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Debilitating landscapes of care and support: envisaging alternative futures

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ABSTRACT

This paper explores the impact of policy changes and budget cuts on services and support faced by people with learning disabilities. Drawing upon collaborative research in England and Scotland and interviews with commissioners and support organisations, we show how landscapes of care and support are unstable and fragmented. We identify how pressures of time, resource and precarisation in the workforce are creating ‘debilitating landscapes of care’ that further erode the capacities of both the people that work in the sector and people with learning disabilities. Some challenges that people with learning disabilities face in this context include finding appropriate local support, narrowing access as a result of reductions in benefit entitlements and identifying quality providers amid a complex array of private and charitable provision. Capacity to cope with these challenges is contingent on access to quality advocacy, supportive family, friendships, productive occupational learning environments and peer support, but these are not always available. The impact of COVID-19 has only served to intensify some of the issues we identify and the urgent need for a response. Our analysis is inspired by Berlant’s (2007) conception of ‘slow-death’ and Puar’s (2017) associated conceptualisation of ‘debility’.

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Introduction

Over the past two decades in England and Scotland an increasing role has been played by the voluntary and informal sectors in the delivery of care and support provision for people in receipt of social care (Pearson & Ridley, 2017; Power, 2014). The governments in England and Scotland are now firmly positioning personalisation and community capacity as underpinning the future of care and support. This restructuring has resulted in a growing amount of social care taking place within community spaces, home space and in alternative third-sector locations, rather than within block commissioned, dedicated local authority spaces. Such de-institutionalisation and an enhanced role for the voluntary and community sector is part of the ‘community turn’ (Macmillan & Townsend, 2006). At best these changes may give people more opportunity for inclusion and more choice and control over

how they live their lives. However, changes to social care and support have occurred within the context of more than a decade of budget cuts under UK government austerity policy.

In this paper, we draw upon collaborative research in England and Scotland with people with learning disabilities and interviews with commissioners and support organisations. The research set out to explore the conditions under which people with learning disabilities can effectively build a life in their local community within the context of changes to social care and support. In other publications, we identify those conditions and the sorts of learning environments that are necessary to fulfil them (Nind et al., 2020). This paper focuses on the context within which people with learning disabilities, commissioners and support organisations find themselves having to navigate – an often unstable, fragmented and atomised landscape of care.

Landscapes of care and support

The phrase ‘landscapes of care’ has been used in diverse ways for the past two decades to help describe the varied socio-spatial variations in giving and receiving care and support (Gleeson & Kearns, 2001; Milligan & Wiles, 2010; Power, 2010). Geographers have utilised an array of metaphors to conceptualise the interactions between different elements of care and support. These include ‘care-scapes’ (Bowlby, 2012), ‘assemblages of care’ (Lancione, 2014) and ‘care ecologies’ (Bowlby and McKie 2019). Many disabled people express a preference for the term ‘support’ over ‘care’ because of the latter’s seeming associations with infancy, paternalism and dependency (Shakespeare, 2006).

In this paper, we use ‘landscapes of care and support’ as a socio-spatial framework to think through the overall pattern and qualities of the care and support landscape. This landscape tends to be relational (Cloutier et al., 2015) and intercorporeal (Macpherson, 2009), for care is rarely one-directional, rather it often involves interdependent, inherently co-constitutive interactions with people, places, institutions, communities and environments (Bondi, 2008). This means that social care users cannot be understood as navigating a static landscape of care ‘surface’, rather we understand that individuals, supporters and their support organisations are together (potentially) co-producing that landscape, and are situated within a constant process of ‘becoming’ in relation to each other and the structures of care and care finance that they must navigate. For this reason, we avoid using the term ‘care market-place’ because we found that all areas were operating on a mixed model of funding with some local authority provision.

We chose not to describe arrangements as ‘assemblages of care’ (Lancione, 2014). The reasons for this conceptual stance are pragmatic, strategic and political. Firstly, the ‘landscapes of care and support’ metaphor is accessible and helped the research retain a relevance and utility to the interdisciplinary team, third-sector audiences and existing policy making communities. Secondly, through this participatory research, we were consciously enacting a form of Disability politics by prioritising the voices of people with learning disabilities over their care or support workers. The intention here was to spotlight their stories and involvement in navigating and constructing new care and support arrangements. Thirdly, we chose to centre our original research on particular human actors (commissioners, support organisations and people with learning disability, which involved a focus on a particular kind of agency within a landscape of care and

support, at the cost of marginalising other possible human and non-human agents [present in an assemblage]. This means, of course, that certain relations and agents are left un-examined here; we have chosen a degree of strategic essentialism, over complexity (Macpherson, 2011). We have not, for example, examined in any detail the important role that buildings may have played in re-producing certain care–relations, where a transition from day service to community interest company took place within premises; nor have we explored in detail the role of parent carers in transitions to new support arrangements (see Turnpenny et al., 2020).

