cis, trans, pansexual, male, female, non-binary and other. The decision to centre the voices of the LGBTIQ+ participants within the studies in this article reflects our wish to give voice to those seeking ways to live their fullest lives and identities within the context of personal support despite facing constrained choices. Cisgender heterosexual disabled people making choices about personal support do also of course make choices based on gender and sexuality, but their choices are less constrained and less subject to disapproval.

What people told us

In the sections that follow, we draw attention to some key, overarching themes by highlighting text in bold and returning to explore these in the discussion.

Navigating relationships with PAs

Although much of what we heard was about some of the challenges of self-directed social care support, we were left in no doubt about people's preference for and commitment to the principles of being in charge of support, beautifully summed up by one participant: 'I wanted to be able to choose. It's transformative if you get the right person.' Most participants could draw on earlier times in their lives when other people and organisations sent random people to their homes to 'do' support to them. For disabled people with marginalised identities, asserting more choice over who supported them was both important and challenging:

> How might they [PAs] react when out and about? Especially in gendered environments, like certain medical appointments. Will they feel confident in maintaining my pronouns, for example, in these settings?
>
> I mean, discrimination from carers and stuff and even abuse at the hands of carers is unfortunately quite a common thing. The kind of more subtle bigotry, that's always a worry because you might not necessarily notice that until you're, like, months into having this carer or something.

These deliberations are of utmost importance. We heard about the significant concerns that some people had about agency staff who they did not know or had never met coming into their homes:

> She was coming in in the morning, telling me that I needed to strip naked and have a hot bath and pray to Jesus to take away my impairment. She was saying that I should put a boiling hot flannel against my genitals to shrink them back into a proper position so that they'd be more appealing to men. I'm trans. *It felt abusive*.

In both studies, we heard of people making difficult and delicate decisions about what to say – and when – to their PAs about matters of sexual and gender identity. These are obviously not small matters given that they involve people coming into people's homes and lives in often quite intimate ways. An early dilemma for our participants was what to say at the recruitment and interview stage about issues of gender and sexual identity. In general, people erred on the side of caution or non-disclosure, but not always:

> I've had people turn out to be homophobic after I've invested time and money in training them. It's critical that they're fine with this part of my life, so I prefer to find out earlier now. I use the same question every time. I look them in the eye and say, 'I have romantic and sexual relationships with other women and am involved in political activities involving lesbian, gay, bisexual and transgender people. Do you perceive any problems as a result of this?'

Those who never or only sometimes disclosed said that they played a 'waiting game' to see how the relationship developed before making a decision: 'I tend to wait until I have developed a relationship with my carers and allow this kind of conversation to develop organically.'

Those who said they never disclosed said they did not want to jeopardise the relationship and, linked to that, were not confident that replacement PAs could be easily found: 'It's really hard to find people who understand autism. I don't want to risk losing someone who can help me well because they object to my sexuality. I honestly do not want to put them off from looking after me.' Decisions and dilemmas about revealing or showing information about sexual or gender identity were commonly discussed. We noted the really high levels of care, thought and energy given to these decisions – labour that is often largely invisible, Additionally, sexual and gender identity are not helpfully conflated as a default given that some aspects of identity can be visible and others not:

> I feel like gender is more important; sexuality is generally quite easy to hide if you want to.
>
> I used to advertise just saying 'man' or 'male' and found that most of the applicants I got were men. I've now reached *an uncomfortable accommodation* with myself where … I post the job saying 'female'…. In terms of care tasks, I remain biologically female … that's quite important information for someone to have. My personal care routine is incredibly intimate, so having people understand what my body set-up is is crucial.

Most people in Study 1 said that they could recount experiences with PAs and staff that were difficult and, in some instances, discriminatory and even abusive. One person said that a previous PA had become controlling and verbally abusive: 'It was very, very difficult.' Another said that one of his PAs was 'lovely' but also 'blatantly homophobic'. Two men said that some PAs refused to carry out some aspects of personal care. One of them said that his PA refused to shave his leg when he needed to wear a leg bag: 'He wouldn't do it, and I was snookered.' Some interviewees were quite careful to not have things or objects in their homes that would out them: 'If I had a copy of *Gay Times*, I would probably make an effort to make sure it wasn't there … especially when you've got a new carer coming in … just in case they're homophobic.' In the same vein, one person (who lived alone in his own flat) referred to his '*secret cupboard*, where I put all my gay stuff in'. He said that he would love to have a rainbow flag on his wall, 'but I can't; I just can't'. One of the interviewees told us about distressing experiences with two different support workers. Having arranged to go on a short break with some gay friends, he told his support worker about it: 'I said to him, "You'll have to be okay with gay people, okay?" He said, "Yeah, no problem." The next day, he started helping me in the shower and he started to wank me off. I reported him to the police.' In another instance, a man who was not out to his family with whom he lived at the time said that he had built up enough rapport and confidence with one PA to come out: 'So, I thought I would tell him about my sexuality, and he went straight downstairs and told my mum. She was crying. She said to me, "Is this true?" So, I had to lie to my mum and say, "I'm not gay."'

