Covid-19 and the Crisis in Social Care: Exploring the Experiences of Disabled People in the Pandemic

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Governments across the world have been slow in reacting to meeting the needs of disabled people during the pandemic. This has exposed existing inequalities in social policies, as well as new support barriers. Debates over social care have focused on Covid-19's impact on those living in residential care. Little is known about the experiences of disabled people who rely on daily support in their homes.
This article reports on a year-long study examining the experiences of disabled people during the pandemic in England and Scotland. It focuses on the crisis in social care and offers evidence of how lives have been disrupted. For many, this resulted in a sudden loss of services, delayed assessments and break down of routines and communities. Findings underline the weakness of social care in its wider relationship with the NHS and show how the social care crisis has challenged the goal of independent living.

Keywords: Covid-19, disability, social care, domiciliary care, home care.

Introduction

Governments across the world have been slow in reacting to the needs of disabled people during the Covid-19 pandemic (Jalali *et al.*, 2020; Kavanagh *et al.*, 2020; International

Disability Alliance, 2021; Shakespeare *et al.*, 2021). The pandemic has exposed, and, in some cases, amplified the existing inequalities in social policies and wider structures, as well as highlighting a new raft of barriers in daily support. In the United Kingdom, the *Coronavirus Act (2020)* and the *Coronavirus (Scotland) Act (2020)* formed emergency legislation that enabled the Government and the Devolved Administrations to develop services and respond to the emerging crises. Among its powers it included the capacity to suspend the provisions of the Care Act (2014) in England and Wales; and in Scotland, it removed the duty of health and social care partnerships (HSCPs) to assess need (Scottish Government, 2020).

From the outset of the pandemic, it has been clear that its impact on the lives of disabled people was going to be profound. Early data from Italy and from China suggested that Covid-19 was much more serious for those with a pre-existing condition (Chen *et al.*, 2020). Disabled people faced a 'triple jeopardy' of higher risk from death, reduced accessibility to health and social care services and the additional impact of social barriers (Shakespeare *et al.*, 2021). To date, most of the debates over the role of social care in the pandemic have focused on Covid-19's impact on those living in residential care homes (Daley, 2020; Glasby and Needham, 2020). Policy responses have largely ignored the experiences of those receiving domiciliary care, even though in England during the early weeks of the pandemic, deaths of recipients of domiciliary care were 1.7 or 1.8 times the usual for this period (ONS, 2020). The home care sector itself is nearly twice the size of residential care, with around 900000 in receipt of support (Holmes, 2016). The rise in deaths among those receiving domiciliary care was similar to home care residents, but received less coverage (Glynn *et al.*, 2020).

The workings of this sector were not fully understood – for example, it has been suggested that those modelling the impact of Covid-19 on disabled people were unaware that workers in this sector might visit multiple disabled people on a daily basis, with many receiving support from a number of different staff (Glynn *et al.*, 2020). As Glasby and Needham (2020) note, domiciliary care – despite supporting more people than in care homes – has largely been ignored from discussion. It failed to even feature in policy discussions about social care during the pandemic: this underlines both its marginal presence and the lack of available data.

In an attempt to bridge this data gap, this article draws on findings from a UKRI funded study which examines the impact of Covid-19 on the lives of disabled people. It presents a wealth of qualitative data about disabled peoples' experience of social care during the pandemic. Drawing on a series of interviews with seventy-one disabled people across England and Scotland and twenty-eight disability organisations, the study unpacks the impact that the Covid-19 pandemic has had on their lives, focussing in particular on the provision of domiciliary care. This is explored through three main themes. Firstly, we examine issues around the negotiation of risk. For many disabled people, the onset of the pandemic in March 2020 brought with it an abrupt change in daily routines and interactions. As the UK entered lockdown, disabled people and their families were left to make fundamental decisions about accessing personal protective equipment (PPE), who should enter their homes, how they could keep safe and what they would do in the event that they or support staff became ill. This links to the second theme about how individual support systems responded to the crisis. For many, this resulted in a sudden loss of services, delayed assessments and break down of routines and communities. Third, we highlight how local authorities (LAs) and/or HSCPs have failed disabled people living in

the community by removing key support without providing any alternative. In particular, this underlines the weakness of social care in its wider relationship with health. Finally, we discuss how this crisis in social care has led to a major challenge to the goal of independent living and the prospects of building a new settlement for social care in the post-pandemic era.