We use the concept of debility and debilitated landscapes of care and support through the analysis to emphasise the wider contextual and structural forms of suffering that affect those involved in giving and receiving social care. This analysis is inspired by Berlant's (2007) conception of 'slow-death' as the 'physical wearing out of the population' (p754) and Puar's (2017) associated conceptualisation of debility as '... endemic, perhaps even normative, to disenfranchised communities: ... not exceptional, not that which is to come or can be avoided, but a banal feature of quotidian existence that is already definitive of the precarity of that existence' (p17). Puar (2017) sees structures of inequity as promoting debility with the compounding of disability and poverty into a 'field of debilitation'. The concept of debility is useful to invite a consideration of what is held in common across landscapes of care and support by a multitude of actors.

The landscape of care and support in the UK has changed significantly over the past decade. There have been reductions in the provision of local authority-run day services and large institutional provision, with a move to outsourcing of care services and more market-led provision (Pearson & Ridley, 2017). Between 2009/10 and 2018/19, the number of jobs for care workers in the independent, charity and private sector increased by 29.7%, while the number working directly for local authorities fell by 37.4% (Fenton et al., 2018). This change must be understood as a part of a longer trajectory linked to the neoliberal project from the 1980s which saw the emergence of the 'shadow state' (Wolch, 1990), triggered by the rise of a contracting culture which fundamentally changed the relations between the voluntary sector and the state (Owen & Kearns, 2006). The deepening of this trend from 2010 increased expectations over service delivery from the voluntary sector. However, this does not mean that the voluntary sector has become entirely subservient and co-opted by the state. DeVerteuil, Power and Trudeau (2020) show how voluntary sector organisations can be 'mediating actors' which can develop their own localised agendas. This work acknowledges the 'politics of possibility' that exists (Elwood et al., 2017,746) within the re-structuring of service delivery. In our paper, we show how the limitations placed on the voluntary sector and commissioners shapes the potential for them to exercise such possibilities.

From 2008, there has also been a growing emphasis on personal budgets in adult social care, reflecting a push by the UK government to instil concepts of personalisation (in England), self-directed support (in Scotland), and establish market-led provision at the heart of services. Uptake of these approaches has varied between local authorities. With personal budgets (money allocated by a local council to pay for care or support to meet assessed needs) still only making up a minority of the provision for people with learning disabilities in the UK. There were 40% of people aged 18–64 with a learning disability receiving a direct payment in 2016–17 (National Audit Office,). However, even when there is no personal budget, personalisation ideology is present (Power et al.,

2020). Significantly, people (and thus providers of care services) are receiving personal budgets that cover a lower level of day support than was previously being given and funding to support people with disabilities is no longer aligned to their care needs (Malli et al., 2018).

The changes to care and support outlined above follow a series of relatively recent policy developments, starting with Putting People First (2008) and culminating in the Care Act (2014). For example, the Care Act statutory guidance (2016) encourages professionals and citizens to share power to design, plan, assess and deliver support together. Similarly, NHS England's (2014) Five Year Forward View refers to the need to 'harness the renewable energy in communities' in new ways. A similar approach to service delivery focusing on community capacity and co-production has been adopted in Scotland with the Social Care (Self-Directed Support) (Scotland) Act (2013) providing opportunities for people with learning disabilities to access support from a range of providers and to develop capacity to co-produce new services. Services had been very institutional and rigid before this, which justified the aspiration of person-centred care. This may have been what Pearson and Ridley (2017) refer to as 'the right plan at the wrong time'.

The move from institutional funding to personalisation at best offers disabled people new ways of purchasing support and the chance to choose from a range of services and activities in their local community. For example, people can pay for support to access mainstream services such as local leisure centres, community clubs, attending classes and training opportunities or specific project-based initiatives (e.g., arts-based workshops; community gardening or dance/drama). However, people with a learning disability in England are less likely than other disabled people to report that there has been a positive change for them (House of Commons, 2017).