Along with the examples outlined earlier, danger was flagged to us by some participants, reiterating that the consequences of these interactions and relationships landing rightly or wrongly were incredibly serious: 'When employing so many people, I have to be more careful about my own privacy on apps like Grindr or kink spaces.

Ultimately, these people know where I live and how to get in, a large amount of my schedule, and personal details.' Decisions to reveal nothing, a little or only some part of gender or sexual identity had a direct impact on the very processes and relationships designed to empower (an obvious point to state is that cis-gendered, heterosexual people out and reveal themselves in interactions all the time in ways that are considered 'normal' and 'unproblematic'):

> Because I don't feel able to come out to my PA (I still present male around her), I'm not able to go out as myself with her.…There is quite a lot I have to hide from her. Being able to explore my gender with the support of my PA is important both to my mental health and to my transition.

In an ableist, cisnormative and heteronormative society, identities were often hard-won and a source of pride and resistance, not peripheral parts of people's identities:

> I am a queer person. My gender and sexuality, along with general outlook on life, is inherently queer. My home, as the PAs' place of work, reflects this to a degree. It gives me a sense of belonging to have that validation around me. Important to feel safe in my home, without needing to hide or feel worried about any aspects of myself. Sometimes, they don't think it is important to care about my gender or sexuality, but it matters to me that they *do* see me and my body as non-binary.
>
> I am out to everyone because … life is too short not to celebrate the things in my life that are the most wonderful. I can't separate my queerness from other aspects of my identity and experience … dating women is just part of who I am, and I refuse to hide it.

There were examples of people being supported by their PAs to do things in LGBTQI+ spaces, for example, activism, community events, dating, pubs and clubs, and these are important to highlight lest the difficulties suggest that there are no important benefits for people in organising support that is empowering:

> My PA was delighted to come on Pride with me. My PAs, I'm very open with them about my orientation and about my gender. I need people to work with me that respect my independence and who are happy to see me participating in my community *doing things that enrich me*.

One of the interviewees who needed physical assistance with sexual activity spoke about how he managed to get support with masturbation. While he got support from some PAs with this, he only asked PAs he felt very comfortable with to the extent that had to plan ahead in a very unspontaneous way: 'You can't meet your needs whenever you want. You have to schedule it.'

Many interviewees talked about how good it would be if there were more LGBTQI+ PAs:

> I'd love to have one actually. I'd feel more comfortable; I could say whatever I wanted. They might even suggest places to socialise and stuff. It'd be good.

> Because for any package to work, the person really needs something a bit more than people just understanding or accepting. It would be really nice to be with people that just know what living a gay life is like or just feeling totally comfortable with somebody else. So, that would be really brilliant.

Support to manage processes and people: having to make bad bargains?

A model of support designed to be liberating was often hampered by processes that worked to do the opposite. The relative absence of good-quality and accessible independent support or brokerage to run direct payments and personal budgets had a detrimental impact. People said that they would welcome support with the practical organisation of funds, recruitment and so on, as well as how to navigate the personal and interactional nature of the relationship(s). Concerns were voiced and shared by disabled people generally given the sometimes-blurred boundaries of the relationship. Support to traverse this really should be in place if the overall aims of maximising choice and control for recipients are to work, summed up by one participant who said that 'Support from others would be empowering.' Others made similar comments:

> Managing that fine line between employer and friend, because it's miserable to spend time with someone that isn't your friend to a certain extent, but, at the same time, it causes a lot of problems when they're too much a friend. So, yeah, advice on how to manage that.

> Like, the council have basically given me no support and particularly things like managing PAs…. I'm like, 'I am a disabled 20-year-old. I don't know how to write a contract.' Some kind of support with the admin side of it is going to be quite helpful.