Prior to examining the data findings, we explore the role of social care as an area of policy provision. We highlight how its marginal role within UK welfare states has emerged over the past thirty years through the imposition of marketisation, personalisation and chronic underfunding. This wider trend has been exposed through the pandemic, leaving many disabled people reliant on a sector in crisis.

The marginalisation of social care in the UK: policy background

LAs in England and HSCPs in Scotland are responsible for funding and ensuring provision of home care services. Their funding comes from Westminster and Scottish Governments respectively and through Council Tax. Whilst accountable to each respective arm of central government, LAs and HSCPs decide the proportions of their overall budgets to be allocated to different services. In addition, fees paid by individual service users form an important stream of revenue. These vary from an individual paying the full amount because they are ineligible for the LA/HSCP contribution, to those who pay a top-up fee and/or income tested charges paid by users of LA/HSCP funded home care. As underfunding has worsened over the last decade, LAs/HSCPs have been required to restructure their eligibility criteria to publicly funded home care. This has led to different local approaches to the individual costs of care and a postcode lottery for service users (Okon *et al.*, 2019; Bottery, 2020).

The marginalisation of social care in the UK can therefore be best understood in the context of policy restructuring over the last thirty years and chronic underfunding. In the early 1990s, the *NHS and Community Care Act 1990* introduced a mixed economy of care as LAs moved to purchase services from external providers, instead of their own in-house provision (Means *et al.*, 2008). In England, marketisation was strengthened further through the requirement that 85 per cent of services should be purchased from private or third sector organisations. Social care was not fully devolved until 1999, so although there were differences – notably the application of the 85 per cent rule only in England – the quasi-market framework (Le Grand, 1991) also applied in Scotland and Wales (Northern Ireland has a separate system of integrated health and social care). This was underpinned by a rhetoric of empowerment in which it was envisaged that disabled people and other user groups would have more choice, control and ultimately independence through their service provision (Pearson, 2019).

From the mid-1990s, there was a move towards substantive changes in service provision and individual autonomy for many disabled people, initially through the introduction of direct payments and then the broader adoption of personalisation in social care across the devolved nations (Pearson *et al.*, 2020). Yet as Glendinning (2012) argues, any potential benefits of marketisation and opportunities for user choice that shaped home care services were highly constrained by underfunding of the sector, relative to need. This has left an increasingly residual publicly funded home care service and a growing role for private funding and supply.

Over the past ten years, health care funding in England and Scotland has broadly kept pace with inflation (Kings Fund, 2020; Scottish Government, 2020), albeit insufficiently to keep up with growing population need. By contrast, social care has been severely cut. In England, for example, there has been a real-terms cut in spending of £300 million since 2010 (Kings Fund, 2020).

Social care across the UK nations is therefore widely acknowledged to be seriously underfunded, operating within a quasi-market structure, and has been criticised for its failure to adequately meet the needs of disabled people (Pearson, 2019). Social care functions in the shadow of the NHS, which enjoys far greater resource allocation and higher cultural and political value (Daley, 2020). In the rare occasions where social care was discussed during the pandemic, the focus was on residential care for older people; the needs of those in receipt of domiciliary care have been largely ignored. This article, by focussing on the experiences of those in receipt of domiciliary care, aims to rectify that gap. Domiciliary social care in both England and Scotland is delivered through a range of options including direct payments or personal budgets, services directly provided by local authorities or through a third party or a mixture of the three. While premised on the ideas encapsulated by the independent living movement (see, for example, Department of Health, 2014; Scottish Government, 2017), drawing on themes around freedom, dignity and choice, there is a great deal of debate as to whether these are actualised. The demands of the disabled peoples' movement for a social care service that enables their civil rights, have largely gone unmet (Pearson *et al.*, 2020). As we discuss later, the crisis in social care is beginning to get some exposure, with the main political parties across the UK exploring the need for reform. We argue here that any reconfiguration of social care must include home or domiciliary care within a framework of independent living as an integral part of this process.

Before examining the study findings, the next section sets out the methodology and recruitment of the study's participants.