The personalisation agenda occurs amid wide-ranging cuts to local authority budgets during the past decade 2010–2020, alongside substantial changes to the sector including the privatisation of the care workforce, marketisation pressures on care providers and wider damage to social infrastructure. Between 2010 and 2015 services such as 'supporting people' (discretionary social care with a preventative or enabling focus) have seen cumulative cuts in the order of 45%. The most severe cuts have been in urban areas with 'the most deprived areas' social care spending (combining all children and adult services) found to have also fallen by 14% (see Hastings et al., 2015). Since 2015 we have witnessed further cuts, and local authorities are now absorbing the additional financial impacts of COVID-19. This intensifies social inequalities and increases inequality between local governments themselves (Gray & Barford, 2018). Such cuts have also resulted in a 'redistribution of societal risk' with responsibility for dealing with social risks increasingly placed with individuals, their families if available, and communities regardless of their ability or capacity to absorb them (Asenova et al., 2015). The outsourcing of risk and responsibility is very significant for people with learning disabilities, particularly when placed within the context of other changes that shrink the public sector and the capacity of local authorities to provide for the basic needs of their citizens.

Research methods

This paper has been developed from co-produced interdisciplinary research with people with learning disabilities in England and Scotland. It represents part of a two-year study which explored how adults with learning disabilities, with the help of others, are building their daily lives when responsibility for daytime social care and support is handed to them. Our research team was made up of researchers from Geography and Education interested in recent changes to care and support, and the informal learning opportunities (including peer-to-peer learning) embedded within such change. Our research team also included three advisory groups (one in England and two in Scotland). These advisory groups met regularly on a bi-monthly basis and included members of the research team, people with learning disabilities, their advocates and other representatives from support organisations.

We conducted focus group and interview research with 43 people with learning disabilities (24 males and 19 females aged 18–70, the majority aged 25–54), 39 people working in support organisations (within 29 different organisations) and 7 local authority staff, including 5 commissioners. The research was carried out in four case study areas (two in England and two in Scotland including an urban and a rural location in each) where there have been significant changes in the provision of care and support. Working with people with learning disabilities (and their advocates where appropriate) we used photo-voice techniques, and supported participants to produce weekly timetables and support circles to visualize and articulate experiences of care and support in interview and focus group settings. We did not cover precise support packages and benefit entitlement as an interview topic with people with learning disabilities. This was because we were interviewing at a time when many people were experiencing changes in their support arrangements and day service closure meaning the topic had the potential to raise significant anxiety and possible confusion over our purpose and role. Therefore, the interview material below must be read within the more general context above.

This paper focuses on the interview material and field notes from the research, because this is where the issues identified above were most apparent. A sample of five qualitative interviews were initially read by the team, discussed and hand coded. Then, the full sample were read, coded and re-coded using NVivo v.12 by at least two researchers from our academic team in order to identify the dominant themes and draw out the important ‘building blocks’ that are required for people with learning disabilities to self-build a life in the current context. For the purposes of this paper, the lead author then re-read through all 39 support organisation and local authority interviews to explore the wider narratives that they contained. Ethical approval was granted by both Universities involved in the research.

Research findings: navigating a debilitated landscape of care and support

In the following sub-sections we outline some of our empirical findings. Firstly, we identify how landscapes of care and support are unstable and fragmented. Secondly, we explore how individuals with learning disabilities are navigating those landscapes both physically and online and the impacts of changes in support arrangements. Throughout we emphasise some of the debilitating experiences that

are held in common between people who work in the sector and those who are supported by it.

Pressures of time and resource are creating unstable landscapes of care and support

What was immediately apparent in this research was the pressure affecting care and support organisations in England and Scotland and individuals working in them. At all levels of the support organisations, we interviewed and encountered, from managers to local authority commissioners and individual support workers, it was evident that a pressure of time and resource was being felt. Cuts to services and support had had much wider impacts than just those directly in receipt of them. For example, many charitable and advocacy organisations that we approached to be part of our advisory groups struggled to lend time for this research, rather we tried to pay for staff time through our research project budget. We also noted how as researchers arriving at support organisations we were looked upon as symbols of hope and optimism (as if we might hold the solutions and the finances) (Macpherson, 2019). Furthermore, the support and advocacy organisations we were working with were operating within a context of significant uncertainty about where the next contract was coming from or the next charitable grant (see also Horton, 2016). During the course of our research, a café that supported people with learning disabilities into paid employment closed due to financial issues, despite being heralded by the local authority team as exemplary. Anxiety around finances and sustainability was palpable across the research sites and often represented a dominant thread amongst interviews with supporters and support organisations (n.b. all names of individuals and organisations have been changed). For example, when Casey (the manager of a support organisation for people with learning disabilities) is asked about the user-led nature of her organisation, she starts by explaining the limiting nature of the funding context:

The climate has changed significantly in the last five years . . . local authority grants, they're much harder to get . . . which means that charities are going for the same funders, so that's increasingly competitive. What we're developing right now is a mixed model of funding. So we're recruiting for a deputy manager as I speak, so it enables me to do more of the business development side of things, because that's going to be key to how we continue [to be] sustainable' (Casey, Manager of Support Organisation)

She went on to explain how it was hard within this context to always be fully enabling of the people with learning disabilities that they work alongside (for example, by recruiting an additional deputy manager with a learning disability), because that takes time and resource away from applying for more time and resource. This results in frustration and a lack of stability and uncertainty for those in receipt of care and support and for employers and volunteers themselves.

