

# Strengthening the Voice of Disabled People in Bristol:

2020

Self-Organisation, Co-Production,  
and Decision Making



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# Preface

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**Disabled People in Bristol have a long and proud history of organising to advance their interests and to push for a greater say over how their communities and city are run.**

Since the late 1980s, Disabled People's Organisations (DPOs) - which are controlled by the disabled people they represent - have been a constant presence within the city in the form of campaigning and lobbying groups, providers of services, or venues for peer support and empowerment. Through the work that DPOs have done, and the challenges they've raised to policies and practices which disempower their members; the way in which Bristolians think about everything from social care to public space and community politics have been affected.

Despite over thirty years of activity and a significant impact on Bristol's civic life, limited attention has been paid to DPOs in Bristol by those interested in the city's community history, or those who investigate its social policy. Instead,

DPOs within Bristol have taken the initiative to describe their own histories, activities, demands, and visions of Bristol's future themselves: with the Bristol Disability Equality Forum's (BDEF's) Forging Our Futures project developing an historical account of the development of DPOs and the Disabled People's Movement in Bristol, and this report giving an account of the current position and activities of DPOs in the city, along with the challenges they face to increasing disabled people's influence over decisions made about their lives.

The current moment allows us to capture both the strength and resilience of DPOs in Bristol as a whole, alongside very real threats to the growth and continued existence of some DPOs - which threaten the representation of disabled people in local decision making processes and their support to take greater control over their lives.





**The last decade has been very difficult for DPOs and the wider Disabled People's Movement across Britain; with the effects of austerity on both disabled individuals and commissioners' budgets forcing DPOs to do more work with fewer resources and leading many to close down entirely.**

Although two important organisations led by disabled people in Bristol closed in the mid-2010s, the majority survived remarkably well compared to elsewhere in the country.

By 2019 many were expanding their influence while new organisations of disabled people were formed to address challenges that had arisen in the previous years. One reason for this success was the flexibility and innovation shown by many disabled activists and organisations; who were able to quickly adapt their activities to address new problems and fit into stricter local government commissioning rules. Another was a much improved understanding of disability equality and the role of disabled people-led groups by some senior staff in the local authority and Clinical Commissioning Group (CCG) towards the end of the decade.

Adapting to the new environment was not, however, either cost free or entirely positive for DPOs; as organisations' changing strategies made it harder for DPOs to coordinate their activities to maximise their influence, while reduced funding and community services led some to worry about maintaining the quality of their responses to increased levels of need caused by austerity.

The original remit for this project, research for which began in May 2020, was to take stock of what DPOs remained active in Bristol and find out: what they do, their aims and visions, how they see their role in the city, and the biggest challenges facing them.

The first of these questions was complicated by the Coronavirus pandemic; during which a number of smaller DPOs suspended their activities and have yet to resume them. For those which continued their work, and provided spokespeople for this research, their answers to the remaining questions were very different from ones they might have given 6 months earlier.

True to the innovation and adaptability they'd shown over the previous decade; DPOs in Bristol responded to a crisis that caused real hardship amongst

disabled people and increased their social exclusion by extending their work to new areas of disabled people's lives.

**Throughout the pandemic, groups and organisations governed by disabled people have addressed problems resulting from coronavirus responses in the public and private sectors in ways that other organisations were unable to.**

These have included providing information on disabled people's rights under emergency legislation, challenging exclusionary and discriminatory policies adopted by local and national government or health services, co-designing policies with transport companies and GP surgeries incorporate disabled people's access needs in their social distancing measures, and providing advice and support to disabled individuals whose access to the services and materials they need had been suspended. It is clear that, without the swift and robust response of DPOs, many Disabled people in the city would have been excluded from decisions affecting them and left with little support.

The combination of the challenges of the 2010s and the unique difficulties of the last year for disabled people and their organisations, reflected in the rest of this report, expose uncomfortable truths about how well disabled people are included in Bristol's civic life, public spaces, and community services. The contributions of DPO spokespeople, however, are not limited to identifying failings by other actors. Their experience of re-evaluating their work to address new obstacles to members' and users' exercising their rights has given DPOs insights into how Bristol and its public institutions can bring disabled citizens into the heart of everything that happens in the city.

**While much of this report is unavoidably critical of how local governments, health services, and other decision makers have engaged with disabled people, these criticisms contain practical steps towards rectifying the problems that they identify; and compelling visions for how Bristol can recover from Coronavirus without leaving any of its citizens behind.**

While we feel that this report does take stock of where DPOs in Bristol have arrived after a tumultuous decade; we also believe that it points further forward than the present moment; incorporating plausible visions for the future and important warnings about risks that may emerge.

The first section of this document makes an argument for DPOs as a key element of any sustainable project for disability equality, explains the theoretical and methodological framework that motivated our research, and lists the DPOs active in Bristol up until the Coronavirus pandemic began. In Section 2, a sketch is made of the challenges to disability equality and empowerment that arose around the country in the 2010s - focusing particularly on how these affected DPOs and on the impact of the closure of two Bristolian DPOs on the communities they served.

The strategic responses of DPOs in the city to the difficulties of the last decade is described in section 3, alongside concerns from spokespeople that limited and uncoordinated reactions to some of those challenges have failed to address important issues of disability equality in the city.

As many of the tactics that DPOs adopted, and much of recent policy making in Bristol as a whole, rely on the establishment of partnerships with diverse other organisations; Section 4 addresses DPOs varied and mixed experience of co-producing projects with state bodies, private firms, and other third sector organisations.

Worries are raised about the level of understanding of disability equality and co-production amongst different local actors, as well as instances of disabled activists' knowledge and skills being exploited by other agencies without respect for their status as partners.

**Examples of good practice are identified and described, and disabled activists' suggestions for promoting the sharing of expertise and genuine partnership working are outlined.**

The final Section reports the activities of DPOs during the first wave of the Coronavirus pandemic, and indicates the ways in which grappling with the most dramatic change in disabled people's social position in the last twenty years

has allowed DPOs to prove again their importance to the disabled population, and develop their abilities to create meaningful change: supporting the city as a whole to function during a period of crisis.







# Section 1: Introduction

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## Background:

This report, carried out by WECIL (West of England Centre for Inclusive Living), was undertaken to explore three key areas of the experience of Disabled People's Organisations (DPOs) currently operating in Bristol. Firstly, to find out the level of activity of DPOs in the city following the 2008 financial crisis and subsequent austerity period - in which many DPOs and other user-led organisations around the country were forced to close down. This level of activity can be partially assessed by the number of DPOs which remain active in Bristol, the number of activities they engage in and the impact of these activities, and their assessments of their (current and future) capacity to engage in projects relevant to their remits. In addition, it is necessary to ask a number of qualitative questions in order to set this activity in context: such as what DPOs believe their role in the life of the city to be, what forms of civic involvement they aspire to in future, and the extent to which their current activities cohere with these roles and aspirations.

Secondly, this report attempts to evaluate the strength of disabled people's and DPOs' "voice" within Bristol's civic discourse - including their influence on the forms in which services are provided to disabled people by state and private agencies, their impact on the city's cultural life, and their inclusion in decision-making processes regarding city- and region-wide policy. From the late 1980s until the mid-2000s, the influence of DPOs in Bristol was largely concentrated in two kinds of forum: the (West of England/Avon) Coalition of Disabled People - a campaigning body made up of DPOs and individual disabled people which intervened in cultural and political debates within the city and exerted external pressure on public and private sector actors to promote disability equality - and policy consultation and implementation boards internal to Bristol City Council (BCC) in which DPO representatives scrutinised and co-produced policy alongside Council Officers and other relevant professionals.

The Coalition folded in 2006, leaving no central organisation to coordinate the activities of DPOs within Bristol. In

the years that followed, two previously internal BCC bodies which addressed disability equality and service provision - it's Disability Equality Forum and Physical Access Chain - became separated from the Council, while others ceased to meet.

The structures of regional governance changed substantially during the 2010s; with the steady division of powers previously held by BCC between the council, the Mayoralty (introduced in 2012), and the West of England Combined Authority (a regional arm of government, formed in 2017, covering Bristol and its neighbouring councils and with control of central government spending on transport, housing,

education and adult training). Decision making over policy in Bristol is further dispersed through the One City Plan: an initiative launched by the Mayor's office in 2016 to 'facilitat(e) participation and collective leadership between many different sectors and organisations' within the city - including private sector firms, universities, sports clubs, and charities - in order to develop policy orientations on issues of connectivity, sustainability, housing, education, health and wellbeing, and the local economy (Bristol One City: 2020, p 6). To date, no systematic attempt has been made to assess the effect of these governance changes on disabled people's self-representation and self-organisation; nor to identify what



opportunities or barriers exist within these new forms of decision making for disabled people and their organisations.

Finally, this research aims to indicate what basis currently exists for disabled people and DPOs to engage in projects of social transformation - whether these be practical or political. Such a basis is constituted by both the level of influence which disabled people collectively exert on decision makers in the various branches of local government (including the local Clinical Commissioning Group, or CCG) in order to change their practices, and the possibilities for disabled people and their allies to engage in activities which change the social landscape of the city independently of local or regional governing bodies.

Being able to take part in projects of the latter type relies not only on the organisational capacity of DPOs across the city, but on their level of independence from city governance, and their ability to mobilise alongside other social actors - including other DPOs and those who have traditionally been marginalised because of race, gender, sexual orientation, or religion. The scope of this basis cannot be reduced simply to analyses of singular organisations or structures of regional governance;

but must engage with complex political and sociological questions; including those of the ideological and practical relationships between DPOs themselves and with other representative groups, the relationship between DPOs and a disabled population increasingly isolated by changes to support budgets and welfare payments, and the extent to which recent changes in disabled people's social position have been recognised and acted upon by DPOs.

## What is a DPO?

At its most basic level, a DPO is an organisation in which disabled people make up the majority of its highest decision-making body (usually a board of Trustees or Management Committee), and which takes action on issues which matter to disabled people. A DPO can be anything from a small activist group to a large service provider - via Community Interest Companies (CICs), local and national lobbying organisations, and bodies which conduct and disseminate research.

