"They have been a saving grace in all this": the role of the third sector in disabled people's experiences of COVID-19 and implications for sector–state relations

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Abstract

This paper explores the third sector's role during the COVID-19 pandemic and its impact on the experiences of disabled people in England and Scotland. It draws on semi-structured longitudinal interviews with 71 disabled people and 31 key informants, primarily disabled people's organisations. The third sector's nimble response, supporting people in myriad innovative ways, emerged as a key finding. In contrast, statutory services were experienced by many as a barrier rather than an enabler, posing doubts about the state's ability to respond to the crisis. Our findings raise questions about the role of the state and the third sector. We employ and critique Young's typology of sector-state relations, concluding that the state needs to engage with the third sector as an equal and strategic partner, recognising its civil society credentials. Further, we raise questions about the appropriateness of using supply and demand models to understand the third sector's societal role.

Introduction

The COVID-19 pandemic has affected the lives of every citizen, but disproportionately and differentially impacted the lives of disabled people (Shakespeare et al, 2021; Shakespeare et al, 2022; Pearson et al, 2022; Scherer et al, 2022). Disabled people often have underlying health conditions, face barriers in accessing the healthcare system and have poorer outcomes once in the system (Dickinson et al, 2020). Government statistics show that 60% of UK COVID related deaths were of disabled people (ONS, 2020) and people with learning disabilities were six times more likely to die of COVID-19 than the general population (Public Health England, 2020). Disabled people have faced a "triple jeopardy" with poorer health outcomes from the disease, reduced access to health care and rehabilitation services and adverse social impacts from government measures to control the virus, such as lockdown (Shakespeare et al, 2021). While the UK and devolved governments took action to prioritise the needs of the most vulnerable through shielding, many disabled people saw their health and social care withdrawn or significantly curtailed resulting in fear, isolation, increased reliance on family and concerns about long-term impacts to physical and mental health (Shakespeare et al, 2022; Pearson et al, 2022; Scherer et al, 2022). Third sector organisations and local community initiatives stepped into this breach, acting as "first responders" and "primary engagers" (Bynner et al, 2021) to provide a wide range of practical and emotional supports.

The pandemic raises important questions both about the role of the third sector in society and the sector's relationship with the state (Kövér, 2021). In this paper we draw on data from interviews with disabled people and their organisations to explore disabled people's experiences of the state and the third sector during the pandemic, and reflect on the role of the state and how it functions in local mixed economies of care. In addition, we explore a more reactive role between the third sector and state in responding to policy directives from central (UK) and the devolved Scottish Government. We define the third sector as existing as part of a public space in civil society, beyond the state and the market, in a "tension field without clear boundaries" (Evers, 1995, p.161). The third sector, then, includes formal organisations as well as informal grassroots initiatives. Our data suggest that for many, statutory agencies were slow to respond to the crisis, both as it emerged and as it progressed. Disabled people relied on the third sector for support, which was flexible and responsive to a rapidly changing environment, whilst providing innovative and tailored responses to emerging and changing needs. Our findings have implications across the sector, resonating with research exploring the role of the third sector with other marginalised communities (Armstrong and Pickering, 2020; Bynner et al, 2021; McMullin, 2021; Thiery et al, 2021).

We use Young's (2000, 2006) theoretical framework to analyse the shifting relationship between the third sector and the state during the pandemic. Young posits that the third sector acts in supplementary, complementary and adversarial roles with the state, acting independently in spaces where the state is absent (a supplementary role), working in partnership with the state (complementary), and/or challenging the state (adversarial). We critically apply this framework to analyse the role of the sector in the pandemic and consider the implications for the future. We argue that through the pandemic the unique position and strength of the sector, with its deep roots in civil society, was demonstrated. The sector draws on and promotes social capital in communities tapping into and building on networks and relationships that facilitate trust and cooperation (Cote and Healy, 2001; Putman, 2000). The sector's civil society credentials, and its role in supporting the "links and bonds of associational life" (Hilton et al, 2010, p285), equipped it to respond to the crisis in a way that the state could not. The pandemic highlights the limits of Young's (2000, 2006) model which does not consider the challenges posed by crisis conditions such as those experienced during COVID-19, nor account for the sector's role in mobilising social capital and stepping in for the state. The centrality and impact of the sector's role necessitates a reconsideration of the future relationship between the sector and the state. We suggest that the pre-pandemic relationship, while important, was largely utilitarian rather than strategic. A rethinking is therefore required to enable the third sector to play a more meaningful role as an equal partner, along with new frameworks for understanding the sector-state relationship.

This article opens with a review of the debates about third sector-state relations and a consideration of the sector's role in the pandemic as well as exploration of Young's theoretical framework. Next, the methods used to collect and analyse the data are presented, followed by the findings. We then conclude with a discussion exploring some of the implications to emerge from the research.

Understanding third sector and state relations

Third sector-state relations

Throughout UK history there has been an interplay in the roles occupied by the third sector and the state, reflecting the evolution of public administration regimes and the changing expectations of the state in responding to the needs of its citizens. With the rise of neo-liberalism and the emergence of new public management in the 1980s, the sector has been brought increasingly closer to the state as a provider of contracted services in a mixed economy of welfare provision (Kelly, 2007). The state's role has shifted from service deliverer to contract administrator, with a resulting growth of the third

sector (Kelly, 2007; Lewis, 1999). The state's close engagement of the third sector has been strengthened under the current regime of new public governance, with its focus on governance networks bringing together state and non-state actors in shared decision making (Pestoff, 2018). The closeness of the third sector to the state has raised questions about the sector's independence and its ability to 'bite the hand that feeds it' (Brandsen et al., 2014; Cullingworth, 2020; Egdell and Dutton, 2017; Milbourne and Murray, 2017).