Methods and participant recruitment

In this article, we draw on the first round of data from a UKRI funded study that aimed to examine the experiences of disabled people in England and Scotland during the Covid-19 pandemic (Shakespeare *et al.*, 2022). Interviewees were recruited via organisations of and for disabled people. We asked a range of organisations to advertise for volunteers and these requests were sent out via both email and mail shots. In total we carried out semi-structured interviews with seventy-one people between June and August 2020. Thirty-two interviewees were recruited from England and thirty-nine from Scotland. Forty-two of the respondents were female and twenty-nine male. Those interviewed had a wide range of impairments: physical, sensory, intellectual and also mental health issues and those with dementia and autism. Many of our informants had multiple impairments and the impairment categories are documented in Table 1. Four identified as being from a Black or Minority Ethnic (BME) community. We sought to recruit from across a range of different ages and seven of the participants were under eighteen; forty-nine were aged between eighteen and sixty-four; and fifteen were over sixty-five. We also tried to recruit across a variety of social locations and prior to the Covid-19 outbreak, seventeen participants lived with their partner and/or school-age children, fifteen with parents or adult siblings, thirty alone, eight in a residential setting and one with a lodger. Many of our respondents – but

4

Table 1 Respondents by impairment category (reproduced from Shakespeare *et al.*, 2022)

Impairment	Number
Autism/neurodiversity	9
Cognitive impairment	5
Intellectual impairment	23
Mental health condition	18
Physical impairment	35
Sensory impairment	15
Total *(including those with multiple conditions)*	105

by no means all – had personal assistants. Although those in this category had a similarly of experiences (and this is documented below), the project as a whole sought to encompass a range of disabled people's experiences, including those of disabled children. We sought to recruit people from urban, suburban, rural and remote-rural settings. Full ethical approval was given by the London School of Hygiene and Tropical Medicine Ethics Committee.

To supplement the individual interviews, and to give breadth to our analysis, we also conducted twenty-eight semi-structured interviews with organisations of and for disabled people and other key informants from across the social services. All interviewees were volunteers and were given a £20 voucher to compensate for their time. We wanted to ensure that we also recruited participants who did not have internet access and worked with organisations to specifically target this group. All participants were guaranteed anonymity and all names used are pseudonyms.

Interviews were conducted either via telephone, Zoom, or where requested, email. Increased use of digital platforms during the pandemic has evidently increased familiarity with video conferencing technologies and this has diversified approaches to data collection (Howlett, 2021). These three interview approaches have previously been shown to be useful, with no marked difference in the quality of data from face-to-face interviews, although we found it can be harder to develop rapport with people with learning disabilities online (Mason and Ide, 2014). Participants were asked about the impact of Covid-19 across a range of issues. These included their physical and mental health and well-being, access to health and support services, relationships, daily routines and their perceptions about government policy and leadership. Interviews lasted between thirty minutes and sixty minutes and were transcribed verbatim for subsequent analysis. Interviews were then coded using NVivo 12 and thematic analysis (Guest *et al.*, 2012) provided the framework. This involved initial coding of interview transcripts to identify the key themes emerging from the data, which were then discussed across the entire team. A coding scheme and codebook was developed through this process. The team exchanged transcripts and cross-reviewed coding of eight transcripts to maximise consistency of coding across the whole project. Our findings are presented in the next sections, starting with a focus on the negotiation of risk for disabled people during the pandemic.

Negotiating risk

The policy focus of social care across many OECD countries over the last 20 years has been the shift to personalisation and more consumerised models of care provision (Power and Hall, 2017; Pearson *et al.*, 2020), requiring many disabled people and/or their families to negotiate their own support. Ferguson's (2012) conceptualisation of this as 'enforced individualism' (in the pre-pandemic environment of service cuts and loss of community spaces) set the scene for many of the issues already in place as Covid-19 emerged. It is clear from our discussion below that these types of individualised negotiations, compounded with the dangers associated with the virus, featured strongly in the experiences of the disabled people we spoke to.

As the UK entered the first lockdown in March 2020, many of the initial national debates across the devolved nations centred on access to PPE and the difficulties in securing it (Boffey, 2020). Many of the organisations interviewed, highlighted the lack of guidance in this area, particularly in relation to their own services. As one stated:

> When the guidance has come out about social care, it's all about over-sixty-fives and nothing recognising the lack of PPE.
>
> (Disability Organisation, England)

For many of the disabled people we spoke to, there was clearly a problem in accessing supplies – leaving them to make their own arrangements. In Glasgow and London, disabled peoples' organisations became the de-facto hub for PPE provision after the local HSCPs/LAs were unable to offer any for disabled people using home care services.