Its social and political significance, however, lies in its role of bringing together and mobilising individual disabled people in a shared understanding of their social position. In this regard,





impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression (1976, p 14)

DPOs form the building blocks of ‘a social movement capable of uniting people who have tended to regard disability as an individual experience rather than as a universal form of oppression which has been imposed on physically impaired people by the society in which they live’ (Pagel: 1988, n.p).

The shared understanding of disability which unites the majority of DPOs, and which forms the major theoretical assumption of this report, was first articulated in the 1970s by the Union of the Physically Impaired Against Segregation (UPIAS):

To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called ‘disability’, of people with such impairment. Thus we define

**This premise, known as the ‘social understanding’ or ‘model’ of disability, determines both how we identify who is a disabled person relative to the governance of a DPO; and the extent to which we can assume a single liberatory project underlying all DPOs - regardless of their diverse activities and aims.**

The first point of interest is that, while ‘disability’ occurs where an impairment is present, disability is not the same thing as an impairment and cannot be reduced to one. An impairment is simply a fact about an individual’s organs or body - namely that those differ from the norm

and do not function in a way common to the majority of other bodies or minds. Disability is the restriction, exclusion, or disadvantage that is imposed separately by the way that society is organised - not caused by any fact about an individual body, but by the exclusionary structures, physical and attitudinal barriers, and relations of power we encounter in society as people with impairments. It follows from this that there is no set list of impairments which tell us what kind of person is disabled; its definition is determined by the extent to which people with different types of organs or thought processes find themselves marginalised or discriminated against by the way the world is organised. As such, for the purposes of this report, being a disabled person is defined as: an individual having some difference of physical or mental functioning and identifying themselves as socially disadvantaged because of it.

This definition includes those who have visible impairments - including mobility and sensory impairments and communication difficulties - but also those whose functional difference may not be obvious to a casual observer - such as people with neurological conditions such as epilepsy or hydrocephalus, people who experience mental distress, people

with learning difficulties, or those with conditions whose main effects are regular pain or fatigue.

The second consequence is that disability is characterised as a restriction of activity and an exclusion from the mainstream of social life; exemplified by the existence of segregated housing and facilities, deep rooted unemployment and under-employment, social isolation, and the marginalisation of people with impairments from both democratic processes and decisions about their own lives. The purpose of collective social action by disabled people is to reverse these disadvantages through increasing the range of social activity available to them and integrating their perspective and demands into local and national decision making.

DPOs may achieve this in three ways:

- By building bonds of solidarity between disabled people which encourage the development of individual confidence, mutual support, and community amongst disabled people; leading, ideally, to those involved increasing their level of skills and resilience in order to assert their wishes and needs in day to day life (Mehta, Taggart, Clifford & Speed: 2020, p 14).
- By representing and acting on the views and wishes of its members and the wider disabled community; including lobbying

and consulting with local and national government and providers of disability services, engaging in campaigns to build support for disabled people's demands, and establishing resources and services required by disabled people to promote their social engagement. Due to the fact that those who control the organisation are those who are excluded and marginalised within wider society, DPOs are able to 'respond more effectively to the rallying cry of 'Nothing About Us Without Us' (...) and the growing realisation of the importance of including disabled people in decisions that concern them.' (Callus: 2014, p 2-3).

- By giving a practical example of disabled people engaging in the social world on their own terms. This example is both a counterweight to prejudices which paint disabled people as vulnerable, passive, and incapable of acting on their own behalf; and an experiment in designing new forms of social interaction and knowledge and with which to critique and replace the barriers to disabled people's full participation in society (Priestly, Waddington & Bressozi: 2010, p 739-40; Finkelstein: 2007, n.p).

While a small peer support or self-help group may only address the first kind of activity, disabled activists have argued that their organisations need to engage

with all three strategies since the early days of the Disabled People's Movement (cf, Mason: 1981; UPIAS: 1981; Davis: 1993; Leaman & Fricke: 1994). In the scope of this report, the majority of DPOs in Bristol can be held to engage in at least two of these strategies - including all of the organisations who provided spokespeople to be interviewed.

In order to capture the range of approaches within DPOs in Bristol, and in recognition of the difficult position within which DPOs have found themselves in recent years both nationally (see Section 2) and locally (see Section 3);

**It was decided that this report would use a broad definition of what constitutes an organisation controlled by disabled people: as any organisation whose highest body contained a majority of disabled people (i.e., where disabled people made up more than 51% of the relevant board or committee).**

Desk based research was conducted to identify which organisations are active in Bristol which meet this definition, and how they described their activities and goals. Subsequently, requests to interview

members or officials were sent to all organisations found. All interviews were semi-structured; meaning that the researcher had a set of questions specifically designed for each interview, and asked unscripted follow up questions after receiving a response. The questions for each interview were designed to spur discussion of the interviewees' understanding of their organisation's goals and strategies, and what they consider to be the most serious barriers to achieving progress towards their ends. As different analyses and strategies entail different kinds of challenges, care was also taken to ensure that questions were sensitive to discussions of how organisations manage potential problems arising in their activity and gave spokespeople an opportunity to share positive experiences and best practice in overcoming these challenges. This involved discussing positive and negative experiences of co-production and joint working with those DPOs who collaborate closely with statutory bodies or external funders, and speaking with 10 those who avoid funding through contracts about how they prioritise their activity in light of minimal resources.

Questions also dealt with issues of organisational capacity, how limits on capacity building had affected

organisations' strategies, and on forms of accountability between those taking organisational decisions and the wider community of disabled people within the DPO and in Bristol itself.

## Methodology and Challenges

Methodological decisions for conducting this research were motivated by critiques within the Disabled People's Movement of approaches towards disabled people and disability in the social sciences and humanities. Most importantly, the author and supervisory team agreed that: a) studies of disability which presume researchers hold greater expertise of the social situation and interests of disabled people than disabled participants reproduce disablist stereotypes of passivity, and are exploitative insofar as they use the knowledge of participants to further the researchers' own claims rather than the concerns of the disabled people (Hunt: 1981); and b) that analyses of disabled people's experience which do not take seriously their claims of how and why they find themselves excluded and marginalised cannot capture the historical context of disability exclusion, or the insights of disabled people as to how this exclusion could be reversed.





Instead, these approaches give rise to a ‘theoretical myopia’ (Abberley: 1987, p 18) which does not treat the information offered by participants as their well-considered view of the exclusion they face - backed up by their practical experience of challenging marginalisation or attempting to lessen its effects. To avoid these approaches when conducting the research; considerable effort was taken to design a research plan that would be accountable to the organisations taking part, and which would be underpinned by assumptions and concerns shared across them. The social understanding or ‘model’ of disability, subscribed to by most DPOs, is the theoretical framework within which the research took place. While different disabled activists hold

different interpretations of the social understanding and, in particular, which elements of modern society are most significant in excluding or empowering disabled people (see Barnes & Mercer: 2006, pp 80-82; Beesley: 2019); the social understanding provides a shared language within which to ask questions about the movement’s development and challenges.

Within this framework, questions of the success of DPOs in enacting their strategies to promote disability equality are understood as fundamentally about the relationship between disabled people, their organisations, and wider social processes: including economic and cultural changes, projects of local and national governments, reorganisations of health and education services, etc. Similarly, operational or strategic problems arising within DPOs - where an organisation finds that it is unable to continue working in the same way, or where a conflict arises over what it’s role and activities should be - are understood as reflecting tensions and complexities in the relationship between disabled people and the rest of society. Attempts to resolve these organisational problems are, then, thought about as ways of managing and responding to wider social developments by an organisation

impacted by them, rather than as simply the result of the wishes or ideas of those who make up DPOs' management, boards, or committees.

Similarly, accepting the premise of the social understanding of disability allows us to assert both that the exclusion of disabled people is not inevitable, and that this exclusion is manifested in a number of different ways throughout society - including discrimination in access to employment and education, failures of representation within democratic processes and policy planning, the existence of prejudice and bigotry towards disabled people in their communities, and an inaccessible built environment. It follows that no one type of organisation, and no single organisational strategy, will be able to overcome the varied and complex barriers to disabled people's full integration in society. The working assumption of this report is that the flourishing of multiple DPOs with separate (even contradictory) analyses of disabled people's social position (and strategies to confront it) is vital to empowering disabled people locally and nationally; and is an end that should be promoted by all committed to building a more equal and inclusive society.

Following Priestly (1997) the research team attempted to overcome problems of accountability by 'placing [the researcher's] skills "at the disposal" of the research participants (...) [so that] the research production process could be collectivised amongst its participants' (p 88). In practice, this involved a three-stage process to ensure that data collected through interviews reflected the concerns and priorities of interviewees, and was used in the report in a way that was faithful to their arguments and reflected their understanding of the situation of disabled people in Bristol.

**A list of interview questions was sent to all participants prior to interviews, with a message that they were free to object to any question or indicate that they would like to discuss a topic not covered in them;**

transcripts of each interview were then sent back to the participant to allow them to correct or amend anything recorded - allowing the interviewee an opportunity to rephrase or add anything that they felt was important to their argument. Finally, a draft copy of this

report was sent to all participants prior to publication; allowing participating organisations to query or raise objections to how interview data had been used, and with the option of penning a rejoinder to be published alongside the report if they did not feel their concerns had been addressed in subsequent re-drafting - although no organisation pursued this option. In addition to control over data, participating organisations were encouraged to nominate multiple spokespeople if they felt this best reflected the scope of their activity or the variety of views and experience within them. In one case (that of WECIL) this led to three different interviews with spokespeople holding different organisational roles; in another (that of Bristol Reclaiming Independent Living), this involved two panel interviews of six activists representing different experiences of disablement and disability organising in the city.

The project as a whole was conducted by a disabled researcher (Luke Beesley) committed to emancipatory disability politics, and supervised by two WECIL trustees (Ruth Pickersgill and Alun Davies). The final version of this report was not published until it was approved by WECIL's trustees as an accurate reflection of the situation of DPOs in



Bristol, and as containing information useful to strengthening the Disabled People's Movement.