> We're not given that kind of learning; we're just expected to, 'Right, here's the money. You go and sort everything out yourself.' And that's why everybody's like, 'But if you go with an agency you don't have to do that.' And I'm like, 'Yeah, but if I go with an agency, I lose my independence.'

These aspects of inadequate support can at times speak directly to the 'complicating' issues of identity, privacy and risk of discrimination:

> I would love for my PAs to help me with that sort of thing, as I get very overwhelmed with it and find categorising things difficult. However, this means seeing personal details like deadname or medical records, which would out me. I therefore avoid seeking much-needed support from my PA with this.

> I find it very difficult to do management and stuff with somebody who's also doing your intimate personal care.

We came to think of some of the difficulties people faced as *bad bargains*, that is, tolerating or accepting, however reluctantly, that a combination of a lack of PAs, a relative absence of administrative support and the understandable concerns about prevailing attitudes towards 'non-normative' sexual and gender identities meant some quite serious compromises to the central tenets of having full choice and control about how support was organised and delivered. Some of these bargains seemed to us to be in quite violent opposition to the basic ideas and tenets of self-directed support:

> I feel a lot of shame, around my gender in particular. I often think about how much easier it would be as a disabled person hiring PAs if I didn't have this to contend with. This is a big reason I accept carers, etc, using he/him pronouns for me. I'm aware of how much easier it would be if I wasn't trans and queer when finding and training PAs.... When I am misgendered, I can struggle with correcting them because I don't want a debate or to have to give a lot of education in the moment, so *let it slide*.
>
> If I fire someone, I've got to have an alternative before I can do that. You can't just find people in two or three hours. It's meant I've had to put up with more bad behaviour if I hadn't had to think, 'Well what's the alternative?'
>
> I worry about losing otherwise good and valuable staff members if I am too open about my sexuality and gender.

Discussion

A central aim of writing this article is to locate the stories and experiences of marginalised disabled people using self-directed social care support within the academic social work and social care literature, and both of the studies included here are, to our knowledge, the first of their kind. Both studies worked in highly collaborative ways so that making sense of the data was a shared endeavour between academic researchers, representatives from disabled people's organisations and people with lived experience of the issues being explored. We recognise that the white bias in both projects is a considerable weakness and limitation and highlights an overall 'crisis of whiteness' in much of the health and social care research currently funded in the UK (Abbott, 2024). We should have attended to the central issue of ethnic diversity by engaging relevant community organisations from the outset rather than, as so often happens, approaching them near the end of the study to 'boost diversity', which is a highly problematic approach.

In the preceding sections that describe our research findings, we emphasised in bold certain text that highlighted the most prescient points we would want to make: 'it felt abusive'; 'an uncomfortable accommodation', 'secret cupboard', 'doing things that enrich me', 'bad bargains' and 'let it slide'. The promise of personalisation, real or illusory, is that it can set those who want it free from the whims and randomness of being supported by strangers over whom they have little say and less control. Living with a marginalised identity becomes harder and harder in the political times that we live in, and home should not be a place where these precarities are inflicted upon people or only averted by people subjugating their true selves, especially when navigating their sexual or gender identity may well have already cost them dear in other aspects of life and relationships. Here, we see too many examples of the operationalisation of the policy working in ways that control and oppress. Much of this is because of a significant lack of investment in advocacy and brokerage services and the hugely precarious situation of self-advocacy organisations and user-led organisations in the austerity decades. (Interestingly, research by Norrie et al [2023] with PAs found a strikingly familiar desire on the part of PAs who said they also appreciated being linked into brokerage and advocacy organisations where they could benefit from training and development opportunities.) However, there is also a range of attitudinal problems built into these processes. One of these is a suspicion that disabled people cannot really be trusted to spend the money 'properly' on approved activities, and another is that the disabled 'recipient' will not deviate from gender and sexual identity norms. Shortages around PAs speak to the ongoing crisis of the social care workforce, which is complicated by the dominance of private and profit-making providers of social care support and about which there is no political will. In their empirical work with both PAs and disabled people employing PAs, Porter et al (2022: 645) reflected on the risks of some disabled people reverting to agency-based care and support for negative reasons:

> A small number of disabled people in this study said that meeting the interpersonal demands of PA were simply too onerous, and, as a result, stated their preference for agency-provided care. This is deeply regrettable if such choices stem from a paucity of support, rather than an authentic expression of choice and control.… Support for disabled people and PAs must therefore be acknowledged, transparently costed and appropriately funded by state care settlements if the right to independent living is to become an equitable reality for all.