Some commentators have argued that sustained social care budget cuts under austerity policy will result in innovations in the sector (Diamond & Vangen, 2017). However, we found that largely this was not the case and where innovation was occurring it needed more fertile ground. We found the local authority sector

interpreting the mandate to promote ‘independence’ and ‘skills’ as a way to justify staff cuts. Here, the creativity that austerity supposedly brings is forcing thoughts around how to cut staffing ‘on the ground’:

We need to try and be cost effective within the packages of care and we’re being quite creative in how we do that, so we’re looking at really maximising use of telecare options. So how can we support people to be more independent, and support their skills to use certain types of kit? We’re looking at things like sprinkler systems because ... the individuals don’t have care needs at night ... (Commissioner)

In the example above, changes in the care marketplace, austerity and associated cuts to local authority budgets have forced commissioners to think ‘innovatively’ about how to cut the care workforce hours they are paying for. Unsustainable funding contexts mean the landscape of care and support for people with learning disabilities *is actively debilitating* – weakening the capacity of both people with learning disabilities and their support organisations. In the following sections, we explore these issues further.

A precarious, poorly paid work force undermines the ambitions of personalisation

Another layer of instability within a debilitating landscape of care is the precarious and poorly paid workforce. Contracting results in insecure employment within organisations in receipt of contracts. Furthermore, it is well recognised that in the United Kingdom the adult social care sector now has a significant and growing problem with recruitment and retention with poor pay and conditions exacerbating this problem. For example, one in seven are on zero-hour contracts and there is a 28.7% annual staff turnover rate (see Kings Fund, 2019, p. 117). A support worker’s actions can be key to realising the potential of people with learning disabilities, but the role is often underpaid. During the course of our research one commissioner explained to us:

You know, we’ve continued to increase our rates, but ... there’s so many other work opportunities around the area in (coastal town) and people will go, “I can earn better money doing less responsibility, doing some other thing” (Commissioner)

A precarious, poorly paid care workforce with limited training, and high turnover cannot support the stated ambitions of the personalisation agendas identified above, rather it is weakening people with learning disabilities. As Lauren explained to us:

My support workers, they would ask me what I wanted to do that day ... we would go to the café and they would talk to each other and not talk to me and I felt like a spare wheel ... so one day I just got up and walked out of the café (Lauren, Person with a learning disability)

There is a mismatch between the policy ideal of personalisation, the aspirations of people with learning disabilities to do meaningful activities/work, and the possible delivery mechanisms available. Lauren’s experience is just one example of this issue. Commissioners are aware of the problems but within a limited funding context they struggle to do anything about it. One ex-commissioner we spoke to during the course of this research had left the role because of the frustrating nature of these issues. It was evident from other interview encounters that commissioners were worn down (albeit in a different and less life-limiting way than those people with learning disabilities). Another commissioner explained:

You've got quite a lot of people who have 24-hour support packages with support workers at home but don't do anything structured with that time. So there's paid worker time probably for five days a week and they're not necessarily doing what I would consider to be good paid structured activities around volunteering or paid employment or even just leaving the house, ... So that's been a definite weak spot I think. (Commissioner)

In many areas there is little joined up thinking or assistance for people with learning disabilities to recruit the right support workers and broker those arrangements. Thus, both people working in the sector and those who are supported by it are encountering experiences of constraint and debilitation. People like Lauren have felt let down by their support workers and other support workers and commissioners are experiencing 'burn out'. Since this interview Lauren has chosen to employ family members themselves in the support role rather than pay for someone outside the family; however, this is not an option open to all.