The beginning of the research project in April 2020 coincided with the first spike of the Coronavirus pandemic in Britain; an event which forced all civic organisations to fundamentally alter the ways in which they work. For disabled people and their organisations, changes to campaign and service priorities were felt particularly sharply. As we and the research participants argue in Section 5: both the Coronavirus pandemic and responses to it across society intensified disabled people's exclusion, placing many disabled people in positions of extreme material hardship, rolling

back social and civic rights for disabled people as a whole, and costing many disabled people their lives. In this climate, DPOs across the country were forced not only to migrate as much of their activity as possible online (and to grapple with the comparatively low levels of internet access amongst disabled people while doing so), but to confront a social world whose hostility to the most basic demands of disabled people had increased seemingly overnight. As we recount, the actions of DPOs in Bristol in the face of this situation were innovative and impressive; it would be naive, however, not to assume that the challenges posed by the pandemic and lockdown to both DPOs and the disabled activists within them left many with little time or energy for engaging in extra work - which is what participating in a research project is. While we believe that the number of responses we received to our call for interviews provides a broadly representative overview of DPOs in Bristol (see below), we are aware that we will have missed insights from those organisations unable to allocate time to respond during the crisis.

A related problem arose in identifying DPOs level of activity during the pandemic, and whether those whose public facing activities had been

suspended intended to resume them when the public health situation permits. Responding organisations made clear to us their immediate plans, as well as their hopes and projections for their role in a post Covid world; but for those who did not respond it is difficult to gauge how, and to what extent, they feel they can continue to intervene in the life of the city - or even if Covid and the response to it has put an end to their organisation in its current form. It is the belief of the team conducting this research that this is a practical problem, not merely one of accurate reporting. If a number of healthy DPOs, responding to the real needs and aspirations of disabled people in Bristol, are forced to close as a result of how the pandemic has been handled; then our social model analysis indicates that this is part of disabled people's marginalisation throughout the pandemic. We also believe that closures of DPOs in this period are neither inevitable nor irreversible; and that sufficient action from the state and civil society towards these organisations and the people they represent may allow them (or organisations much like them) to operate successfully.

As such, our survey of active DPOs in Bristol at the end of this section includes those whose websites or newsletters report activity after December 2019<sup>2</sup>



and do not advertise the folding of the organisation - even if we have not been able to verify organisational activity since the end of March 2020 (when the first national lockdown began). While we have no direct testimony from organisations who did not respond to our call for interviews; we believe that many of the challenges they face will be experienced by those DPOs who took part in the project. As such the findings of this report will be, at least indirectly, relevant to non-responding organisations.

More prosaically, the coronavirus pandemic and lockdown had a profound impact on the day-to-day work of conducting the research. It had been planned that the researcher would spend the majority of their working time in Bristol, and would be available to attend meetings and public facing events hosted by participating DPOs while the research was conducted. In this way, it was hoped that the researcher could 'get under the skin' of participating organisations - forming a greater overall picture of how they function and interact with the wider community, building informal rapport with activists and staff outside of an interview setting, and gaining a more practical understanding of the opportunities and challenges to expanding their influence.

Lockdown made this impossible; with all face-to-face contact between people cancelled across the country. While the researcher was able to attend online project meetings run by Bristol Disability Equality Forum (BDEF)<sup>3</sup>, all other contact with DPOs and their spokespeople was carried out via email or video calls specifically around the research. We have attempted to minimise the risk of any misunderstanding on the researcher's part arising from contact being more limited than hoped for by ensuring that participants had as much say as possible over the finished report; but we are aware that it is possible that questions used in interviews would have been better focused and more sensitive to organisations' priorities had it been possible to immerse the researcher more in their operations.

2- A date picked to allow for activity in the financial quarter prior to lockdown, adjusted to reflect the usual impact of the Christmas/New Year break on the activities of voluntary and community organisations.

Finally, and unrelated to the pandemic, much time was spent deciding the time frame on which we asked spokespeople to reflect.

The research team were aware that the current activities of DPOs and forms of disability representation within the city cannot be understood independently from the legacy of disabled people's activism in the 1990s and 2000s. Attempting to integrate the history of disability activism in Bristol over the last thirty years into this current report would, however, stretch its remit and divert from its core task of describing and analysing the current position of DPOs and the strength of disabled people's influence. It would also unnecessarily preempt work being undertaken by BDEF's 'Forging Our Futures' project.

### **A three-pronged approach was taken to support this report to reflect the development of disabled people's social position and representation in Bristol over time.**

Firstly, participating organisations were asked, where possible, to put forward at least one spokesperson who had significant experience of disability activism in the city over the last 20 years (whether in their current organisation or another).

Second, we asked all interviewees to consider the development of their

organisation and activism since 2007 (the year after the Coalition folded, and before the financial crisis of 2008/9); covering a period which includes significant reorganisation of local government and health services, the introduction of the Equality Act, the foundation and closure of numerous national and local DPOs, and programs of welfare reform aimed specifically at disability benefits. In practice, spokespeople who discussed the development of disability activism and self-organisation in Bristol focused on either the mid-to-late 1990s or the early-to-mid 2010s.

Thirdly, we approached a number of disabled activists with experience of working in the Disabled People's Movement in Bristol individually to request contextual interviews focused on the development of disability activism in the city. Of these, we received one response from Liz Crow, not involved in a participating organisation at present, but with experience of working with both the Coalition and WECIL in the past.

## **Disabled People's Organisations in Bristol**

The list below was compiled through a

mixture of internet research (searching 'Bristol', 'Disabled People', 'User-led', 'Disabled People's Organisation' and 'self-organisation' in different combinations), signposting through interviewees and their organisations, and contacting nation- wide DPOs to enquire if they are active in Bristol. When it was unclear if an organisation remained active after December 2019, we sought confirmation either from the organisation or through others that work with them. Where this was impossible to secure, we omitted them from this list.

All organisations below were contacted and invited to take part in this project - either via email or through the contact forms on their webpages.

## Bristol Disability Equality Forum (BDEF):

Formed initially as an equalities committee of Bristol City Council, BDEF is currently governed by a board of trustees - made up of at least 75% disabled people and representatives of other organisations working on disability issues in Bristol. Organised in local groups across the city, and centrally through its office in St Pauls, BDEF uses the insights gained through its outreach work to represent disabled Bristolians in policy consultations and co-production

processes with the local authority, housing providers, and statutory health services. As a campaigning and lobbying organisation, BDEF also offers opportunities for disabled people in the city to raise their concerns directly to decision makers in large meetings and hustings events; as well as through awareness raising on issues that matter to disabled people, providing training on these issues for outside agencies, and supporting groups of disabled people who wish to campaign on an issue.

In 2016, BDEF launched The Disabled People's Manifesto; a wide-ranging policy document based on consultation with local disabled people, and including demands for change across the city in nine key areas of disabled people's lives<sup>4</sup> - engaging with social problems including hate crime, discrimination in employment and education, the accessibility of the lived environment, and the organisation of independent living services for disabled people in the city.

This document is motivated by 'the over-arching theme (...) that it's time to redress the balance between income - generation, (and) the needs of our

most 'advantaged' and disadvantaged residents, including Disabled people' (p 7).

During the pandemic, BDEF successfully lobbied for a dedicated response team in the City Council for disabled people who employ their own PAs to support them with sourcing personal protective equipment and up to date public health guidance, and for disabled people's support workers to be included in the 'key worker' category of the local testing regime. BDEF's ongoing projects include Making Change Happen - a peer support and empowerment group designed to promote disabled people around the city to identify and campaign for the reforms most important to their lives -, and Forging our Future - in which young researchers conduct and disseminate an oral history of disability activism in Bristol, while promoting accessibility to the city's museums and cultural spaces. BDEF provided one spokesperson to be interviewed for this project. <http://bristoldef.org.uk>

### Bristol Epilepsy Network (BEN):

A group of people with epilepsy which hosts peer support fora, discussion groups on topics relevant to

neurodivergent people, and talks from academics and medical professionals. BEN is a member organisation of BIMHN. The Network was forced to cancel all face-to-face activities during the pandemic and it is unclear whether these have yet resumed. BEN did not offer a spokesperson for interview - <https://bristolepilepsysite.wordpress.com/>

### Bristol Hearing Voices Network (BHAVN):

A group of people who hear voices, see visions, or experience other unusual sensory perceptions, set up to challenge stigma related to these experiences and promote techniques for people to take control over intrusive perceptions and their lives. Prior to the lockdown, BHVN ran weekly peer-support sessions which situated intrusive perceptions within a disability rights, rather than medical or psychiatric, framework. BHVN has supported research into non-psychiatric explanations for intrusive perceptions, and ran equalities training on intrusive thoughts and perceptions to public and private sector bodies before the pandemic hit. As part of their outreach work, they have taken part in designing the Experts by Experience program across the city, and have funded four of their members' places on the Time



for Recovery program. BHVN is also a member organisation of BIMHN. They were forced to cancel all face-to-face activities during the lockdown, and it is unclear what activities have resumed as yet. BHVN did not offer a spokesperson for interview - <https://www.hearing-voices.org/groups/bristol-hvn/>

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## Bristol Independent Mental Health Network (BIMHN):

Initially formed as a new services users' group to liaise with the Primary Care Trust in 2010, BIMHN was formally constituted in 2014 and later merged with the Independent Mental Health Network (IMNH); it is currently the largest branch of the IMHN in the country. BIMHN is governed by an elected committee of its members - individuals who have experienced mental distress or ill-health, and self-organised groups of mental health service survivors.

It's organisational remit includes consultation with service providers, raising mental health service users' concerns in service design and lobbying for redesign where necessary, holding decision-makers in mental health services accountable to service users, and awareness training for employers and organisations on the experience of mental distress.

BIMHN is involved in a diverse range of activities: contributing members to the Suicide Prevention Transformation Fund Working Group - which oversees NHS funding for suicide prevention in the city, running user consultations on proposed treatment pathways for those experiencing mental ill-health, promoting community initiatives which challenge mental health stigma alongside the Time To Change programme, hosting feedback events as part of the newly merged Clinical Commissioning Group's (CCG's) review of services, promoting awareness raising events by organisations representing people who experience Obsessive Compulsive Disorder (OCD), and supporting people in Bristol who experience OCD to launch their own self-organised group.