The shifting relationship between the state and the third sector is particularly evident in adult social care. While the third sector has long played a role in social care, predating the creation of the welfare state, its provision became more central and formalised after the *1990 NHS and Community Care Act* heralded changes in the role of local authorities from direct providers to purchasers of services (Dickinson et al, 2012). In both England and Scotland there has been increased reliance by local authorities on the third sector to deliver social care, particularly in the context of the personalisation agenda and measures to integrate health and social care (Dickinson and Glasby, 2010; Dickinson et al, 2012). The personalisation agenda, espousing a similar philosophy to that of the third sector, has brought many disabled people's organisations (DPOs) into the delivery of social care services to disabled people (Pearson et al, 2022).

DPOs occupy a distinctive place in the third sector, evolving as they did out of disabled people's activism (Campbell and Oliver, 1996). This activism gave rise to the influential social model of disability, identifying societal barriers as the cause of disadvantage and challenging the individual model that views impairments as the causative factor. The strong ethos of many DPOs is born out of the philosophy of "nothing about us without us", putting disabled people's voices at the centre. Many DPOs, including those with activist roots, have become involved in the provision of social care, while others have maintained a focus on campaigning and amplifying voice (Barnes and Mercer, 2006).

Third sector-state relations and roles during the pandemic

Over the course of the pandemic, the third sector experienced something of a renaissance, credited for its quick response to the needs of citizens, ability to reorient staff and services, and resilience (Armstrong and Pickering, 2020; Bynner et al, 2021; Dayson et al, 2021; Harris, 2021). Harris (2021) charts the central role of the sector in supporting the government's shielding initiative for the UK's most vulnerable and in substituting for the state, responding to the needs of approximately 10 million citizens deemed to be at moderate risk. Reports from third sector organisations and government highlight the sector's essential role at the frontlines of communities (e.g., Inclusion London, 2020; Scottish Renewal Advisory Board, 2021). More than 4,000 mutual aid groups emerged

within days, supporting individuals across the UK and interacting with public services (Rendall et al, 2022). The third sector's unique positioning, with its roots in communities and relationships with organisations across all sectors, emerged as vital throughout the pandemic.

Young's framework of third sector-state relations

In this paper we employ Young's (2000, 2006) theoretical framework to analyse the impact of the pandemic on sector-state relations. Young argues that the third sector acts in supplementary, complementary and adversarial roles to the state. In the *supplementary* role, the sector operates independently, responding to demand unfulfilled by the state. Initiatives are volunteer driven and/or supported by non-state funds (eg, donations, foundations, fees). An inverse relationship exists; as government takes on more responsibility for services, less resource needs to be raised within the sector. There is a rich history of the third sector acting in a supplementary role to the state in supporting the needs of disabled people, with the third sector's role growing out of the disabled people's movement, organised largely by disabled people themselves (Barnes and Mercer, 2006).

In the *complementary* role, the sector works in partnership with the state to provide public services, largely funded by the state. In the past twenty years, the sector's complementary role has expanded beyond that of a service provider to play a role in policy development and local governance reflecting the belief that governance through networks is essential in tackling society's 'wicked issues' (Pestoff, 2018; Rittel and Webber, 1973). There is a direct correlation between the state's increased responsibility in meeting the needs of its citizens and the growth of the third sector given the state's reliance on the sector to deliver public services. The complementary role of the third sector in its relationship with the state has become dominant, bringing with it risks that the sector fulfils a transactional function as a service provider on behalf of the state, acting as a "shadow state" (Wolch, 1989) rather than holding the state to account on behalf of civil society (Milbourne, 2013). Despite the centrality of the third sector, funding models are predominantly short-term, resulting in the sector's persistent precarity (Bridge et al, 2020). The state's expanded role in the lives of disabled people has meant that DPOs that may have previously acted in a supplementary role – securing non-state funding for the provision of services – are now in a complementary relationship with the state, delivering services funded by the state.

In the *adversarial* role, the sector lobbies for changes in policy and ensures that the state is acting in the public interest. DPOs have a long and rich history of campaigning for the improvement of disabled people's rights and for the provision of appropriate services. The supplementary, complementary and adversarial roles are not mutually exclusive and indeed organisations can act in all three roles.

Young's model reflects a demand and supply model, focusing on the provision of goods and services; it is critiqued for its focus on the "efficiency of exchange rather than the distinctive values and social relations" (Smith and Gronbjerg, 2006, p.229). Despite its genesis in the US context and its transactional focus, Young's model has been regularly cited in the UK third sector-state literature, with a recent resurgence in the context of the pandemic (Bynner et al, 2021; Dayson and Damm, 2020; Rendall et al, 2022). We add to these debates, employing Young's framework to aid analysis of how the third sector-state relationship played out in the disabled community during the pandemic. COVID-19 threw society into an unprecedented crisis, testing the ability of the state to respond to the needs of its citizens, particularly those considered vulnerable to and from the disease. This paper explores how this crisis impacted and reshaped the relationship between the third sector and the state, highlighting the central role of the third sector at the frontlines, exemplified through the experiences of disabled people.

Methodology

This article draws on data from a year-long UKRI-funded study exploring the experiences of disabled people during the COVID-19 pandemic in England and Scotland. A qualitative longitudinal research methodology was adopted to gain rich insight into the lived experience of disabled people at two different time periods during the pandemic. The longitudinal nature of the research enabled the team to collect data about the immediate impacts and medium-term consequences of the pandemic and the associated government interventions (Treanor et al, 2021). Qualitative semi-structured interviews were employed to give participants some control over the interview, to facilitate a more natural conversation and to generate in-depth data (Mason, 2002). A total of 132 interviews were conducted with 71 disabled people, including 11 carers or guardians. In addition, 54 semi-structured interviews were conducted with 28 DPOs and 3 key informants from the statutory sector, including 2 social workers and a health and social care worker. The first round of interviews took place from June-August 2020, the second between February-April 2021. Ethical review was granted by the London School of Hygiene and Tropical Medicine Research Ethics Committee (Ref: 21878).