People were left on their own and had to make decisions about their own safety and who they should allow to enter their homes. As Ashley explained:

> This has been one of the big stresses . . . what PAs [personal assistants] to have in [the house] and whether there are PAs that I should only have do things for me outside the house.
>
> (Ashley aged fifty-seven, England)

The pandemic clearly created stresses in the relationships between disabled people and their PAs. Chris, for example, explained this had led to some uncomfortable conversations with her daughter's support workers:

> They [support staff] were all getting asked . . . 'where have you been?', you know, 'you'd better not have been mixing with people. And that was pretty stressful, because staff were sick of me . . . I was probably not very nice, to be honest, to be around.
>
> (Chris, mother of Fra aged ten, Scotland)

When travel halted, some PAs were stranded, either in the UK or back in Eastern Europe. In some cases PAs were willing to self-isolate and form a 'bubble'. Others made their own arrangements and negotiated what they perceived to be an acceptable level of risk with their support staff. For example, Amanda created an area in her house where her PA took off her coat and shoes and sanitised her hands before entering the house. She also

agreed when she would be expected to wear PPE. These type of individualised negotiations often left disabled people at risk:

> She [the PA] chose not to wear a mask. I was quite happy if she wanted to wear a mask. But . . . she only wears a mask if she's been supporting someone before she comes into me. But if it's just me, no mask.
>
> (Amanda aged sixty-two, Scotland)

For Anna, the risk of having her PAs in the house was felt to be too high and in the absence of any formal guidance, she made an alternative arrangement:

> When things were getting a bit scary about the pandemic in March [2020], I decided that I would come and stay with my parents, just because, you know, to have a twenty-four-hour support package . . . so that would mean people coming in and out of my flat all the time. I would have no control over where they had been or who they had been with.
>
> (Anna aged twenty-seven, Scotland)

A number of people therefore opted to move in with another family member. Whilst this had been a workable solution in the first few months of the pandemic, at the time of interviewing, Anna felt she was being pressurised by her care providers to return to her own home and reinstate the care package. For her, the presence of up to ten PAs over the course of a week felt far too risky. In another case, we spoke to someone who – with his wife – had opted to have his care provided by their sons, who had returned home from university. As a consequence, they lost their support package.

Other risks included concerns about securing their basic support needs and food in the event that either they or their PAs became unwell with Covid. Kayla had begun rationing her food, fearful that she would not have any support. There was a lack of information about what would happen. Arthur pursued this directly and wrote to his local authority and eventually to his Member of Scottish Parliament to find out:

> What happens if my PA gets ill? How do I find another one? . . . I didn't get any replies. No one replied.
>
> (Arthur aged fifty-six, Scotland)

Arthur's attempts to find out more information about possible disruptions to his support raise broader issues about the loss or reduction of services in the pandemic. This is explored in more detail in the following section.

Service reductions and lost communities: Covid-19 and the removal of key support

Like the wider population, lockdown brought an immediate change to routine, services and support structures. Yet for many of those we spoke to, this was compounded through an expectation that the family would take over care, whilst others had their support abruptly cut.

> It was the 16th of March. We began our shielding . . . and Jack has stopped going out. He has a personal system, or a carer wherever you want to spend the most . . . and is given the three direct payments from social care. So that had to stop. So that was kind of his whole life really was going out one on one with his carer and he would access all of his education and all of his socialisation through this . . . So all of that for him [was] stopped [on the] Monday, he was at home with us, 24/7 . . . which was incredibly difficult for him.
>
> (Vanessa, mother of Jack aged seventeen and Archie aged twenty, England)

In Glasgow, one disabled peoples' organisations told us that these types of cuts had happened to over 1800 social care packages in the city. They stated, this was done:

> in the most brutal of fashions and left many people with absolutely no support . . . it really does worry us that we are not going to get it back.
>
> (Disability organisation, Scotland)

Those without family or friends nearby were left feeling lonely and unsupported. The development of online support and new communities by many of the disability organisations we spoke to provided a critical line of communication and community for many of our interviewees.