Fragmented provision and narrowing eligibility meant some people lacked access to services

Choice is promoted under the personalisation agenda; however, some areas we researched were particularly underserved; not only was there no choice, in places there was no appropriate local services whatsoever. There were gaps in provision for specific user groups with complex needs, for those deemed too able to receive support but who were unable to access work, and for particular age groups. Individuals we spoke to found themselves at groups targeted at younger people or at the local day service just because of a lack of alternatives. For example, Sarah explained to us 'I don't have much friends [in the area] and there's nothing to do [laughs] [...] That's why I told my mum I want more stuff to do'. Helen also told us about her day service she attends five days a week 'I don't like it here at all [...] I want to get out of here. But I'm afraid I'm stuck, I have to stay here. I've got nowhere else to go.' People with learning disabilities cannot realise their potential if there are no options available to them. Ailish, a community worker from 'Connecting Communities', a not-for-profit social enterprise explains, 'There aren't the choices available in the area for people to spend their money, whether their money is Direct Payments, personal health budget or self-funded.' (Ailish, Connecting Communities). When Senior Social Care Officers in local authorities were asked about community-based services in the area, they were also aware of, and frustrated by, the issues, explaining '... there's not a lot out there, employers or, well, just anything in general. The community's not ready for it ...' (Senior Social Care Officer).

In addition to the fragmentation and absence of appropriate services identified above, support organisations and local authority employees explained how people with more complex needs or behaviour which challenges have a particularly difficult time finding services locally to support them. This was the case even within our two urban case study areas (where there are more social enterprises and private providers to choose from). This meant that some people with learning disabilities were unable to find community placements and were instead stuck at home primarily reliant on parent carers. We spoke to a parent carer who felt her adult child had been 'abandoned'. She explained how care workers 'choose easier jobs' than her adult child (who had behaviour which challenges) so she could not find a suitable personal assistant. She explained how she ended up doing an

80 mile each way trip once a week to the service that would take her adult child. She did not want her daughter back in a 'secure' residential facility, but she was struggling in the community, could not find local appropriate services and needed respite (n.b. this data was from our observations rather than a formal interview). Commissioners were aware of gaps in provision. When asked if there were any particular omissions, one stated:

I think one of the main gaps for us is that no one particularly wants to support those people that have got more complex needs, so you know, you've still got a gap in provision in the city for people either with, mainly autism and challenging behaviour, so again ... we've got all these great services in and around the city but no one can take this person (Commissioner)

Supporters of people with learning disabilities also spoke of the difficulty of finding things to do in the mainstream community that were appropriate for those with specific types or levels of impairment. For example, support organisations described how an event promoted as 'autism friendly' was appropriate only for those at the milder end of the spectrum. Furthermore, people with complex needs or with behaviour that challenges often require staff that are known to them; however, community-based support was often experienced as more transient and unreliable compared to day service provision. For Charlotte, manager of an advocacy organisation, the changes in service provision brought some even more concerning possibilities that highlight how cuts and privatisation are disproportionately affecting those who lack support and advocacy:

I think the biggest risk in all of this is that people become invisible and with the transition from having residential homes to small individual flats, with domiciliary care going in and out, people are becoming more isolated ... less networked, the service is becoming sort of private, very variable in their quality and their ethics ... We need to know about people, not have them sitting in a little flat having their services taken away. I worry about people with learning disabilities who don't have families or don't have outspoken families. I think if the social worker needs to cut their ... spendings ... then what's the incentive for say a really hard-pushed social worker to call an advocate to oppose them and to speak up for that person? (Charlotte, Manager, Advocacy Organisation)

Lack of visibility is a significant outcome of the outsourcing and cuts described above, however the policy intentions were for people to be out in their communities more, not less. For example, Care Act (2014) Statutory Guidance states a need for 'active involvement in their local community'. In this unstable, fragmented, landscape of care it clearly can take a great effort to get out into the community and get what you need. Advocates, family, supporters are essential to making this happen. The experience of this fragmented and unstable landscape of social care is very uneven. Not everyone with a learning disability experiences it in the same way, some can build a good life (there are pockets of promise) and those with enough capacity (advocacy, support, the 'right sort of learning disability', networks, opportunities, social and cultural capital) can exploit these.

People with learning disabilities involved in our research expressed a desire to work, wanted greater opportunities to work and be a part of user-led organisations. As eligibility rules are tightened, many people with learning disabilities are now not entitled to support or have had significant cuts in their support from services, so occupy an 'in-between' space – judged to be 'too able' to receive care/support, but without the necessary skills to gain employment or get involved in mainstream college or community activities (see also Hall & McGarrol, 2012). For example, Annie lived fairly independently in her own flat

within some newly built, private sector 'supported living' accommodation. This accommodation had no communal spaces, no lift and the experience of it seemed quite isolating for her as a young wheelchair user. She did not have any supportive local family but had day service provision three days a week. The following interview exchange illustrates some of the challenges for her on the four days when she is not attending funded services;

Q: Do you get out of the house much?