Disabled people were mainly recruited through DPOs and other third sector organisations, who were asked to share a flyer describing the research and outlining what participants could expect. Potential participants were asked to contact the research team directly. A Participant Information Sheet and Consent Form were sent to interested individuals, with Easy Read versions available. Participation was voluntary and all were offered a £20 gift voucher to compensate for their time. The mode of

communication reflected individual preference, with most interviews conducted by Zoom or by phone, and in three cases by email. In most cases consent was secured verbally, and where interviews were not in real time, via email.

Participants were asked about the impact of COVID-19 on their general and impairment related health, mental health and well-being, care, access to healthcare, daily activities, relationships, as well as their perceptions about government policy and leadership. Where guardians or carers participated in the interviews, they were primarily communicating the views and experiences of disabled people. Interviews were between 30-90 minutes long and were all professionally transcribed verbatim.

Thematic analysis (Guest et al, 2012) was used as an overall framework for analysis. After initial familiarisation and inductive coding of themes emerging from the data by the Glasgow and London teams separately, a coding scheme and codebook were developed by the full research team collectively and iteratively. NVivo was used to support the coding process and coding practice; emergent themes and categories were discussed at regular team meetings. To ensure consistency of the coding approach, eight transcripts were cross-reviewed by different team members and differences discussed.

We spoke to 32 disabled people in England (primarily from Greater London and East Anglia) and 39 from across Scotland, from a range of urban, suburban, rural and remote-rural settings. Almost 60% of participants identified as female and 6% identified as being from a Black or Minority Ethnic community. Prior to the pandemic, 24% lived with their partner and/or school-age children, just over 20% lived with parents or adult siblings, 42% lived alone, 11% lived in a residential setting and 2% lived with a lodger. Participants had a wide range of impairments, such as intellectual impairments, autism and neurodiversity, dementia, mental health conditions, physical impairments, sensory impairments and chronic illnesses; 33% had two or more impairments.

The following section explores the study's findings. Quotes from England are referenced with an "E", Scotland with an "S". Where quotes are from the second round of interviews, they are denoted with the number 2. Interviews with key informants follow the same pattern but with the letter "K". Pseudonyms are used that reflect participants' gender and nationality; where quotes are from organisations, the role of the individual is provided. Organisations names are only given when used by participants.

There are, of course, limitations to our study. Individuals were recruited through organisations where they were members and/or service users, and while participants contacted us directly, it is

possible this association affected how they spoke about DPOs. While we do not claim that our findings can be generalised to all disabled people, or that the role of the DPOs can be generalised to the whole of the third sector, our evidence does raise questions about the implications for relationships between the broader third sector and the state. Similar findings about the role of the sector and questions about third sector-state relations have been raised by others (Armstrong and Pickering, 2020; Bynner et al, 2021; Dayson et al, 2021; Harris, 2021; McMullin, 2021; Thiery et al, 2021).

<u>Findings</u>

Across the interviews the pivotal role of the third sector in responding to the needs of disabled people during the pandemic emerged as a dominant theme. Third sector organisations were quick to respond, recognising the need for comprehensive support to meet both the pre-existing needs of disabled people and to tackle new challenges created by the pandemic. In contrast, statutory services were widely experienced as slow or unresponsive. Here we explore two related findings: the role of the sector in the lives of disabled people and the experiences of disabled people and DPOs with the state.

The third sector at the front lines

The evidence from the research demonstrates that, in general, third sector organisations responded quickly and effectively to the COVID-19 crisis. In a matter of days, the organisations we interviewed had repurposed themselves, adapting and developing services and supports, sometimes in entirely new ways. All this was achieved amidst significant upheaval and uncertainty, including managing changing regulations, funding challenges, staff on furlough, reduced numbers of volunteers and repurposing IT systems for online delivery. Despite these challenges, organisations were driven by a singular focus to meet the needs of their members and service users. Participants used evocative language to describe the third sector's role in their lives: Hannah, a woman with physical impairments and mental health issues, referred to a DPO as a "saving grace" (S21). Isla, a woman with dual sensory impairment, spoke about a DPO saying, "they are just saving my life at the moment psychologically that lot" (S31). Belinda, a woman with mental health issues, stated "I would be in a bad way if they had their funding withdrawn" (E26). For some the third sector was literally a lifeline.

Evidence from our study indicates that third sector organisations attended to a wide range of needs from the most basic (such as the provision of customised food parcels and prescription delivery) to

the defence of human rights (for example, speaking out against Do Not Resuscitate Orders, applied to vulnerable people without their consent). At the outset of the pandemic many organisations set up online and phone surveys to determine the needs of their communities and were among the first to highlight the impact of the pandemic on disabled people (for example, Glasgow Disability Alliance, 2020; Inclusion London, 2020). The third sector provided a bulwark against the isolation of the pandemic, particularly amongst those who were shielding. Emotional support was made available through helplines: Belinda commented, "I call the Mind helpline most days, and that's really helpful" (E26). Volunteers helped mitigate the isolation of people living alone, as reflected by Jason, a man with a physical impairment and mental health issues: "there's a Mind volunteer who phones me on a Friday and has been constant through lockdown, so I've actually looked forward to that" (2E29).