BIMHN is also involved in independent policy recommendation work; most recently as part of the Mental Health and Housing Working Group. This working group identifies the service gaps that exist for those experiencing both mental distress and the risk of homelessness, and makes recommendations to close these using 'BIMHN worked alongside its IMHN partners to provide up-to-date information on how to joined up leadership and action at strategic levels' (Thrive: 2019, p 5). During the pandemic

and lockdowns, access mental health support remotely. BIMHN did not offer a spokesperson to be involved in this project - <https://bimhn.org.uk/>

## Bristol Reclaiming Independent Living (BRIL):

formed in May 2019, BRIL is one of the newer DPOs currently active in Bristol; it's also distinct from other organisations in that the cause for its creation is an explicit critique of existing disability activism and organisations - and in particular of ways in which the language of the Disabled People's Movement has been co-opted and redefined by statutory bodies and charities without sufficient challenge from DPOs. Believing that phrases like 'independent living' and 'choice and control' are now not only being defined in a way unaccountable to disabled people, but are also used to justify the withdrawal of financial and service support which allows them to exert genuine control over their lives; BRIL functions as both a campaigning body and a forum for disabled people to conduct peer-support and identify the issues that affect their lives the most. In order to maintain its independence and ability to challenge any practice that it believes threatens the progress of disability rights, BRIL does not compete

for local authority or NHS funding - although it does engage in dialogue with local government and other service planners on issues that affect disabled people. During the lockdown period, BRIL has campaigned successfully to ensure that people with communication support needs could be visited in hospital by their PAs, and continues to campaign for the involvement of DPOs in planning NHS responses to the pandemic. Adopting, at its founding meeting, the position that disabled asylum seekers should have a right to independent living support; BRIL has been involved in solidarity campaigns for disabled asylum seekers facing the threat of deportation and challenging Home Office decisions. BRIL supports the introduction of a National Independent Living Support Service, free at the point of use and funded by central government, as an alternative to existing social care markets. BRIL provided six spokespeople for interview, of which four confirmed that they were happy with their contribution being used <https://twitter.com/brilliving?lang=en>

## Bristol and South West Disabled People Against Cuts:

The regional branch of Disabled People Against Cuts (DPAC). Vocal supporters of the National Education Union's

'Five Tests' campaign for school safety during the coronavirus pandemic. No spokesperson was offered by the branch for this project - [https://twitter.com/dpac\\_bristol?lang=en](https://twitter.com/dpac_bristol?lang=en)

## Bristol Survivors' Network (BSN):

Initially formed as a branch of Survivors Speak Out in the early 1980s; BSN has since expanded its remit to represent all people with experience of mental distress in Bristol, not only those who've experienced intensive therapeutic treatments or detention. BSN's aim is to share information on developments in MH services and feed back into these processes by issuing comments and statements on how these services are delivered and the assumptions underlying them. BSN campaigns broadly for better quality mental health services, and for a greater respect for service users' voices in how these services are planned and administered; involving campaigning around crisis house provision in Bristol and conducting hospital visits alongside Healthwatch and BIMHN (of which it is an organisational member). Prior to the lockdown, the organisation arranged monthly socials as a forum for peer-support and information gathering. BSN did not offer a

spokesperson to be interviewed for this project - <https://bristolsurvivorsnetwork.wordpress.com/>

## Centre for Deaf and Hard of Hearing People (CDHH):

The CDHH was founded after the closure of Bristol's previous Centre for the Deaf in 2012; and is currently based at the Vassal Centre in Fishponds and run by a different management team to its predecessor. CDHH operates as a resource centre for D/deaf and hard of hearing people in Bristol, and as a vehicle to push for greater integration of D/deaf and hard of hearing people into both the life of the city and the debates which take place about its future. In addition to running an equipment service for home adaptations and supporting Smart Energy GB to ensure that the information about smart meters is accessible to BSL users; CDHH takes part in the Council's Voice and Influence partnership and provides Deaf Equality Training to public and private sector service providers. During the pandemic, CDHH was involved in the national 'Where's the Interpreter?' campaign for BSL translations of the government's daily briefings, ran a weekly BSL coffee morning via Zoom, and continue to offer equality training and equipment

assessments remotely. CDHH provided one spokesperson for interview - <http://cfd.org.uk/>

## Driving and Mobility Centre (DMC):

Originally founded as the Disability Living Centre in 1994, providing advice and access to a wide range of aides and adaptations to support disabled people to live independently, the organisation changed its name and re-orientated towards driving assessments after its funding from the local authority was cut in 2012. At present, it is funded by the Department for Transport to conduct driving assessments for people who've recently experienced a new impairment or a change in an existing condition. These assessments include making recommendations on safety within the vehicle, and the advice on in-car adaptations to keep disabled people on the road. The DMC did not offer a spokesperson for interview for this project - [\*\*https://drivingandmobility.org/\*\*](https://drivingandmobility.org/)  
**JobsNetwork Bristol (JNB):**

JNB was set up by two former tutors of Action on Disability and Work UK's (and later WECIL's) Work Club. Registered as a Community Interest Company,



with one disabled director and another with an hearing impairment who describes himself as 'having experience of disability', JNB runs IT training courses for disabled people and people experiencing long term unemployment in locations across North Bristol and South Gloucestershire. During the lockdown, they were able to move some of their training online. JBN provided two spokespeople for a single interview, and consented for its use in this project - <https://www.wellaware.org.uk/organisation/job-network-bristol-2/>

### Bristol Sight Loss Council (SLC):

This is the Bristol branch of the national Sight Loss Council; an initiative funded by the Thomas Pocklington Trust and designed to bring together blind and partially sighted people to campaign for equal access to goods and services, take a role in the design of community infrastructure and resources, and to support those with sight loss to have a meaningful say over wider areas of community life. Sight Loss Councils' activities are streamlined into six campaign areas: technology, employment, transport, sport and leisure, health and social care, and education.

Since its formation in May 2019, BSLC's work has included providing visual awareness training to GP service managers and front line staff, lobbying for the formation of a visual impairment advisory group for First Bus and pushed for greater accessibility of information as part of that group, and taking part in the review of City Council funded rehabilitation services for people with sight loss. During the pandemic and lockdown, BSLC has worked with supermarkets to increase home delivery slots for people with a visual impairment, advised other organisations on alternative communications methods for those who do not use digital media and on making socially distanced activities accessible for people with sight loss, and set up a groups to provide feedback to the Bristol City Council's recent street redesigns. BSLC provided two interviewees for one interview, and consented to the transcripts of those interviews to be used in this project - <https://www.sightlosscouncils.org.uk/bristol>

### Self Injury Self Help Bristol (SISH-Bristol):

A group of people with experience of self injury or harm which runs peer support groups across the city (including women's only spaces) and user-

designed educational courses for people experiencing self injury and have also taken part in reviews of local medical services. SISH-Bristol were forced to cancel all face to face activities during the pandemic, and these have not yet been resumed. SISH-Bristol did not offer a spokesperson for interview - <https://sishbristol.org.uk/>

### Social Anxiety Bristol (SAB):

Formed in 2015 by former service users of the Social Anxiety West support service; SAB ran peer support sessions led by people with lived experience of social anxiety prior to the lockdown. Since March, they have been forced to cancel all face- to-face meetings and at the time of writing these have yet to resume. SAB did not offer a spokesperson for interview - <https://socialanxietybristol.org.uk/frequently-asked-questions/>

### WECIL (West of England Centre for Inclusive Living):

WECIL was founded in 1995, after the West of England Coalition of Disabled People secured funding from the local authority to start a Centre for

Independent Living in the city. While a distinct organisation, with a focus on providing services directly to disabled people separate to the campaign activities of its parent organisation, WECIL and the Coalition were closely linked while the latter existed - with advice databases, training plans, and personnel shared between the two organisations. The pair also worked to reinforce each others' activities; with WECIL attempting to implement priorities identified by Coalition campaigns in its dealing with the local authority, and the Coalition campaigning on issues flagged up by those using WECIL's services. By 2001, WECIL was the largest user-led disability organisation in Britain (Barnes & Mercer: 2006, p 98), and remains one of the largest today with over 4000 members. WECIL describes itself as being 'here for whatever disabled people need', and aims to create an holistic range of services which can intervene at different points in disabled people's lives.

These include disability benefits advice, support and advice for those who employ PAs through Direct Payments, employment support programs, and a range of activities for young people - including befriending, short breaks, and a forum for young people to learn about

disability rights and engage in workshops across a range of topics. WECIL has recently acquired Bristol Physical Access Chain, a group of disabled people who undertake accessibility audits on public buildings and infrastructure, who were previously a part of the local authority.

During the pandemic, WECIL managed to maintain much of its activity while working remotely, took part in a national coordinating group of DPOs who are members of Disability Rights UK, and liaised regularly with the City Council and Mayor's Office on the local response to the pandemic. WECIL provided three different spokespeople for three interviews, reflecting the breadth of organisational activity. All three interviewees have confirmed that their transcripts can be quoted in this report - [\*\*https://wecil.co.uk/\*\*](https://wecil.co.uk/)

# Section 2: The Social Context for Disabled People and Their Organisations in Britain

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## Disabled People's Experience of the 2010s

On the 6th of October, 2016, the United Nations' Committee responsible for the monitoring of the Convention on the Rights of People with Disabilities (UNCRPD) published the results of its first ever investigation into 'grave and systematic violations' of disabled people's rights, as defined by the Convention, in a signatory country. The investigation began after 'reliable' evidence of breaches of the Convention were brought to the Committee's attention by a Disabled People's Organisation (DPO), with further evidence supplied by Non-Governmental Organisations (NGOs) working in the fields of equality and human rights. Of the 118 countries eligible for investigation by the Committee; the United Kingdom was the

first (and, at time of this report, the only) subject of such an investigation (Jones et al: 2017, p4-5). The subsequent report by the UN Committee painted a stark and worrying picture of the social position of disabled people in the UK. Not only did the Committee find infringements by the state of three separate clauses of the UNCRPD5, but that the Government's actions (or some cases inaction) on issues of disability equality negatively affected numerous areas of disabled people's lives. The Committee argued that disabled citizens had been disproportionately impacted by changes to housing benefit (ibid, pp 11-12), the introduction of a 'cap' on overall welfare benefits (p 19), restricted eligibility criteria for extra cost benefits (p 20) and income replacement (p 24-5) benefits designed to support disabled people, the introduction of one-size-fits-all welfare to work schemes for





people unemployed for a long time (often replacing more accessible job training schemes) (p 31-33), and reductions in funds allocated to Local Authorities (LAs) to organise personal support for disabled people in local areas (p 22). Alongside these ‘existing laws, regulations and practices that discriminate against persons with disabilities’ (UNCRPD: 2017, p 2), the Committee noted a number of concerns that the UK government was not doing enough to safeguard disabled people’s basic human and civil rights in broader social life. In particular, they argued, more needed to be done to promote disabled people’s access to justice, through making court processes accessible to people with learning

difficulties, removing barriers for D/deaf people’s participation in jury service, and reforming the eligibility criteria for Legal Aid - which they concluded barred many low-income disabled people from enforcing their legal rights.