A: Not really, no.

Q: Any sports, go swimming or-?

A: Well I need to start going swimming actuallyBut the trouble is, there's not enough people for me to go swimming with ... E has got an injury, and R is actually busy at the other houses, so it's quite difficultand I need someone that can actually take me swimming ... swimming is actually good exercise for me, it loosens my muscles.

Q: So when did you last go swimming?

A: Oh god, I was going to say a long time ago ...

Q: I'm really sorry that that's not happening for you at the moment because that sounds really important ... And Saturday and Sundays apart from that what would you hope to do?

A: [Sighs and pauses] Go out more. ... [Then later in the interview] I'll tell you what I want to do, I want to start to look for a job role [laughs], any job, any job that is actually suitable for me.

We found commissioners in local areas had limited capacity to support the community initiatives that would help people like Annie. Little attention was paid to potential seed funding for friendship groups or social enterprise development that might help to address such needs. For example, one commissioner explained to us how:

Most of our funding is meeting our statutory duties ... we still have support services for those below care eligibility that help keep a number of people ... secure in their tenancies, food in their cupboards ... we continue to protect them knowing that- ... if you take them away, they'll be knocking on your door six months' time with a much higher need. But the focus is really on-, most of the time is on those people that ... do meet eligibility ... and trying to make sure we can manage those in affordable way. (Commissioner)

Despite these challenging circumstances, some people with learning disabilities are building a life in the community effectively. Our advisory group members and research participants described the importance of peer support initiatives and social enterprises that they could regularly go to, to work or meet friends. One good example of this was the Bookshop Project which supports over 60 people with a learning disability to gain skills and experience in customer service, selling used books and CDs. The project runs a peer-mentoring scheme to support new arrivals, fostering informal learning and peer support between people with learning disabilities. This occurred with the help of small grants from a range of charitable trusts and donations – typical of the sort of mixed funding model we have found across the sector. The funding now pays for the managers' full-time salary, a part-time support worker and rent for the building. The volunteers with learning disabilities now engage with members of the community on a regular basis – talking to customers, selling books and engaging in fundraising activities on behalf of the organisation, but due to a reliance on short-term charitable donations and grants continuity of funding was far from certain.

Sustaining community facilities, volunteer centres and hubs like the Bookshop Project where people can network, identify opportunities, look out for each other and skill share is essential for a positive landscape of care and support to be realised. However, commissioners felt relatively powerless to support such important initiatives, because of the imperative to focus on those most in need. One explains:

Before we can balance our budget in February, we're still looking at £11 million worth of savings to find. Some of that will come later . . . But it's very difficult then to go, "I just want a little bit of money 'cause I want to do some [pump priming] around social enterprise development." It's really hard to do that, really hard to do that.

This absence of material and financial support for small social enterprises, community interest companies, friendship groups, peer support and other preventative, community-based support (which is supposed to be the future of care according to the policy rhetoric) is very significant.

As much as we would want to be trying to support people away from day services into opportunities to sort of work, financially that's becoming more and more challenging. It's an area that's not statutory for the Local Authority, you know, in these cost-saving times . . .
(Commissioner)

Navigating a new social care landscape: contemplating a move to personal budgets

Given the wider contexts outlined in this paper, it is unsurprising that some people with learning disabilities and their supporters are resisting moving to personal budgets. There was a general fear that any attention to benefit changes might ultimately result in cuts to service entitlement. In some instances support organisations also described the high expectations placed on parents to manage payments (shift patterns and multiple care workers) and regional variability in support to manage payroll, employee relations, etc. The supposed 'freedom and choice' of moving to personal budgets appears in reality to be (for some) 'a burden not worth contemplating'. For example, Angela and Sandra at the Castle Hill Resource Centre identify in relation to self-directed support that:

It's only just now that you're starting to have good practice examples that alleviate some of the anxieties for parents and carers, 'cause they're seeing through other people that it can work. But they're also seeing the downside where providers, you know, the continuity of staff are maybe different . . . we did a big consultation . . . and the main focus wasn't about, you know, whether or not they were meeting their outcomes of having a variety of activities, it was health and safety . . . [and] . . . you know, if so-and-so's off sick, they're still getting their service . . .