The sector's role extended far beyond the provision of services, as organisations created and sustained communities and advocated for disabled people. Participants provided examples of organisations that created alternative communities online, such as Get2Gether, an organisation of and for disabled people, that moved its discos, karaoke and speed dating events online. New supports were set up to respond to the isolation of lockdown; for example, an online pub hosting social events was set up by disabled people for anyone experiencing isolation, bringing together disabled and non-disabled people. This inclusive pub not only broke down barriers of access but also barriers of attitude. Describing the pub's impact, one of the organisers of this grassroots initiative commented:

> I particularly know of people with chronic illness, fatigue, pain, you know they are finding it a real lifeline… it's really building a community in building independent connections of the pub and people are finding each other and supporting each other (EK5).

The ability of disabled people to engage online was made possible, in part, by the provision of digital devices and broadband access, as well as the related training required to navigate the digital world, particularly critical given that 56% of digitally excluded adults in the UK are disabled people (ONS, 2019).

The sector worked with disabled people, co-creating and co-producing new services that met their needs, as defined by them. In Scotland some participants talked about being consulted by ENABLE, a large charity for people with learning disabilities, for input about what support they might need and how it could best be provided. ENABLE provided a phone line for individual emotional help and a range of online group activities; it also responded to evolving needs, providing twice weekly updates about the latest official guidance and facilitating discussion to enable people to discuss what the guidance meant for them. In England participants told us of the beneficial work done by Beyond

Words, a charity that produces wordless picture books to support people with learning disabilities and communication difficulties. Poppy, a woman with learning disabilities, said, "Well, now we feel perfect ... thanks to helper Sarah with the virus book, which is a really good book... We love them" (E12). The books, including titles such as *Good Days and Bad Days During Lockdown,* were provided free for download and included guidance on how to facilitate the reading. The publications were made available online and by summer 2020, *Beating the Virus* had been downloaded 15,000 times.

There was evidence from individuals and organisations about a distinct community development ethos in the approach to engaging with disabled people. One organisation in Glasgow, traditionally a campaigning organisation, attempted to phone all its members at the onset of the pandemic, reaching 1,200 people within the first five weeks. These calls were designed to check on people's wellbeing, identify needs and ensure safety. The organisation quickly organised and delivered customised food parcels, provided weekly wellbeing calls and secured iPads and broadband access to digitally isolated members. They also provided regular online classes such as singing, dancing and meditation. Hannah expressed the difference the wellbeing calls made to her isolation:

> I must admit they have been helping me so much the last few weeks just with wellness phone calls and it has made such a difference to just talk my problems through with somebody and to actually be listened to because as a disabled person, especially with mental health problems, people don't want to listen to you (S21).

Hannah was also provided with an iPad and the training to use it by the organisation. While she was unconfident about the technology when we first spoke, by the second interview she was adept and had begun organising online social sessions for other members:

> I had a Boxing Day bonanza and things like that... But then the group became so popular that I've now got to run it every Saturday because they can't be without it… I think that's what's kept me going, to be honest… Yeah, I feel better when I'm helping people, I like to do that (2S21).

The organisation's approach addressed immediate concerns such as food provision, moving to emotional support needs, then equipping people with the means and confidence to connect with and support others. This community development approach enabled individuals to exercise agency. The holistic response was a characteristic of the third sector that was evident across the interviews with both individuals and organisations. The ability of organisations to respond quickly and comprehensively was facilitated in part by the flexibility of funders who relaxed spending criteria, allowing budgets to be repurposed to meet emerging needs.

The role of DPOs in advocating for disabled people's needs was very present in the lives of participants, with a number speaking about the comfort this advocacy provided. Valerie, a woman with a visual impairment, talked about the RNIB's interventions to "make the government aware that blind people are very, very vulnerable in this situation" (E07). Isla spoke about an organisation for deaf and blind people that advocated for the government's daily briefing to be available in appropriate formats:

> I have to credit the CEO who was knocking at the door and saying don't forget about these guys... you've got all these people sitting in isolated places and they don't know what's going on and they're scared (2S31).

This intervention resulted in the Scottish Government's daily briefings being sent out to its members in a customised accessible format. Also in Scotland, organisations supporting people with learning disabilities advocated for unpaid carers to be prioritised for vaccinations in the same way as paid carers were, thereby protecting those they cared for. Practical measures were taken by organisations to support disabled people and to help raise awareness, such as producing exemption lanyards for those unable to wear masks.

There was some critical feedback from individuals about the third sector. Those in receipt of social care expressed concern about cuts to their provision and particularly the closure of some day services; it is important to note, however, that these were systemic changes that affected all providers across the social care sector (Pearson et al, 2022). Others complained about limited access to third sector staff who were unable to visit because of the restrictions. Overwhelmingly, however, participants were positive and many glowing in their recounting of the role the sector played in their lives. The sector's impact was summarised by a manager from a DPO operating in the Scottish Highlands:

> I'm not sure that that's fully understood because without the work that the third sector have done, in supporting our members and supporting the wider community, we'd have been on our knees (SK8).

The research highlights the responsiveness of the third sector and the vital role it played in the lives of disabled people. The sector's agility is in stark contrast with the experiences of many participants in accessing statutory services.

The role of the state

In contrast to the sector's response being 'fleet of foot', statutory services appeared to be 'caught on the back foot'. The UK and Scottish governments both passed legislation to respond to the COVID-19 pandemic. There was evidence of a significant reduction and in some cases withdrawal of statutory services, particularly in social care, where the prioritisation was on hospitals and then care homes (Pearson et al, 2022). The needs of disabled people, particularly those receiving domiciliary care, did not appear to have been considered, leaving individuals to organise alternatives to care and to negotiate Personal Protective Equipment procurement for themselves. For some participants this led to a reliance on the family or other informal carers, in some cases necessitating a return to the family home. The cuts left many concerned about the long-term future of their care packages, fearing their ability to manage during the pandemic would be seen as evidence of a reduced need for state support.