Despite the harshness of the Committee’s report, activist scholars such as Clifford (2020) argue that the UN’s investigation underestimated the human and social impact of the austerity period on disabled people. Reforms in the areas considered by the UN

Committee did not occur in a vacuum - and were accompanied by reductions in resources for local advice and welfare services, resources used by many disabled people to stabilise the effects of their impairment (such as wheelchair services and mental health support), community transport schemes, and programs to increase access to employment and education. Clifford argues that the period between 2010 and the present can be described as a partial 'resegregation of society' in which disabled people became increasingly alienated from social life through poverty, isolation, and the development of hostile political discourses to justify changes to welfare policy (pp 182-185). This development not only contradicted the aim of DPOs to increase disabled people's social participation, but posed significant barriers to expanding and maintaining disabled people's involvement in DPOs or any other community groups. If a person is unable to access the transport they need, support to get out of the house or manage their home, or to meet regularly with other people; their ability to participate in organisational projects or governance will be impeded.

Spokespeople from organisations in Bristol experienced the broad changes in the social position of their members

and prospective members in two ways: as a trend which convinced people of the need for collective action on issues of disability equality and rights, and as erecting practical barriers to the involvement of some disabled people in their activities. A spokesperson from BRIL, an organisation founded in 2019 which traces its roots further back into the 2010s, explained; campaigns to oppose some policy changes towards disabled people received significant public support and led to the formation of new DPOs:

*'In Bristol, we formed the campaign to keep the ILF [Independent Living Fund] open in a conference at City Hall (...) and it was one of the most well attended events for a long period of time - it was rammed right up to the rafters in the main hall. Subsequent to that, the ILF Action Group was set up as a subgroup of BDEF. (...) So that's where the IL Action Group and eventually BRIL came from'*

The BDEF spokesperson also witnessed a significant level of activity from the wider disabled community and its allies during the earliest stages of austerity:

*'In the introduction of the austerity period, we were quite active and able to make highly visible objections to what was going on; there were demonstrations and rallies*

*and things like that going on.'*

Another BRIL spokesperson gave a personal testimony of how decreasing support, combined with the lack of disabled people's representation in national decision making, led to them becoming involved in disability activism through the ILF campaign:

*'In Bristol, there were only 104 at the outset of the ILF: and because of the nature of the people receiving help from it, it was going to be diminished. You weren't having people increasing it. You got the feeling the government thought that 'they're not going to kick up that much fuss'. In the actual finish, I think it was 100 - the four others were sadly deceased. (...) You're talking about our lives. It wasn't just a committee - that's what made me join. I'm watching the news about the government going to court, and I'm thinking 'hang on, that's my life; you're discussing my life'. Basically, that's what it was. I'd accepted being disabled, but it was helping me live my life. If I'd been abled (sic), I'd have worked. I'd been a working mum, and contributing financially to the household; I was disabled, so I couldn't do that. In fact, it was a financial liability to the household. I thought 'no it isn't, this isn't right'; and that's when I met (two other BRIL members), '*

Other interviewees also reported encountering dissatisfaction among disabled people with the level of representation available to them, and the extent to which their concerns were being acknowledged by both politicians and those providing services in their communities. As a jobsNetwork spokesperson put it:

*'(O)bviously, there's a lot more there to support disabled people than there used to be. There are a lot of advances, but one of the clear issues pushing against that is that disabled people don't feel represented by their MPs'*

A WECIL spokesperson, directly involved with the Physical Access Chain, explained that the lack of attention to, and representation of, disabled people in public life makes a fairly obvious case for the necessity of disabled people's self-organisation:

*'I was involved with the Labour Party with the redevelopment of Broadwalk. The developers had some really nice ideas about what they would do, but they didn't really take on board equalities issues in the design of the shopping centre. So that's an ongoing issue with developers, and probably always will be. That's why I think DPOs are*

*getting more important, not less. Groups like the SLC, BPAC, BDEF to a lesser extent, the deaf groups, groups like Older People's Voice - as a lot of disabled people are older people with age-related impairments; those groups' voices need to be heard louder'*

Despite some renewed interest in disability activism, and the practical case for increased disability representation; interviewees outlined a number of practical, economic, and personal challenges for disabled people involving themselves in the movement - especially if they were not previously active with a disabled people's organisation. One WECIL spokesperson explained:

*'Gosh, I think most days I'm pretty disheartened. There's been a whole heap of things, obviously economic things are major things. I think most disabled people are worn down by the system, benefit assessments, and discriminatory government policies; I think the energy to fight for change has kind of dissipated. There's so much that's so awful, that I don't think people know where the heck to fight. Before, there were some very specific campaigns that people joined in on, but there's so much now that people don't know where to start when it comes to campaigning'*

Material problems, particularly those linked to benefits, were raised by other interviewees too. The WECIL spokesperson working in BPAC reported that reassessments for disability benefits and personal support hadn't directly affected BPAC's work; but that he put this down to the experience and professionalism of the group's members, and noted that he was aware of other settings in Bristol where disabled people's civic involvement had been affected due to the strain of the assessment process:

*'I think there were members who had issues with, particularly, the transfer from DLA to PIP. There were two members I can think of who had issues with reduced funding and hours for PA's. That obviously impacted on the way they lived their lives and that includes working with BPAC. I must say that those two members were extremely professional at the time, and it didn't really affect the work they did with us that much - but it certainly had a huge impact on their personal lives, as it did for many disabled people. Being registered blind I've been quite lucky, cause I'm still on DLA and haven't had to go through the traumas of PIP testing; but at the disabled employees group at BCC (which I used to provide an admin function for) many people had issues with benefits which did seriously impact on their abilities to work in BCC because*



*it was such an ongoing concern for them. I don't think it had a real effect on BPAC as a group, as those who did experience those issues continued their work for BPAC without fail.'*

A spokesperson for the Sight Loss Council argued that a reduction in services for visually impaired (VI) people had made community access in general harder, and meeting with other visually impaired people especially so:

*'I've seen, sadly, a decrease in services for VI people. We had a local organisation, which used to be Bristol Royal Society for the Blind, then became Action for Blind People, and then became RNIB; although they had their national aims and objectives, they had a lot of local facilities available - so different clubs, groups, and social events which most of us attended. There were also external events put on that we could also go to, and they worked with us to organise participations in marches and demos - the one in London on benefit changes, for example. So there was a lot of support out there and, I guess, a real sense of community - places for us to meet, ways for us to get to know each other. Throughout the last decade, those facilities decreased anyway, they became more and more external, or things were removed: I'm told it came down to funding, space, and changes*

*in the way they worked. Last year, the office for the RNIB in Bedminster closed - which caused a massive uproar in the VI community because we saw that as our place, our main hub where we'd go, where we'd get information, resources and so on. There were protests and all kinds of things going on.*

*They opened just a working office in another part of Bristol - but that was just for staff - and they tried to outsource a lot of the social things, leisure activities, and learning how to use technology: so they worked with partners (libraries, different places like that) to host those. They provided training and help for volunteers, but it was effectively these other places that were hosting these events that we were used to going to in one central place we all knew. There are still things out there - although I feel not as much as there once were. -, there's groups that meet for socials, a basket making group, someone who teaches guitar, groups that just do pub socials, but they're spread out all over the city. (...) (T)hey are harder in many cases to get to. I'm sure some people are happy to, perhaps, have some events happening nearer to where they live; there are others who feel it was better to have a central space to go to.'*

This interviewee experienced the reduction in services not only as depriving individual VI people of things which were useful to them or supported them, but as a loss of control by the VI population over their relationship to their wider communities - something they also believe self-organised groups of VI people are well placed to reverse. They argued that the SLC had already taken important steps in asserting blind and partially sighted people's rights to be included and make decisions about how they integrate into the life of the city.

*'I think we did lose control over the things provided. We've tried to get some of that back by arranging our own groups. I think a lot of people liked the fact that things were arranged that we could go to, and sometimes there was funding available for things. It's all a bit harder now. For example, the logistics of VI people arranging by themselves to meet up in a Cafe are quite difficult - and one of the great things about the SLC is that it raises awareness of the extra support we'd need in situations like that -, but if it's a noisy or a busy, cluttered environment you'd need support with bringing drinks or food to a table and it's all just a bit more challenging. There are some of us who do that in their personal lives and it's fine; there are those who don't because they*

*got sight loss later in life or perhaps they have mobility difficulties - so all sorts of things make a difference for how we can access things when there isn't any support for that anymore. We're starting to get some of that control back now; the SLC is running forums with VI communities to find out what people want and work with other organisations on how to achieve that'*

## DPO Closures

DPOs and other organisations containing disabled people and users of local services in their leadership were put under considerable strain at the same time as disabled individuals were encountering barriers accessing their communities. Membership audits undertaken by Shaping Our Lives (SOL) and the National Survivor User Network (NSUN) - national federations of organisations led by disabled people and other marginalised groups - showed widespread closures amongst their member organisations across England. SOL reported that 26% of its member organisations had closed between 2016 and 2019; 124 groups in total (SOL & NSUN: 2019, p 2). NSUN had experienced a similar level of closures amongst its member groups, but in a shorter period of time: with 117 organisations closing in between 2017 and

2018, and an additional 50 organisations believed to have closed in 2019 (NSUN: 2019, p 1). Since these review surveys were conducted, user-led groups have continued to close (NSUN: 2020).