While the principles of personalisation emerged from the disabled people's movement itself, there are critiques of it as a representation of individualised neoliberalism in the social policy and social care system (Williams-Findlay, 2015) and as an approach suited only to a relatively small group of disabled people:

> This neoliberal 'will to empower' individuals, however, necessarily entails the assumption of the responsibilities and risks of purchasing and providing care. The development of personalisation offers an explanation: it was the outcome of an (unlikely) alliance between a neoliberalising welfare state and disability organisations adopting a civil rights-based social model of disability; significantly, a model developed almost exclusively by politically active physically disabled people. (Hall, 2011: 599)

The problems associated with the marketisation of social care largely fall to individuals to bear in the landscape of self-directed social care, and our findings echo those of the much larger national survey of PA employers:

> Direct payments and PA arrangements only work when there is a sufficient supply of suitable PAs in the market. If there is not, we not only have lost any 'choice', but we are left with trying to create a market that does not exist. This is very harmful and dangerous for individuals with direct payments. (TLAP and LGA, 2022: 10)

Control, it seems, is a precarious commodity, and we are even seeing some local authorities quite explicitly turn their backs on basic notions of independent living and equal rights (see Series, 2023; Ryan, 2024). In a section of their article headed 'Turning the clock back? Shifting power relations with local authorities', Pearson et al (2020: 291) view this regression as 'social work reasserting its power' and write: 'We were told about a number of cases which suggested a fundamental retreat from policy discourses around choice and control. At its most acute, examples were given where it would appear that the entire independent living philosophy had been rejected by individual local authorities.' It would not be the first time that principles designed to challenge structural inequalities have been co-opted by the neoliberal urge to maintain power. Here, we ask the troubling question about where choice and control are actually situated, and very similar discussions rage about the use of the term and the implementation of the idea of co-production, an idea increasingly hijacked to make ongoing power inequalities in social care (and indeed social care research) seem less unpalatable (Williams et al, 2020).

For those of us who remain optimistic about the potential of self-directed social care support, the ideological narrative and policy/practice reality that disabled people are lucky to have anything much at all is deeply worrying. The idea of 'being enriched', whether that constitutes a holiday to Florida or having PAs be completely on board with your gender or sexual identity, is increasingly presented as a lofty notion indeed. As citizenship rights get stripped away from disabled people (Morris [2016] is particularly compelling on this), sexual and gender identity rights are less well developed by comparison to other areas of disability rights claims (physical access, jobs, healthcare and so on) (Shakespeare, 2000; Shuttleworth and Mona, 2020). What our research shows is the possibility of support relationships that promote, what McLaughlin (2020: 398) refers to as, 'an ordinary, dignified life'.

How can change be brought about? Quinn (2009) argues for the potentially transformative power of legal rights, focusing particularly on the United Nations Convention on the Rights of Persons with Disabilities. However, legal frameworks are generally inaccessible to individuals given the immense time, energy and cost implications. One way of doing this, he suggests, is to support minority voices to become more prominent and to 'put the person back in the frame' in order to mitigate against their relative powerlessness. This approach may go some way to change shared beliefs about what is possible and desirable, and if beliefs are challenged, then the chances of changing practices are at least enhanced. A gradual acclimatisation to the new cultural values and norms could 'nudge meaningful change'. So, how can new values and norms be produced to 'put the person back in the frame'? One place to start is with stories and research data because, as Owen et al (2009) write, personal narratives help undermine stereotypes and bring lost or silent voices to the fore. Plummer (2004: 14) is an established exponent of the transforming nature of 'intimate stories' and suggests that the concept of 'intimate citizenship' links the public and private, representing 'the decisions people have to make over the control (or not) over one's body, feelings, relationships; access (or not) to representations, relationships, public spaces'. For stories to lead to change, Plummer argues that they need to persuade people that the storyteller and the listener occupy 'unassailable common ground' and that the effect of storytelling can disarm prejudice. This is not a task that should rest solely with disabled people themselves, and one of our findings spoke to a relative lack of solidarity coming from the non-disabled queer community. We are grateful to the people who shared their stories with us, and we hope to play our own part in effecting change.

Funding

The research in this article was funded by the National Institute for Health & Care Research (NIHR), School for Social Care Research. The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

Acknowledgements

We are grateful to all our research participants and collaborators.

Conflict of interest

The authors declare that there is no conflict of interest.

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