Where statutory services failed, the third sector stepped in to support people. Arthur, a man with a physical impairment and mental health issues, described his role in providing peer support through his affiliation with a local organisation:

> So, lots of people that haven't been getting support have been washing up on my doorstep… I'm hoping to solve little problems before they become major issues… I don't begrudge the help I'm giving to people … My anger and upset is towards the statutory organisations, not towards the people I'm helping (S12).

In the follow up interview, he noted the challenge of providing support: "when one couple has gone from 21 hours … professional support a week down to less than an hour, it takes a lot for peer support to make up that kind of difference" (2S12). Jason felt that government initiatives were not helping him; he stated, "I've been reliant on… the community initiatives" (E29). Amanda, a woman with dementia, described receiving exercises from a charity that was concerned about her frailness; she commented, "and I needed to build up. And because of lockdown, I haven't had the input from professionals to help me build up" (S01). The third sector's central role was referenced by many participants, with several using the language of the sector "filling the gaps". Caitlin, a woman with a physical impairment, commented, "The people that are helping out most are the charities, they're catching people falling through the net" (S07).

Statutory services relied on the third sector to provide support and reach vulnerable people. DPOs were contacted by local authorities for support in contacting disabled people; a DPO chief executive in Scotland commented, "the local authority needed us in some ways to know what was happening" (2SK1). Belinda struggled to get mental health support from her GP: "I just got told that they weren't

doing routine services any longer. They put up a website, where they got a list of charities which offers support" (E26). Across participants there was strong criticism about the inadequacy of the state's response and the difficulty of accessing support, or even making contact. Participants described trying to reach statutory workers, spending hours calling a number that was constantly busy.

In Scotland there was a noted contrast between the experience of participants with local authorities and their opinion of the Scottish government, which was widely credited for strong and clear leadership, particularly through the daily briefings. DPOs spoke about the efforts of civil servants and senior politicians to reach out to disability organisations to gain an understanding of the needs of disabled people. Many DPOs had easy access to senior civil servants and Ministers and were regularly consulted through the pandemic. An organisation that works with people with profound and multiple learning disabilities recounted the efforts of a particularly committed senior civil servant who took on the community's concerns about the need for people with learning disabilities to retain their personal assistants when in hospital. This advocacy led to Jeane Freeman, then Cabinet Secretary for Health and Sport, issuing guidance to the NHS, Health and Social Care Partnerships and social work departments indicating that social care packages were to be maintained in hospital (Freeman, 2020). This example demonstrates the close working relationship between DPOs, their families and the national government, a closeness facilitated in part by Scotland's smaller size comparative to England, as well as the Scottish Government's proactive approach to the sector.

In both England and Scotland, the state played a key role in providing funds to the third sector, enabling it to respond to community need. The response was quick in Scotland, whereas the Westminster government was much slower to respond with UK-wide funding and did so only after a concerted campaign by infrastructure organisations (Harris, 2021; Dayson and Damm, 2020; Macmillan, 2020). The state and other funders, both in England and Scotland, loosened their administrative and budget oversight allowing organisations to repurpose budgets enabling them to respond flexibly and quickly. The chief executive of a DPO reflected on the impact of this change:

> Actually, that has been really welcomed, because it's meant that, you know, you're not jumping through hoops for hoops sake (2SK3).

Despite the provision of emergency funding and the experience of being trusted by the state, DPOs in the second round of interviews reported that they were seeing signs of traditional ways of working returning and funds drying up. This was also evidenced in the experience of individuals, as reflected by Hannah who stated, "But the funding's changed and all the classes have changed to

fortnightly… that's when things get difficult when you've nothing to look forward to (2S21). The shifting relations between sector and state is aptly captured by a DPO chief executive:

> So a lot of us are quite anxious that we're starting to see controls taken back. 'Cause there was a ceding of power. And I don't think this is about third sector versus private sector. For me, this is about citizen first. How do we put the citizen really, truly at the heart of the design of what's coming next? (2SK19).

Despite its financial insecurity and the precarity of its workers, the third sector, rather than the state, acted as a bulwark for many. The state's reliance on the third sector raises questions about the relationship between sector and state and what the future holds as we emerge from the pandemic. Stan, a man with a dual sensory impairment, suggested, "maybe it's better that the charities do this [provide support services] and leave the government to get on with doing the governing that they've got to do" (2E22).

Discussion and implications

While the state had an active role in steering society through the pandemic, for many disabled people in our study it was the third sector that provided the help and support needed. The pandemic exposed deep cracks in the state's ability to respond to crisis conditions, whilst highlighting the flexibility and responsiveness of the third sector. Established third sector organisations and emergent initiatives, such as locally organised mutual aid groups, stepped into the breach created by the withdrawal, temporary cessation and inaccessibility of statutory health and social care services.

Crises such as the pandemic both highlight and test third sector-state relations (Kövér, 2021). COVID-19 has demonstrated how central the third sector is in society, playing a vital role in responding innovatively to citizens' needs. The sector has been a core partner to the state, a role that extends far beyond that of delivery agent. The state relied on the sector in multiple ways; for example, our study provides evidence of the state's reliance on the sector's relationships and contacts to identify vulnerable citizens who were prioritised for support, as well as on the sector's role in providing direct support. Our findings also show that the sector was at the frontlines in responding to basic needs, such as access to food and medication; findings consistent with other evidence (Armstrong and Pickering, 2020; Bynner et al, 2021; Harris, 2021). While both governments prioritised those most vulnerable through its shielding programme, they relied on the sector and grassroots community responses to address the needs of the majority, which included many disabled people. Clearly the sector could not and should not be relied on to meet the needs of all citizens; this is the

role of government. However, the pandemic highlighted the limitations of the state and the essential role of the sector, and civil society more broadly, in the vanguard of crisis response.