While SOL and NSUN's definition of a user-led organisation does not set a lower limit for the proportion of disabled people on the main decision-making body of an organisation (SOL & NSUN: 2019, p 1), and is thus wider than the definition we use in this report; it is clear that the kinds of organisations we define as DPOs would be included in their definition of a user-led organisation. On this basis, it's likely that trends affecting user-led organisations will directly impact those organisations who are majority controlled by disabled people. This is reinforced by the findings of surveys conducted by SOL and NSUN of their member organisations revealing a set of similar concerns to many voiced by participants in our project - including the reduction of government funding to local authorities, badly designed commissioning processes, and unsustainable pressure on organisations' resources through increased workload, (SOL & NSUN: 2019, pp 3-4; NSUN: 2019, pp 14-5). These specific concerns will be dealt with in their local context in Section 4 of this report.

The South West of England has seen fewer closures of user-led organisations than most other areas in the country; with only organisations in East and the North East England reporting fewer closures in 2017-2018 (NSUN: 2019, p 1). This, alongside the fact that our research identified 14 DPOs operating in Bristol up to December 2019 including a number formed during the 2010s, indicates the resilience of local DPOs and an ability of disabled activists in Bristol to adapt to difficult conditions. While South Western user-led organisations may not have closed at the rate of those in the North West and London (with 16 and 26 closures reported in the NSUN survey respectively (ibid)); 9 user-led groups ceased operating in the South West in the two years covered by NSUN's research - itself a worryingly high number. Each user-led group, whether they be a DPO or not, constitutes a service or form of representation that was designed (partly or wholly) by the community it serves; and which may not be available to it from another source. In terms of Bristolian DPOs, spokespeople identified the closure of two organisations in the 2010s as having a lasting impact on disabled communities in the city: that of the Centre for Deaf People in 2012, and of People First Bristol and South Gloucestershire in 2015.

The Centre for Deaf People was run by and for the deaf community; providing BSL social spaces, information and training events, facilities for sports and leisure, and a venue for large gatherings of BSL users for recreational and campaigning purposes. Some of its functions, particularly those dealing with providing accessible information and equipment support, have been taken up by the Centre for Deaf and Hard of Hearing People (CDHH) - a separate deaf and hard of hearing people-led organisation established after the old Centre was wound up, and which currently uses a mixture of office-based and floating service delivery. As the CDHH spokesperson explained, while the closure of the old Centre had the positive effect of many Deaf people organising their engagement with their communities more creatively, its closure without alternative services or information resources being already available was deeply distressing for many:

*‘For a lot of people it was almost their second home. A lot of people grew up there, their whole life was there. It was a social thing, it was meeting other deaf people. It was finding information about what was going on. It was access to equipment, training, activities, and so on. Losing that space overnight had a real knock on effect*

*- but mostly to the older generation who grew up with it. The younger generation weren’t that bothered, because they’d made themselves more mainstream. They were happy to go to their local pub, or go clubbing at any nightclub in Bristol. They didn’t really need one building to shut themselves away in. I think one of the problems is that people wanted a safe space to stay away from the lack of understanding “out there”. It was their safe space, their safety bubble. Having that popped was almost like releasing them into the wild, and they didn’t have the skills or understanding of how the mainstream world worked; ‘cause they’d shut themselves away for so long. So that became an issue’*

Unlike the deaf community, Bristol residents with learning difficulties (LD) did not see the establishment of a new user-led group or DPO following the closure of the local branch of People First Self Advocacy. The group provided a space for people with LD to support each other to speak up about the issues that affected them most and to make their views heard by local services and decision makers, as well as running social events and peer support groups for women and BAME people with LD. One of BRIL’s spokespeople argues that its closure is indicative of wider problems facing DPOs and self-advocacy groups, and has had a



significant impact on both the wellbeing of people with LD in Bristol and their ability to take control over their lives and communities:

*'I can tell you what I've learned from people; which is that when People First closed a lot of people were really devastated. They told me that we need something like that in Bristol - these were people with learning difficulties, mostly people living in 'supported living' - if I can use those awful terms. I remember speaking to someone who worked with that organisation - this is a non-disabled person - who gave me some unbelievable accounts of what happened to people because they became so isolated. The whole point of self-advocacy is that it's a group of people supporting each other to speak out and against things, to have confidence to say 'I want my life to be the way I want it'. When it fell away, it led some people to become so isolated that what happened to them was really grim. (...) They were a really strong group, and there were particular people involved who kept that group going. I remember one guy telling me - a non-disabled person who supported his sister - that he was kicked out from meetings because they said 'no, this is for us' - which I thought was brilliant. I think part of it mirrors what's happening generally across the country in that self-advocacy groups*

*have seen their funding slashed, the value of it hasn't been recognised in the same way as DPOs are struggling generally'*

The gap left by People First has allowed organisations not accountable to people with learning difficulties to mimic the rhetoric or self-advocacy and self-empowerment without handing control of organisational decisions or activities over to their users. The same interviewee continues:

*'In Bristol, the charity and voluntary sector is huge, and very charity and medical model, and they've stepped in. The service providers all have their own little 'speaking out' type groups which are run by professionals, they're not run by people themselves. That's coalesced into a situation where it feels like - I don't know, you'd have to talk to people. I think a lot of people don't feel it's possible to have a People First type group anymore. I might be wrong, I hope I'm wrong'*

This situation has been exacerbated, in the same spokesperson's view, by the failure of DPOs in Bristol to support people with learning disabilities by either addressing issues that matter to them, or by working to integrate them better into their organisation's governance structure:

*‘The first thing is that DPOs in Bristol need to acknowledge that, to some extent, they have failed to support autistic people or people with learning disabilities - I’m speaking generally, across the city’*

While not committing to quite the same conclusions, one WECIL spokesperson accepted that more needs to be done to ensure that people with learning difficulties are represented within the leadership of DPOs:

*‘The other gap I think there is, is that we have been (and are every day getting more) skilled in ensuring people with learning disabilities are fully engaged, included, and participative in co-production and leadership of service design and in WECIL’s work as a voice organisation; but that representation is entirely lacking at board level. We’re a pan- disability organisation, and we don’t tend to ask questions about impairments unless it’s absolutely necessary: but you can tell visually that we have a board which is made up of people who mostly have physical impairments and that there isn’t representation of the LD community who make up a significant proportion of our users and members’*

The closure of People First in the city emphasises both how damaging the closure of a DPO can be to disabled

people’s ability to control their own lives, and that the role of that organisation will not automatically be replaced by other DPOs or mainstream service providers. Some interviewees were particularly worried that the closures and weakening of DPOs around the country have had a detrimental effect on disabled people’s ability to present themselves as autonomous actors, rather than passive objects of state or other charity, in even those political movements sympathetic to their interests. In relation to the use of victimhood narratives in the anti-austerity movement, Liz Crow notes:

*‘There did seem to be a resurgence of movement in response to austerity; but it wasn’t a movement founded in the social model - to give you the short cut. We’d spent 20 or 30 years fighting against the label of victim, for example; and a really strong through thread of the anti-austerity movement was the theme of disabled people as victims of this policy. We were poor disabled people being put into even worse positions by the measures being introduced by government. We didn’t see any of the kinds of stuff we’d worked so hard on in the austerity argument - like stuff on choice and control, which was completely absent from much of the narrative. As a short-term response, it kind of makes sense; but it’s coming from people*

*who haven't got the historical embedding of it and I don't think they could see the dangers of reintroducing something we'd worked so hard to get rid of'*

At the same time, an approach to disability as pan-impairment and socially created was made more complicated by a turn towards impairment specific identities by many disabled people involved in social and community activism. As a BDEF spokesperson argues; this mirrors a more general pattern of community activism within the 2010s, but undermines the cohesion of a social movement built around disability being separate from impairment, and which seeks to unify disabled people regardless of what impairment they have.

*'Intuitively, I think yes; not just for disabled people ourselves but for lots of groups of people austerity brought about a fracturing of people - students having demonstrations just about student fees with only a few disabled people attending, disabled people having a march about benefits with very few students attending, etc. (...) but there's also been a fracturing and drift back into impairment groupings rather than the sense of a cohesive movement we had for a while. So you've got people who describe themselves as 'neurodiverse' rather than disabled; which has been a big element of*

*change within self-organisation. You've got another one coming up with hidden impairments. The DPM has brought it upon itself to some extent; in that it should've, but hasn't, explicitly shown that it's work is there to benefit people with hidden impairments rather than just those with visible ones'*

Another concern raised was that the weakening or absence of DPOs meant a loss of accountability towards disabled people by those representing them in consultations with local decision makers. As a Sight Loss Council Spokesperson pointed out, without pressure or prompting from DPOs, many organisations do not feel the need to include disabled people in discussions of changes to their services whatsoever:

*'I think there are some organisations who've set up focus groups for people with different impairments to come along and speak about their needs. I remember myself going to one set up by Lloyds Bank when there were changes there; and I remember there being something to do with the theatres - but I've not personally been involved in consultation groups where big changes are happening and I've felt that organisations are including VI people. I'm not sure how the one with the Temple Meads development is going;*

*that's got people from the deaf community coming, and obviously us. So we're getting to have our say there. But I don't personally feel that's something which is happening a lot: I don't think it ever really did, and it doesn't seem to now'*

## Conclusion

DPOs and DPO activists have been placed in a paradoxical and intensely difficult position throughout the 2010s. While developments in welfare and other public policies have reinforced the need for disabled people's collective self-organisation and self-representation; they have simultaneously erected significant obstacles to disabled people organising to defend and expand their own interests. With disabled individuals experiencing greater difficulty accessing both their communities and means of representation, and user-led groups around the country closing at an alarming rate; there is a risk of re-segregation becoming entrenched as disabled people progressively lose access to those bodies designed to represent their interests and aspirations.