For the first five weeks, Adam's self-directed support (SDS) package was reduced from twenty-four hours support a week to just six. This raised real concerns as to how he and his sister (with whom he lived) would receive even basic food supplies without the help of his remaining support and those in the local community:

> My sister and I are both shielding so it was just not being able to get shopping in . . . we've got good neighbours and that helped us, but really we were struggling to manage without PAs coming in.
>
> (Adam aged fifty-two, Scotland)

Jonathan's (aged seventy-three, Scotland) stair lift had broken during lockdown and at the time of interviewing, he had been stranded upstairs in his house for fourteen weeks. In addition, two of his four PAs had stopped working for him, his support package was cut by ten hours per week and his family had to cover the missing hours. Families often had to step in and provide support. Abbey told us how her brother's package of thirty-eight hours per week was removed with very little notice:

> So I think on . . . the 17th March, the [care company] who provide most of Maurice's care, phoned me up and said, 'Obviously this virus is getting more serious, so we've had to prioritise . . . the support we provide and in two days, Maurice's care will be ceasing altogether and it's over to you . . . '.
>
> (Abbey, sister of Maurice aged fifty, Scotland)

The cuts in service were not just implemented by LAs/HSCPs, but also, in many cases by private sector companies who felt unable to continue to provide the service.

As well as removing services already in place, care assessments were also put on hold from February 2020 and in some LAs/HSCPs, this lasted until the September. As one of the

social workers we interviewed conceded, this had both an immediate impact and raised questions as to whether support would be available at all in the longer term:

> I've got quite a few service users of mine where they've been, kind of, left in limbo a little bit at the moment and they were part way through a process before the pandemic. And that's, kind of, stalled because resources are getting moved around with the local authorities [HSCPs] to look at other things as a priority at the moment.
>
> (Social Worker, Scotland)

The pandemic also brought with it a strain on care workers and we were told of instances where staff inevitably struggled with the physical and mental toil of the virus. Some care staff also had to self-isolate, either because of their own underlying health conditions or that of another family member. When this happened, individuals were often left without care or support, unable to recruit appropriate replacements.

In addition, some social care provision was removed to provide support elsewhere. The loss of services, routines and associated communities clearly transformed the lives of many of those we spoke to. Before the pandemic, people such as Sally (aged thirty-eight, Scotland) and Sam (aged forty-four, England) had spent most of their time either in local drama or art classes or at the gym. These organised groups were where Sally had met her friends and as a result was 'never in the house'. Losing this routine meant that all her social relationships had disappeared, making her feel 'sad and angry'. Others were really concerned that service cuts made as an emergency response to the pandemic would become permanent, as individuals were seen to have 'coped' or family had stepped in. Lucas had no family and expressed real terror:

> If I die, who would know? Who would even care?
>
> (Lucas, aged fifty-five, England)

Michael's sister, Alice also emphasised the importance of structure and routine in her brother's life. Before the pandemic, she described him as being in a 'really good place, coping with life and really enjoying himself'. However, when his day care package was stopped during the first lockdown, this led to a deterioration in his mental health and well-being. When support was resumed, this was only on a partial basis, leaving his elderly parents responsible for making up the shortfall. The lack of communication from social workers during this time caused real concern as to how this would impact Michael's support over the long-term:

> The worry with that is that if social work aren't aware of how difficult it is for my parents to cope, that when re-enablement comes in with the packages post Covid, we're worried that funding might be cut.
>
> (Alice, sister of Michael aged thirty-eight, Scotland)

Those in receipt of a direct payment through the English or Scottish systems were generally more able to manage the stresses and strains of Covid because they were in charge of their support. For Donna, this had allowed for more flexibility in maintaining her son's educational support at this time:

> So he's been educated at home through a personal budget through the local authority. So we had quite a good routine centred around [him]. Tutors coming in, having a full-time carer, and a part-time carer that swap between them.
>
> (Donna, mother of Ryan aged sixteen, England)

As detailed earlier, they were, however, often left to negotiate issues such as PPE and shopping if they were not on a shielding list. The response of LAs/HSCPs also often demonstrated a lack of understanding around independent living, direct payments and PAs as to who was ultimately responsible for their employment. Some of our participants initially chose not to carry on with the care and support provided as part of their direct payment to reduce risk, as we describe above, and sought to place their PA on furlough. Yet some LAs/HSCPs directly challenged this decision, asking instead that the worker be redeployed to work in support services for older people, particularly the care home sector, assuming that they had the power to redeploy. Not only did this demonstrate a lack of understanding of direct payments, it also shows how the focus in social care was almost entirely on care of the elderly and care homes.

System failures: deteriorating relationships with statutory social care services

The examples above highlight some of the impacts on disabled people when their services were cut or stopped as the pandemic took hold. Whilst service providers were working under unprecedented circumstances, for many of our respondents there was a real breakdown in support and access to information. As stated, new social care assessments had been suspended and, in many areas, this was in place for at least four months. Many of those we spoke to were very frustrated in trying to contact social work departments to discuss their situations, with limited access given to direct phone lines or email addresses. If they did get through, it was felt that social workers were often very poorly informed themselves.