Where the state did play a transformative role was in relaxing its regulatory and monitoring role of the third sector. In England, Charity Commission guidelines were loosened, enabling the sector to mobilise support in health and social care (Harris, 2021). The financial support and permissive authority of the state and other funders enabled organisations to repurpose budgets, commit resources where needed and test out new models of support. For many, this new approach changed the power dynamics between state and third sector partners, resulting in true partnership working, valuing third sector organisations as equals and recognising their unique role in communities. The state looked to and relied on the sector for their leadership in the pandemic response. The shift in the relationship highlights the recognition of the third sector's proximity to and connection with citizens, situating the sector within civil society rather than more instrumentally as a service delivery mechanism to government. The closeness of the third sector to citizens, its roots in communities, its knowledge of people and their needs and its ability to respond nimbly to those needs, highlight the unique strength and positioning of the sector. It confirms the widely held belief of the sector as responsive, dynamic and innovative, a conclusion also reached by others (Harris, 2021). The sector's distinctiveness lies in its embeddedness in civil society, its mission-based ethos and its ability to nurture, build and mobilise social capital.

As noted, Young's (2000, 2006) framework posits that the third sector acts in roles that are supplementary (fulfilling demand not met by the state), complementary (working as a partner with the state to fulfil demand) and adversarial (challenging the state). The framework treats the sector as additional or oppositional to the state, as residual to the state rather than central. The crisis conditions of the pandemic highlighted the weaknesses of the state in responding to its citizens; its focus on the NHS and those deemed most vulnerable had a significant impact on disabled people in care homes, on those receiving domiciliary care and on people reliant on day services (Pearson et al, 2022) and on people with learning disabilities (Scherer et al, 2022). The pandemic brings the assumptions of the sector's residual status into question. Through the pandemic, the sector stepped into the void left by the state, in areas that are the domain of the state and where there is a statutory responsibility. The sector was a central actor, responding to need and substituting for the state, providing emergency cover. Where the state withdrew from its role, the sector stepped in. What is unique about the pandemic is that the state became reliant on the sector to support citizens in areas that are arguably the responsibility of the state. The sector, despite its significantly lesser status in terms of resources and capacity, mobilised effectively in the face of the pandemic and was able to reach citizens in ways that the state could not and did not. Importantly, the sector's ability to

respond was, in part, enabled by the state which made resources available, allowed organisations more agency in utilising resources and relaxed oversight measures. The state's reliance on the sector highlights the importance of state funding, ensuring the sector is equipped to respond nimbly to emergencies. A secure third sector ensures that citizens have a safety net.

The appropriateness of Young's model as a way of understanding the relationship between the third sector and the state has been brought into question by the pandemic. The simplicity of the model fails to capture the complexity of the relationship and the unique role played by the sector. Most of the organisations we spoke to were funded to some degree by the state, hence their role was not supplementary; most were active in fighting for the rights of disabled people so were clearly in an adversarial role. The complementary role, then, is the only way through which to understand the sector's vital and strategic leadership throughout the pandemic both in its partnership with the state and in the daily lives of disabled people. The framework, however, presents the relationship as a subsidiary one in which the sector acts in a support role rather than a strategic leadership role. The state is viewed as being in the driving seat, complemented by the third sector. This view does not reflect our findings which suggest that the sector played a vital co-piloting role, suggesting in fact that the state was dependent on the sector. This dependence is not captured in Young's conception of a complementary third sector role. The pandemic requires an expansion of Young's complementary role in order to extend the relationship with the third sector beyond that of a utilitarian, subordinate one. The pandemic has shown the importance of the sector as a *strategic partner* to the state, taking leadership in responding to citizens' needs even in areas that are the state's responsibility. Further, the pandemic highlights the significant interdependence between the third sector and the state.

Significantly, the pandemic raises questions about the effectiveness on relying on models such as Young's that are rooted in economic theories that do not consider the communitarian dimension of the third sector. These instrumental approaches are based in the individualism of rational choice theory concerning the fulfilment of service demand, reflected in Young's characterisation: "Through the complementary lens we see one sector engaging the other in order to get the public's business done together" (2006, p52). While often cited in third sector literature, the pandemic has raised new questions about the appropriateness of this model for describing the role of the third sector in society. The strength of the sector's roots in civil society, and its ability to be agile and mobilise resources in response to the pandemic, have highlighted what is distinct about the sector. Our reliance on demand and supply models to understand the sector-state relationship constrains our understanding of the sector, divorcing it from its civil society roots. It is time for us to develop theoretical models that bring together both the sector's communitarian and service dimensions.