Bristol and South Western England have bucked the trend of demise amongst user-led organisations, with a relatively small number closing and

a greater number being formed in the last decade. Those DPOs that have closed, however, have left obvious gaps in both representation of communities and the range of services demanded to promote empowerment and social inclusion. People associated with DPOs in Bristol are also concerned that the weakness of DPOs across the country has led to the loss of a cohesive and comprehensive approach to disability politics amongst disabled people, and of collaboration between disabled people and local government in the planning and administration of services and infrastructure that disabled people use.







# Section 3: Responses to 2010s - Strategies and Orientations of DPOs in Bristol

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## Framing the Problem

The issues facing DPOs across the country can be expressed in their simplest terms as the requirement to do more with less. Both traditional funding for DPOs and other community organisations through local authorities, and novel funding through central government and third sector grants, have shrunk and become more prescriptive over the course of the last decade - with both often reserved for service delivery and contributing little (if anything) towards the core costs of running an organisation.

At the same time, a greater level of need amongst disabled people is generated for the kinds of services or activities that DPOs provide, and those who govern DPOs are as likely to be as affected by detrimental policies as the communities



they serve - making their continued participation in organisations of whatever kind difficult in many cases (SOL & NSUN: 2019, pp 3-4). DPOs, and other user-led organisations, are often forced to compete for funding with much larger organisations; who, unlike their mostly

local- or community-based competitors, are able to utilise economies of scale or cross-subsidisation in order to offer services to a local authority at a reduced price.

Public resources are thus diverted away from local players, accountable to the disabled people they work with, towards larger organisations who progressively grow in size and influence - with the top 3% of charities controlling 81% of voluntary sector income by 2018 (ibid, p 2). DPOs' experience of funding and commissioning processes in Bristol is discussed in more detail in the next Section.

In addition to these resource stresses on DPOs, there are additional dangers relating to their status as organisations which aim, at the very least, to represent the interests and views of marginalised people; and at the most to play a central role in their emancipation from social oppression.

If reductions to funding to a DPO cause it to act in a way that's perceived negatively by the communities it serves (such as through the reduction of service quality below an acceptable standard or the imposition of charges on users), or if they are perceived as unwilling to raise issues on their members' behalf which may cause conflict with funding bodies; their credibility as community or activist

organisations is diminished, and they risk becoming indistinguishable from service providers and advocacy organisations neither run by nor accountable to disabled people themselves.

This section outlines the strategies used by DPOs in Bristol to attempt to deal with the dual challenges of surviving and attempting to further the aims of disability equality in a climate of sparse financial and time resources. As each strategy adopted to cope with these challenges is dependent on the specific position of the organisation in question (including its size, current level of activity, organisational culture, constitution, and relationship with other bodies in Bristol), they are arranged here by subsections related to each participating organisation.

Where possible, similarities of strategy or orientation with non- participating DPOs in Bristol are indicated at the end of each description. In recognition that all possible strategies contain risks of unintended negative outcomes, this section ends with some of the concerns raised by participants about the overall strategic orientation of DPOs in the city.



## DPOS Strategic Responses

### Targeted and flexible interventions: JobsNetwork and the multi-purpose service

As a small community interest company, with a two-person executive and without access to a large pool of employees, JobsNetwork have focused on providing small-group IT training to disabled people and those who have been out of work for a sustained period of time. As a single activity, employment-based IT training has the advantage of multiple funding sources; with work regularly

commissioned by the Good Things Foundation, and local authorities in the area funding various training schemes within neighbourhoods. As one of the spokespeople from JobsNetwork pointed out, however, its key advantage is that the skills provided through their training are transferable to other areas of a disabled or marginalised person's life - offering alternatives to depending on others for access to goods or communication, and creating a greater overall impact than that measured by commissioners:

**‘We have an ethos - and we won’t give away our whole strategy today - but the way I look at it is that supporting people with computers is a great form of equality.(...) (W)hen we use computers there is an equality there. It can be a great way of integrating people with an impairment’**

While rooted in the tradition of independent living - increasing the level of control that disabled people have over their own lives - this impact can also be framed so as to fit into different value frameworks held by funders in order to increase referrals or commissions from other organisations. This can be



most clearly seen in regards to social prescribing, a method of commissioning used by NHS England and schemes funded by them:

*‘What we, and those in Good Things Foundation, are trying to do is be able to support people in health, work, online shopping, and independence through using the computer; ideally, that’d reduce costs to the health service, help reduce costs of people staying on benefits long term, and promote independence. (...) Some of that would definitely be classified as social prescribing. If a person is unemployed they may face financial difficulties, they may have some health problems, so we’re the additional support available for accessing training and looking for work’*

By adopting an activity which furthers the aims of independent living and in which larger state and charitable bodies take an interest, JobsNetwork may have been able to maximise funding sources; the funding they receive, however, remains modest from each source. They find that some markets within Bristol are difficult to break into at all, meaning that much of their work is spread out over a geographical area that extends past the city limits in order to compensate. This has created some difficulties with securing office premises and

appropriate spaces to organise training in; with JobsNetwork having to hire or borrow other organisations’ space and equipment in order to run sessions until recently. Limited and hand-to-mouth funding, at least at this point in time, also creates barriers to expanding the scope of the service offered. A particular concern is the costs involved in supplementary software that helps develop skills taught on the training courses:

*‘With computers there can be a lot of cost involved. We used to have a free subscription to the ancestry software<sup>6</sup> when we were at the Vassal Centre, but we don’t have that now and there’s a monthly cost. Before, some of our members would go home and do some of the ancestry at home, and they can’t do that now due to the cost. When I did have it, some of the people had done quite a bit already so we could spend time on other things (...) We often support people who haven’t worked for several years; and if you can support them with things they are interested in you can motivate them more easily.’*

While JobsNetwork’s model of running one service with a series of ad hoc funders is uncommon amongst DPOs in Bristol; it shares a similarity with the Driving and Mobility Centre (DMC) in focussing on one form of service

provision which is compatible with both the aspirations of the Independent Living Movement and state funders. In the case of the DMC, this takes the form of driving assessments; which allow disabled motorists to maintain the use of their vehicle and thus travel independently, and are funded in part or whole by the Department for Transport or an individual's private health package or the NHS.

## Consultation at the top: the Sight Loss Council and initiative taking

The Sight Loss Council as a national organisation occupies a rare position amongst DPOs; it is funded entirely by grant money through the Thomas Pocklington Trust, and each branch is made up of a small group of blind or partially sighted volunteers who have been through an interview process to confirm that their levels of skill and experience are compatible with the SLC's areas of work. The group of volunteers are then responsible for deciding and carrying out the SLC's work in the area. As the Volunteer and Engagement Manager explained:

*'Any person with VI over 18 can join the SLC. They become a volunteer for the Thomas Pocklington Trust, who pay my*

*wages and the costs of running the SLC and developed the concept of it; If anyone wants to join, they contact me, fill out an application form, undertake an interview, and then we take up references. They are then supported by me as a volunteer manager. There's no time limit. Technically the size of the SLC is 12, but we can be flexible about that; so if we have more than 12 people that's no problem. We have agreed terms of reference between councils, and obviously we have the six core areas of employment, education, health/ social care, leisure, recreation, transport and technology. Each SLC develops its own annual business plan, which is worked out with all council members'*

As they go on to point out, this process has ended up with the SLC in Bristol having a highly competent and experienced group of volunteers - some of whom have previously worked in the areas the SLC intervenes in or for local government in the region:

*'Basically, each SLC member has leadership responsibilities, decided within the council. (...) I'd say I'm extremely lucky to have the members I do; and I know not all councils have a membership which is as competent and skilled and proactive as Bristol's. The only reason we've delivered what we have in the last year is because our members*

*are extremely good at what they do - they are extremely competent, extremely motivated.'*

This resource of skills and experience allows the Bristol SLC to get around what one spokesperson identified as the primary problem with most consultation processes between public or private sector organisations and Visually Impaired (VI) people - that of adaptations or changes to policy suggested by VI people not being acted on:

*'I've been involved, through different organisations and independently, with talking to other places - whether that be GP surgeries or corporate bodies, there was certainly a project with Barclays bank about making their website more accessible - where I've gone to do talks about improving things with them. People had the right intentions and wanted to make the changes. But then nothing would happen. Sometimes it was down to funding, sometimes it was down to them thinking that the changes we were asking for weren't very realistic or achievable. Obviously, blind and partially sighted people are a minority, and I think sometimes organisations feel that it's not worthwhile doing it - although they wouldn't actually say that. Predominantly it's 'I don't have the power to do that' that's the response that I'm used to hearing. It was impossible to actually get*

*to the top to speak to the people who would be able to make a difference or influence people to make change. Whereas with (another member)'s contacts, and we're quite a determined group, we have gone to the top and talked to people who can affect changes and achieved major changes in most of our areas - whether that be in health or social care or transport.'*

So far, and it should be borne in mind that the Bristol group only formed in summer of 2019, both spokespeople reported that the strategy of initiating discussions and working groups at the top of organisations and services had been going remarkably well. Despite the organisation's youth, and the onset of lockdown 10 months after its founding, meaningful work is underway in all six of its target areas; with changes to policy and information resources already secured from some of the largest local organisations and a number of working groups set up with officers from the local council:

*'(W)e've been going in with a very diplomatic and solutions based attitude. In the past, it's been very easy to go and tell people where they're going wrong and how they're just not meeting our needs; whereas now the SLC goes and tries to gently persuade what the problem is and how it*

*might realistically be rectified. There are some organisations that are quite busy, like the hospital and things, that don't always get back to us and getting meetings in the calendar can sometimes be challenging; but I don't personally feel that's because they don't want to. I think they're happy to work with us but don't always get it together to put meetings in the calendar. But we're quite persistent and we do get there in the end. (...) I think sometimes there's a fear, with some organisations, that what we want from them might cost them money or resources they don't have. But we kinda just work with them and tailor our approach to whoever we're talking to.'*

*'On the pavement and road issues, for example, we picked up that the Mayor announced all this money was coming for changes: we contacted BPAC and the officers. We now have a fortnightly meeting; us, BPAC, WECIL, and the officers so we can directly influence them. Which is great, officers have been helpful and constructive. That's a product of our gently, softly-softly partnership-orientated approach; if we'd yelled at them, we wouldn't be there. It's long term stuff I think. As frustrating as it is, you have to build those relationships with officers and politicians to get that come back from them. In a year's time, I'd hope that officers and organisations would be more proactive; but I don't think it would*