Small organisations and personal assistants purchased through personal budgets can be in a better position to tailor support, personalise care and enable people to learn to safely take risks. However, questions of consistency and reliability of such alternatives were identified as issues that prevented a move to self-directed support. In these instances, there seems to be a genuine tension between the interests of parent-carers and those they support and unintended consequences of diversifying provision. The benefits to people with learning disabilities of variety and stimulation (that are potentially achievable through devolved services) may conflict with the need for reliability –

to know that the person a parent-carer supports is occupied for long enough periods to make working possible (9–5 not odd hours). Self-directed support often relies on the unpaid labour of family members for transport to placements and to fill gaps in care between placements, and this additional labour is clearly gendered. Further, building-based services provide a point of contact for carers, regular contact with a group of peers and colleagues for staff members. Overall, devolved services result in a loosening of ties between families and providers, weakened communication and a loss of *relevant* community for *both* staff and those who are supported. The landscape of care was not only fragmented, it was atomised. In two of our case study areas, there were friendship groups operating that helped ‘fill the gaps’. However, local authority funding was not ring fenced for these important sources of support and in one other of our four case study areas funding had recently been withdrawn for such social groups.

Friendship groups were also found to be a good place to share and compare information about different local providers. This was important because it is not always clear who the quality providers are. Online there is an abundance of information about care and support organisations, however, this information is not always up to date, appropriately tailored to its learning disabled audience or even representative of the lived experience of those in the organisation. When asked about sources of information for small-scale providers that people can find, one supporter explains to us ‘There are so many directories, it’s–, and they’re all disjointed, no-one seems to know exactly which one’s best to go to’ (*Ailish, Connecting Communities*).

An organisations’ public face (social media appeal, web pages, marketing) may differ significantly from the quality and service found ‘on the ground’. In the case of two day services this ‘look versus experience’ issue was very evident. The language on the website and marketing material sounded user-led but the experience was not. One area’s local authority put on an annual in person event to showcase options, particularly targeting those in transition from college. However, the challenge of choosing the right providers has also moved online, with an increasing presence of small providers and micro-enterprises on social media and increasing use by those with mild-moderate learning disability of social media platforms. It was observed how being assertive seems to be an essential skill to navigate this new landscape of care.

Younger people do appear to be more assertive and know what they want, where people maybe about my age that maybe had gone through the care system might be slightly more reticent or not as confident, just because of the environments that they’ve been brought up in. (Ellie, Person with a learning disability)

One private provider was even putting on a festival to attract clients. The operations manager of Evolve, a day service, told us that they had been running for two years and explained that she was also a trustee for ‘Evolve Fest’ a charitable wing of the private enterprise that provides a music festival to help attract clients. This may appear superficially to be a good thing. However, this service was not user-led in a meaningful way and it is not clear how people with learning disabilities and their supporters navigate this complex arena of private and charitable provision. Equipping people with learning disabilities and their supporters to navigate this new landscape of provision or recruit appropriate PA support is key. For example, one of our case study area peer support

groups was funded by the local authority to provide a quality checking and reporting service.

Conclusions: envisaging alternative futures

In this paper, we have shown how landscapes of care and support in England and Scotland are fragmented, unstable and unable to support the stated aspirations of the personalisation agenda. The twenty-percent cuts to local authority budgets that are anticipated in the wake of COVID-19 will only further exacerbate these problems. Personalisation policy puts an emphasis on placing choice and control at the centre of people with learning disabilities' community lives. However, this vision cannot emerge without significant government investment and support in the network that surrounds each person. The notion that communities will simply 'host' people with learning disabilities without investment and that free 'community assets' will underpin this is unrealistic.

The concept of debility has been useful to invite a consideration of what is held in common across landscapes of care and support by a multitude of actors. We found an erosion of capacity and experiences of fatigue across the sector. Local authority cuts have resulted in the erosion of public sector services and the sorts of 'community assets' that personalisation and self-directed support policies are supposed to rely on. Shildrick (2019) observes that such 'structural organisation of social and economic relations under capitalism produces debility as its by-product in the very material sense of exhausted bodies and minds' (p600). This exhaustion was very evident amongst support organisations, local authority employees and commissioners as they faced new pressures of time and resource. We found the conceptual move from disability to debility and from disabling to debilitating, useful in this analysis because it helped to highlight that changes in care and support have resulted in forms of suffering, frustration, exhaustion and disillusionment across the sector. Unlike Puar (2017), however, we do not wish to disavow the utility of Disability as a term, the concept of disabling socio-spatial arrangements or the crucial political gains of disability activists in their focus on minority politics still maintains currency. We recognise the useful specificity of these approaches.