On the stage where third sector-state relationships have played out, the pandemic has seen the sector playing a leading role, after years of being considered a lesser member of the cast. The sector's role has been widely recognised and celebrated. For example, the Social Renewal Advisory Board (2021) initiated by the Scottish Government brought together diverse stakeholders to make proposals for how Scotland could benefit from the lessons and different ways of working seen through the pandemic. The final report places civil society in general and the third sector in particular at the heart of change. However, despite the calls to "build back fairer", and the wide recognition of the critical role played by the sector, there is a real concern that the opportunity to have meaningful debate about the future role of the sector will be usurped by path dependency in the way the state operates. Kövér (2021) questions whether changes in relations precipitated by COVID-19 will lead to "a real structural revaluation... or will the aftermath take the form of a carnival, where everyone leaves their comfort zone for a while, but ultimately returns to their routines when the fantasy ends" (2021, p21). In our second round of interviews, some organisations commented on the resumption of pre-pandemic relationships, with statutory actors curtailing freedom to innovate, tightening oversight and restricting funding. In addition to concerns about the state reverting to type, there are also serious questions about the pandemic's deleterious impact on the sector. Organisations have reported financial challenges, reduced staff, concerns about potential growth in services and decreased capacity and fears about the future of state funding (PBE, 2021). Burnout and the mental health impacts on staff are also a concern (SCVO, 2020).

For those within the sector, and the people supported by it, there is a deep hope that emergence from the pandemic will not be accompanied with a "return to [the] routine" (Kövér, 2021). The sector's leadership during the pandemic has provided a glimpse into its capacity and unique ability to work closely in and with communities. The pandemic has shown that a more equitable partnership with the state is possible, one where organisations are treated as peers rather than contractors. While there will always be a power differential, there is potential for a change in the underlying conditions of sector-state relationships. To achieve "a real structural revaluation" (Kövér, 2021, p21), lessons from the pandemic need to be learned and operationalised. Key amongst these is that the sector needs to be trusted and empowered to respond to the needs of its communities.

As we emerge from the pandemic and continue to reflect on and analyse the sector-state relationship, we need to further develop our theoretical tools. The demand and supply models that have been used to analyse sector-state relationships have focused on only one aspect, reflecting a utilitarian view of the sector. The sector's response to the pandemic has underscored the more complex role of the sector as a reflection and enabler of civil society, building and mobilising social capital. Future models need to be developed that bring together, rather than compartmentalise, the

sector's multifaceted role, emphasising the value of the sector's deep roots in civil society and enabling a more comprehensive analysis of the sector state relationship.

Notes

References

Armstrong, S. and Pickering, L. (2020) Left out and locked down: Impacts of COVID-19 lockdown for marginalised groups in Scotland, University of Glasgow https://scotlandinlockdown.files.wordpress.com/2020/12/scotlock_project_report_full_dec2020-2.pdf

Barnes, C. and Mercer, G. (2006) Independent futures. Creating user-led disability services in a disabling society, Bristol, Policy Press.

Brandsen, T., Trommel, W. and Verschuere, B. (2014) Manufacturing civil society: practices, principles and effects, IIAS Series: Governance and Public Management, Basingstoke, Palgrave Macmillan.

Bridge, S., Murtagh, B. and O'Neill, K. (2020) Understanding the social economy and the third sector, Bloomsbury Publishing.

Bynner, C., McBride, M. and Weakley S. (2021) COVID-19 pandemic: The essential role of the voluntary sector in emergency response and resilience planning, *Voluntary Sector Review* (Online 16 July).

Campbell, J. and Oliver, M. (1996) *Disability politics: understanding our past, changing our future*, London, Routledge.

Cote S. and T. Healy. 2001. The well-being of nations. The role of human and social capital. OECD Publishing, Paris.

Cullingworth, J. (2020) Democratic governance through intermediary bodies: a case study of third sector interfaces in Scotland, Doctoral dissertation, University of Glasgow.

Dayson, C. and Damm, C. (2020) Re-making state-civil society relationships during the COVID 19 pandemic? An English perspective, *People, Place and Policy* 14(3): 282-289.

Dayson, C., Bimpson, E., Ellis-Paine, A., Gilbertson, J. and Kara, H. (2021) The 'resilience' of community organisations during the COVID-19 pandemic: absorptive, adaptive and transformational capacity during a crisis response, *Voluntary Sector Review*, 12(2): 295-304.

Dickinson, H., Carey, G. and Kavanagh, A.M. (2020) Personalisation and pandemic: an unforeseen collision course?, *Disability & Society*, 35(6): 1012-1017.

Dickinson, H., Allen, K., Alcock, P., Macmillan, R. and Glasby, J. (2012) *The role of the third sector in delivering social care*. School for Social Care Research.

Dickinson, H. and Glasby, J. (2010) *The personalisation agenda: implications for the third sector* Third Sector Research Centre Working Paper 30.

Egdell, V. and Dutton, M. (2017) Third sector independence: relations with the state in an age of austerity. *Voluntary Sector Review*, *8*(1): 25-40.

Evers, A. (1995) Part of the welfare mix: the third sector as an intermediate area, *Voluntas: International Journal of Voluntary and Nonprofit Organizations*, 2:159-182.

Freeman, J. (2020) Social care in hospital. Letter, 17 November 2020, https://www. sdsscotland.org.uk/wp-content/uploads/2020/11/Letter-Cabinet-Secretary-Social- Care-in-Hospital-17-11-2020.pdf.

Glasgow Disability Alliance. (2020) *Supercharged: a human catastrophe - inequalities, participation and human rights before, during and beyond COVID19*, Glasgow.

Guest, G., MacQueen, K. and Namey, E. (2012) *Applied Thematic Analysis*, London, Sage.

Harris, M. (2021) Familiar patterns and new initiatives: UK civil society and government initial responses to the Covid-19 Crisis. *Nonprofit Policy Forum* 12(1): 25-44.

Hilton, M., Crowson, N., Mouhot, J. F. and McKay, J. (2012) A Historical Guide to NGOs in Britain. Charities, Civil Society and the Voluntary Sector, Basingstoke: Palgrave Macmillan.Kelly, J. (2007) Reforming public services in the UK: bringing in the third sector, *Public Administration,* 85(4): 1003-1022.