There also appeared to be confusion over how services would be paid for during lockdown and this was often compounded by poor communication. This was explained by disability organisations that worked with SDS users:

> Each local authority [HSCP] sends a letter to all its SDS users basically setting out guidelines as to how things were going to work around things like whether people should stop . . . you know, whether people were going to carry on paying their PAs if they weren't using them. And, you know . . . some of those letters were really scary. They were quite threatening.
>
> (Disability organisation, Scotland)

Others were left paying for services that had stopped running. In Maurice's case, his sister had had to borrow over £3000 to cover the replacement day care support costs of his PA. The local HSCP had taken twelve weeks to process their request for SDS and at the time of interviewing, they were still waiting for the funding to be reimbursed.

There was also evidence of different approaches and flexibility being offered between local areas. As discussed earlier, Anna had moved back in with her parents during the first lockdown. Her HSCP had enabled her to make payments to her mother and sister for her support needs during this time. By contrast, in a neighbouring HSCP Hannah was also

keen to avoid her regular carers and live instead with her father to create a safer living environment. Her father had discussed this with his employer and they had been sympathetic to the arrangement. However, unlike for Anna, the Social Work department was unwilling to support this. This had negative repercussions for Hannah and her father:

> So my dad knew if there was a lockdown that there was no way I could spend it in that house so [he] ended up phoning in sick at his work and taking time off to get me settled . . . . So his work said to him, see, since you're caring for your daughter, if her social worker just sends us an email, we'll furlough you . . . I told my social worker this, she then told me, 'no, I can't do that. It's a third party' and I said, 'but I'm giving you permission and I'm the person whose details it is you're giving out'. 'No, I can't do that'. So her option was for me to send my dad home and allow strangers to come in and put myself at even more risk. So what ended happening was my dad had to go home and apply for Universal Credit so it's left us both in a very bad situation and we're both in separate houses . . . I could have been fine.
>
> (Hannah, aged thirty-five, Scotland)

In other examples, we were told how social workers had been in regular contact during the early months. In Sue's case, what was initially experienced as supportive resulted in a much less favourable outcome:

> I had a phone call from a social worker . . . We had a chat and [she] asked me how we were doing and I thought 'that's so kind' and said 'we're doing really well'. But actually it's been really tricky because . . . we can't access services. So she rang me three times a week for about three weeks and it was all about reducing the budget . . . All we got was a letter telling us that they were reclaiming the budget.
>
> (Sue, mother of disabled child, age not given, England)

There was a lack of communication between LA/HSCPs and disabled people and support was sometimes changed without consultation.

> Well to be honest I am quite surprised that the council hasn't really contacted us, to be fair, I think we have sort of been left in the lurch.
>
> (Simon, father of Peter aged 20, Scotland)

People had to work with what they were given, rather than what they actually needed.

There was a failure of local services to provide for even basic needs for disabled people who were isolated in their communities: this meant that the pressure fell on third sector organisations to fill in the gaps. Many organisations quickly shifted the focus of their work:

> We spoke to maybe 1200 people at five weeks [and] by thirteen weeks we had spoken to over 3500 people, it's staggering . . . Honestly, I'm so proud of it. But it's not like it was a brilliant design, we did just come up with it and implement it . . . it just happened because we had brilliant people who were passionate about disabled people's human rights.
>
> (Disabled peoples' organisation, Scotland)

Whilst this clearly provided a safety net for many disabled people, it does raise questions about the level of support offered by statutory services, their prioritisation of needs and the pressure on the system.

Discussion and conclusions

The pandemic has exposed and magnified the existing frailties in social care. This impacted on both those who received care and those who provided care. The inadequacy of domiciliary social care and social support across many OECD countries, as well as in the UK nations, has been well documented (Martinelli *et al.*, 2017) and evidence is now emerging about how Covid-19 has had a similar effect on disabled people internationally (see, for example, Safta-Zecheria, 2020 (Romania); Kavanagh *et al.*, 2020 (Australia); Zhang and Chen, 2021 (China)).