Like Puar (2017) we see structures of inequity that promote debility and compound disability and poverty into a 'field of debilitation' experienced by support organisations, people with learning disabilities, carers and commissioners. Cuts in local authority run day services, patchy charitable provision and an emerging care marketplace has resulted in an atomisation and wearing down of supporting organisations, gaps in provision and a lack of sustainability. We used the phrase 'debilitating landscapes of care and support' to represent the extent of this issue. Our findings suggest that there is limited scope for a 'politics of possibility' or a mutualistic relationship between local authorities and voluntary sector organisations in this context (Elwood et al., 2017, as cited in DeVerteul, Power and Trudeau, 2020: 931). Rather, both occupy a debilitated and debilitating space.

Personalisation and the marketisation of care places an increasing responsibility on individuals, which deepens inequalities. Opportunities available to people with learning disabilities were dependent not only on their locale, but also on the resources, capacities (and even existence) of people, advocacy and support networks. This results in unequal benefits of the personalisation agenda and a weakening of the capacity of disadvantaged

people with learning disabilities to build a good life. We found that 'high quality' opportunities for people with learning disabilities, that provided an environment where people could learn, develop and have a say in the running of their support organisations, were very limited, over-reliant on a few good citizens and often insecure in terms of continuity of funding streams (Power et al., 2020)

At the outset of this research, we thought that this landscape of care would also differ significantly between the two nations. Earlier research in this field had pointed towards Scotland's apparent rejection of the 'personalisation' model dominant in England and other neoliberal welfare states (Hall & McGarrol, 2013). However, adult social care services have been significantly cut in Scotland as well. Policy ambitions focused on 'co-production' have been compromised and put into place in an era of austerity (see also Pearson et al., 2018). Across the study, many people with learning disabilities revealed to us how they struggled to find appropriate support. The policy idea was that 'community assets' underpin delivery of the personalisation and self-directed support agenda. However, this assumes that community opportunities are free and freely available – that there is a reserve of existing community assets and 'renewable community energy' locally available to support people with learning disabilities in their communities. Our research found that this was not necessarily the case and that opportunities were often very limited in England and Scotland.

The experience of people with learning disabilities within this debilitated landscape of care and support is very uneven. Some people with a learning disability we spoke to showed us how they can build a good life and those with enough capacity (advocacy, support, the 'right sort of learning disability', networks, opportunities, social and cultural capital) can exploit these advantages. However, there is significant variability in provision and a retreat by some commissioners and other local authority employees to focus primarily on cost-saving measures and solely those people with learning disabilities deemed most in need. This means there has been limited realisation of the policy ambition of choice over care and support. Those people with 'behaviour which challenges' or other specialist requirements might find themselves having to travel a long way or moving regions to find the right support. Meanwhile, those who just needed a 'bit of a helping hand' are often being overlooked.

As eligibility criteria is set at 'critical' and 'substantial' levels of need, many people with learning disabilities occupy community spaces. It is very hard to build a good life in the community if there is not a suitable social infrastructure, and opportunities and advocacy available. This lack of social and physical infrastructure is what Shaw (2019) has referred to as the 'slow uricide' of austerity – where public institutions, social housing and other common spaces are eroded. This disproportionately affects people with learning disabilities and other groups that rely more heavily on public sector spaces and provision. This combined with a reduction in both informal and formal care and support structures across the UK, has resulted in less choice and weakened control for people with learning disabilities. This fragmented, unstable and debilitating landscape of care and support is worthy of further research, including a more comprehensive geographical consideration of major gaps in provision.

Certainly, peer support, care co-operatives and friendship groups should be integral to the delivery of personalisation and self-directed support. The role of personal assistants, care workers and small support organisations is also a key to delivering positive changes

in this new landscape. There needs to be new ways of forging long-standing friendships and community, with networks established in every area for both workers, small organisations and those supported by the sector, and not subject to the levels of regional variability currently evident. Whilst this need for networks, supported employment solutions and friendship groups is recognised in the rhetoric of associated policy documents, it is not given ring-fenced funding to facilitate delivery. Our interest in such collectivist solutions does not mean we are proposing a return to large institutions, or wholly public sector funded care and support arrangements. Rather, we think that for people with learning disabilities to live a fulfilling life a nuanced approach needs to be taken that recognizes the value of collectivist solutions and acknowledges the needs of all those that work in and are supported by the sector. This includes more money flowing directly to care and support workers in the sector to aid retention, through care co-operatives and other micro-enterprises. Furthermore, commissioners need appropriate budgets and real power to steer more radical change in what is funded and incentivised (advocacy, community brokers, small support start-ups, friendship groups) and changes to the care market (care workers co-operatives, support for CICs, further reductions in funds and closures for unprogressive care, work and support solutions). Otherwise, people with learning disabilities, commissioners, support organisations and care workers in the sector will continue to be saddled with a debilitating landscape of care.

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