Kövér, A. 2021 The Relationship between government and civil society in the era of COVID-19, *Nonprofit Policy Forum* 12(1): 1-24.

Lewis, J. (1999) Reviewing the relationship between the voluntary sector and the state in Britain in the 1990s, *Voluntas*, 10(3): 255-270.

Inclusion London. (2020) Abandoned, forgotten, ignored: the impact of the Coronavirus pandemic on disabled people: interim report, London. https://www.inclusionlondon.org.uk/wp-content/uploads/2020/06/Abandoned-Forgotten-and-Ignored-Final-1.pdf

Macmillan, R. (2020) Somewhere over the rainbow – third sector research in and beyond coronavirus, *Voluntary Sector Review*, 11(2): 129–136.

Mason, J. (2002) Qualitative researching, 2nd ed, London, Sage Publications.

McMullin, C. (2021) Migrant integration services and coping with the digital divide: challenges and opportunities of the COVID-19 pandemic. *Voluntary Sector Review* 12(1): 129-136.

Milbourne, L. (2013) Voluntary sector in transition: hard times or new opportunities? Bristol, Policy Press.

Milbourne, L. and Murray, U. (2017) Civil society organisations in turbulent times: a gilded web? London, UCL Institute of Education Press.

Office for National Statistics (2020) Coronavirus (COVID-19) related deaths by disability status, England and Wales: 2 March to 15 May 2020, London: ONS.

https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/2marchto14july2020

Office for National Statistics. (2019) Exploring the UK's digital divide, London: ONS
https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04#:~:text=For%20internet%20non-users%20aged,aged%2075%20years%20and%20older

Pearson, C., Watson, N., Brunner, R., Cullingworth, J., Hameed, S., Scherer, N. and Shakespeare, T. (2022) Covid-19 and the crisis in social care: Exploring the experiences of disabled people in the pandemic. *Social Policy and Society*, Online: 1-16.

Pestoff V. (2018) Co-production at the crossroads of public administration regimes, in T. Brandsen, T. Steen and B. Verschuere B (eds) *Co-production and Co-creation: Engaging Citizens in Public Services.* London, Routledge, pp.27-36.

ProBono Economics (2021) *PBE Charity Tracker*, ProBono Economics in partnership with Charity Finance Group and the Chartered Institute of Fundraising, London
https://www.probonoeconomics.com/quarterly-covid-charity-tracker-survey-results-april-2021

Public Health England (2020) Deaths of people identified as having learning disabilities with COVID-19 in England in the spring of 2020. https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities

Putnam, R. (2000) Bowling alone, New York: Simon & Schuster.

Smith, S.R. and Gronbjerg, K.A. (2006) Scope and theory of government-nonprofit relations, in G. Sonnevi (ed), *The nonprofit sector: A research handbook*, 2nd ed, New Haven, Yale University Press.

Rendall, J., Curtin, M., Roy, M.J, and Teasdale, S. (2022) Relationships between community-led mutual aid groups and the state during the COVID-19 pandemic: complementary, supplementary, or adversarial? *Public Management Review*, 1-21. DOI:10.1080/14719037.2022.2084769

Rittel, H.W.J. and Webber, J. (1973) Dilemmas in a General Theory of Planning, *Policy Sciences* 4(2), pp 155-169.

Scherer, N., Wiseman, P., Watson, N., Brunner, R., Cullingworth, J., Hameed, S., Pearson, C. and Shakespeare, T. (2022). 'Do they ever think about people like us?': The experiences of people with learning disabilities in England and Scotland during the COVID-19 pandemic. *Critical Social Policy*, Online: 1-25.

Scottish Renewal Advisory Board (2021) If not now, when? The Scottish Renewal Advisory Board report. https://www.gov.scot/publications/not-now-social-renewal-advisory-board-report-january-2021/documents/

SCVO (2020) *Coronavirus and the impact on the third sector: a review of the literature*, SCVO. https://scvo.scot/policy/research/evidence-library/2021-coronavirus-and-its-impact-on-the-scottish-third-sector-a-review-of-the-literature-september-december-2020

Shakespeare, T., Ndagire, F. and Seketi, Q.E. (2021) Triple jeopardy: disabled people and the COVID-19 pandemic, *The Lancet*, 397(10282): 1331-1333.

Shakespeare, T., Watson, N., Brunner, R., Cullingworth, J., Hameed, S., Scherer, N., Pearson, C. and Reichenberger, V. (2022) Disabled people in Britain and the impact of the COVID-19 pandemic, *Social Policy & Administration*, 56(1): 103-117.

Thiery, H., Cook, J., Burchell, J., Ballantyne, E., Walkley, F. and McNeill, J. (2021) 'Never more needed' yet never more stretched: reflections on the role of the voluntary sector during the COVID-19 pandemic, *Voluntary Sector Review* 12(3): 459-465.

Treanor, M. C., Patrick, R. and Wenham, A. (2021) Qualitative longitudinal research: from monochrome to technicolour, *Social Policy and Society*, 20(4): 635-651.

Wolch, J. (1989) The shadow state: transformations in the voluntary sector, in J. Wolch, M. Dear (eds), *The power of geography: how territory shapes social life.* Republished 2014, Oxon, Routledge, pp.197-221.

Young, D. (2000) Alternative models of government-nonprofit sector relations: theoretical and international perspectives, *Nonprofit and Voluntary Sector Quarterly*, 29(1):149-172.

Young, D. (2006) Complementary, supplementary or adversarial? A theoretical and historical examination of nonprofit-government relations in US, in E. Boris and C. Steuerle (eds.) *Nonprofits & Government: Collaboration & Conflict,* 1st ed, Urban Institute Press, pp.31-67.