Even as governments moved forward with personalisation policies which promoted the goal of independent living for disabled people prior to the pandemic, this was always a precarious aim as social care budgets were drastically reduced (Power, 2014; Pearson and Ridley, 2017). Yet as noted, social care policies over the past decade have emphasised discourses of autonomy, choice, control and dignity (Department of Health, 2014; Scottish Government, 2017) as the cornerstones of independent living for disabled people. The response to the Covid-19 pandemic brought a sudden and more acute wave of service cuts; the needs of disabled people were deprioritised, and the focus was placed on health (Glasby and Needham, 2020). It was clear from our interviews that this has had a profound impact on the lives of disabled people and their capacity to live independent lives. Forcing people to rely on families, curtailing care, failing to negotiate or consult and not providing adequate support led to a breakdown of the principles that underpin independent living and the wider aims of social care.

As discussed earlier, the policy framework for social care over the last thirty years has brought with it a push towards independent living embedded in a discourse of consumerism. This has led to an expectation that disabled people and their families can 'self-build a life as individual consumers within a care market' (Power *et al.*, 2021: 1). Yet as Dickinson *et al.* (2020) have observed, Covid-19 has exposed many of the limitations of personalisation schemes within social care. During the pandemic, many disabled people have been left to negotiate their own risk, either through accessing PPE, or as to whom they considered safe to enter their homes. It was apparent from our interviews, that some LAs/HSCPs were still unaware as to where the nexus of control lies within personal assistance packages. This often led to very different responses to support between LAs/HSCPs, suggesting that the extraordinary circumstances of Covid-19 may have increased, rather than reduced the differences between localities (Bottery, 2020). Indeed, our findings suggest that often innovative emergency support came not from LAs/HSCPs, but instead through familial networks and third sector organisations. Where such support was absent, disabled people floundered. The absence of support from statutory services reiterated the exclusion of home care from Covid-19 policy planning and exposed the fragility of independent living as a wider policy goal.

It has long been acknowledged that social care across the UK is a sector in crisis (Ferguson, 2005; Glasby *et al.*, 2021) and in need of urgent reform. Whilst the Covid-19 pandemic has exposed many of the inequalities at the heart of health and social care policy, there has been a muted response from governments to the failures of the social care

systems and their impact on the lives of disabled people. Social care is often presented alongside health, and in Scotland has been formally integrated (Pearson and Watson, 2018), while in England the policy drive is towards greater integration (DOHSC, 2021). Yet it remains an unequal partner within a policy arena characterised by a long-standing systematic divide (Daley, 2020). Even when political and public attention was turned to social care in the early months of the pandemic when the catastrophic policy of discharging Covid patients to care homes (Bell *et al.*, 2020; Daley, 2020) became apparent, no attention was given to the emerging crisis for those in receipt of services in their own homes. Our findings set out here reveal another tier to the crisis in social care.

Governments north and south of the border have committed their administrations to major reform of social care. In Scotland, the findings of the *Independent Review of Social Care* led by Derek Feeley (Scottish Government, 2021) have been broadly welcomed by the Scottish Government. These centre on a proposal to 'shift the paradigm of social care support to one underpinned by a human rights-based approach' (Scottish Government, 2021) and develop a new National Care Service. This would remove social care from the control of HSCPs and instead develop a centralised structure to deliver a more unified system of care. It remains to be seen whether Feeley's proposals are realised in legislation. In England, there has also been assurances that a major review of the social care system will appear (House of Commons Library, 2020). Reform has been long delayed and a source of considerable frustration for many in the sector, with most of the discussion around policy change in England centred narrowly on the funding of social care for older people (Mitchell, 2017) and the more recent debates on increasing national insurance contributions (Stewart, 2021). This has left DPOs and other third sector organisations to ensure that these interests are promoted. For example, the *Social Care Future* movement – a grassroots collaboration of individuals and groups with an interest in England's social care reform – has sought to frame the debate around a more direct engagement with the principles of independent living (Social Care Future, n.d.).

The pandemic has underlined the weaknesses and failings of social care in England and Scotland and made the case for reform. In any review of social care, the role of the third sector – particularly disabled people's organisations – should be central as providers of flexible and innovative support. In both England and Scotland, social care is delivered under the control of Departments of Health *and* Social Care, but these have both operated more like Departments of Health. At the forefront of any change, there has to be a recognition of the importance of all sectors of social care, including domiciliary care, and its positioning as an equal partner with health. Unless and until social care is given the status it deserves, disabled people will continue to be marginalised and their needs unmet.

Acknowledgements

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