*bother the SLC - (others) can speak for the members - as long as members feel that something happens even if we have to initiate the contact. As long as it happens, as long as they are willing to talk and respond, I don't think members worry about how that happens'*

Relying on a small team of volunteers with extensive work experience raises obvious questions of representation and accountability; with it being far from certain that the changes to organisational practice recommended by SLC members would be those suggested by VI people throughout the city. Bristol's SLC respond to this by soliciting feedback from VI people through the forum of Vision West of England - a non-disabled led charity operating in the region - as well as through their contacts with other organisations working with blind and partially sighted people in the city:

*'(T)he VI forum, which is for us to engage with the VI community in Bristol; where we tell them what we've done, ask them what changes they would like to see, and ask them what they think our priorities should be. The last one of those we did was in March, and although the turnout wasn't huge we had some really good feedback that helped inform our business plan. We're hoping to have another one of those very*



*soon. In terms of how we engage with people and keep them up to date: Vision West of England do a monthly newsletter that we put a piece in to explain who we are and update on what we're working on and seek feedback through that. We are also on social media, and are trying to get ourselves known in the other VI organisations'*

While conducting feedback and sourcing the insights of the VI people through larger service providers gives the SLC access to a large and representative sample of VI people in the city, it does make the Council dependent on those organisations continuing to operate at an appropriate scale to engage regularly with a large number of people. As we noted in the previous section of this report, service providers working with the VI community have not always been able to maintain the scale of their interventions during periods of financial difficulty. Similarly, it remains to be seen how well the self-consciously diplomatic approach of the SLC in Bristol towards its collaborators may cope if the demands of VI people in Bristol begin to conflict more seriously with the policies and resource constraints of the city's key players.

## Opening up the city: CDHH and making the mainstream world accessible

For the CDHH, the changing demographics of the Deaf and Hard of Hearing communities around the country, combined with indications that previous forms of representation and community support for Deaf people in particular were no longer viable, forced a fundamental re- evaluation of the role of a Deaf organisation. In Bristol, this was complicated in particular by the closure of the Deaf Club in 2012 - an institution greatly missed by many British Sign Language (BSL) users, but which closed under contentious circumstances and did not offer a model of support that CDHH's governors felt should be replicated:

*'(S)omething we get asked a lot by the deaf community is 'are we going to have a new centre, is that the future?'. My honest answer is: no, not yet. At the moment, no. What we realise is that, across the UK, there's a lot of deaf centres or clubs that have closed down - the money's not there. They've run out, or they've been unable to get funding, or something similar. The problem is the people who're actively using the deaf club are the older generation; the*

*younger people don't want that because they want to be part of, to have access to, the bigger world. So, you can't keep a deaf club open which is only for the older generation'*

The loss of demand for centres and clubs, however, does not indicate a reduced need for support in accessing community services or civic life for either hard of hearing or deaf people:

*'To start with the hard of hearing community, (...) one of the big problems they have is that most people are new to hearing loss, they acquire it later in life. So there's a problem when they go to the doctor, he sends them to hospital for a hearing test, which says they need hearing aids, these are ready in a week, the doctor tunes them and then sends them off. Good luck. Goodbye. Out the door. Very little explanation of how the hearing aid works; very little information on how it affects your mental health; very little information on what's out there in terms of support; very little information about how to adjust to wearing hearing aids. (...) The other problem is people's lack of understanding of hearing loss. You get people who say they do deaf awareness training. I don't do deaf awareness training, I do deaf equalities training. My argument is that you should already be aware that there are deaf and hard of hearing people*



*out there: I don't need to make you more 'aware' - there's really nothing more to tell you. But what I am gonna train you on is how to engage with these people; how to communicate with them, how to adapt, how to do different things so that they can engage. People with hearing loss withdraw from social situations, from family activities, and just shut themselves in the corner. You're teaching people how to adapt and make changes to make them part of a bigger group. Some of these changes are minor. That's the problem, the lack of understanding of how it can affect a person's mental health and emotional well-being' The CDHH spokesperson argues that this lack of awareness of how to include people with hearing loss is particularly pressing given recent indications of both*

*the scale of social isolation that deaf and hard of hearing people experience, and increasing hearing loss across the population:*

*'It is estimated that between 60,000 - 80,000 people have an hearing loss of some kind in Bristol. A huge number. In the UK it's 12m, and expected to jump to 16m by 2035. So that's between 80-100,000 in Bristol if we make that jump. We're the single biggest disability group in the UK, but we're so underfunded - hardly any support. (...) The problem is the population of people with hearing loss is growing so fast. People in their forties and their fifties are getting hearing loss earlier - because of MP3 players, iPhones, and how noisy the world is is unreal. The problem we're gonna have is that it'll become an epidemic'*

*'We worked out that for deaf, and particularly for hard of hearing, people as they get older only really go to three places: they'll go to the GP, they'll go to the pharmacist, and they'll go to a local shop or a big shop. They won't go to other places much. Those are the only three places they feel almost safe. (...) It's terrifying, it's so sad. They stop going to coffee shops, they stop meeting their friends. They just stop.'*

From the CDHH's standpoint, the role of a user-led organisation in addressing

the dual problems of social isolation and further hearing loss is a wide-reaching and comprehensive program of promoting awareness of the communication and equality needs of deaf and hard of hearing people through a combination of joint working with other organisations to improve access to mainstream services, Deaf Equality Training, and providing an hearing equipment service for individual Deaf and Hard of Hearing people:

*'Our thinking is that what we should be doing is working with other organisations to make their services - day centres, or whatever -, more accessible so that these people can join them. So these services could get extra funding to support deaf people, and we'd provide them with the guidance or information they need. (...) (T)hat's what we need to do - make the mainstream world more accessible. It's shutting ourselves away that makes people think we don't exist - like we're a unicorn or something'*

The aim of CDHH has been to collaborate with organisations across the private, public, and third sectors to ensure: firstly, that services provided across the city are accessible to Deaf and Hard of Hearing People; secondly, that those with hearing loss remain

included in activities associated with their life before hearing loss, and to support workplaces and social spaces to incorporate people with hearing loss into their activities; and thirdly, to promote Deaf and Hard of Hearing people's active participation in debates about how the city is run or could be improved. Such an approach allows the CDHH to engage in a number of different areas and activities and, similarly to the SLC, to pursue the aim of greater community integration through partnerships with diverse organisations. In many cases, this has led to really positive outcomes:

*'(W)e've been working really closely with the Bristol Dementia Wellbeing team. We've done some workshops with the deaf community to find out the impact on their lives: if their parents have dementia, or if they have dementia. The Dementia Wellbeing Team have been coming along to that, and have been looking at ways to improve what they do. They've even bought equipment from us for when they have to meet someone with hearing loss - so they can boost their voice a little bit if someone's hearing aid isn't working or they don't have aids. So they've been very interested in this area, and feeding back from the workshops to their colleagues. (...) We're also looking at a training plan for people who care for someone with*

*dementia and also happen to have hearing loss themselves. We've also done a training program for how to interpret for someone with dementia and (who) is a BSL user: the communication is very different, so how to adapt, address, and not take over - to let them speak without speaking on their behalf. There's a doctor from Manchester who developed the package and we invited her to Bristol. It went down really well, and we're looking at running a twice yearly program for interpreters from all over the UK. We've done a fair bit of work on this, and people have been quite receptive'*  
(content in brackets LB)

*'The smart meter project was really because a bid came up looking for Deaf and hard of hearing organisations to work with them. The Government set the smart meter people a deadline for getting 11 million people to get smart meters, and they were nowhere near that. So how could they improve access to improve the numbers? We took part in that; we were very early on in the days of the development of the centre, (...) we were doing a national project, managing it locally. It was a way of showing people 'look, we can do projects like this'. It was fantastic, and we did really well on it'*

Joint working and co-produced projects are, however, only as effective as all parties are willing to make them. On a

number of occasions, CDHH have found that organisations that have expressed an interest in working with them have either become non-committal at key points, or have frozen them out once it was felt convenient to do so - creating an obvious drain on the organisations capacity to engage in other activities and sometimes leading to the CDHH's work going unpaid. A related risk of orientating much of the organisation's work towards a wide array of other bodies is that of organisational expertise being exploited: with other parties trying to take advantage of CDHH's openness to collaboration to secure information or services they'd otherwise have to pay for. These problems are discussed in more detail in the next Section. User-led mental health organisations in Bristol (particularly BIMHN, and the Survivors and Hearing Voices Networks) appear to share CDHH's orientation towards working with a number of diverse partners in order to improve understanding of their communities' communication and access needs - with collaborations with other third sector services, academic and research bodies, and employers fairly common throughout mental health activism in the city. As indicated above, there is also considerable similarity between the CDHH and the SLC in this regard, although the CDHH does not structure

its activities in discrete areas of work in the same way as the SLC.

## The 'all-in' approach: BDEF and alliance building

Unlike the two DPOs examined above, BDEF and those discussed below operate as pan-impairment bodies (including, representing, or providing services to disabled people with differing conditions), and do not limit their membership or organisational governance to either those directing a private company nor those who have passed an interview process. This more open approach to organisational membership and representation allows for a greater level of engagement with a wide spectrum of disabled people in organisational decision making, and incentivises those within the organisation to think of disability as a singular social phenomenon rather than as relating to distinct conditions. It does, however, place greater strains on an organisation in terms of both representation of, and the delivery of services to, the disabled people it works with. As resources provided to it become slimmer, the reduction of services may become unavoidable - a situation in which it is likely that some disabled people are more negatively affected than others. Similarly, as conditions for



disabled people in other areas of their life deteriorate, an organisation is likely to be compelled to intervene in more areas than it had before, while many disabled people who'd previously contributed to its work are unable to maintain their level of involvement. Both pressures may lead to the organisation's activities and personnel becoming more representative of certain impairment types, economic classes, ethnicities, or gender than the disabled population as a whole.

As the BDEF spokesperson pointed out in our interview, avoiding under-representation is not something the Disabled People's Movement has always been successful at. In relation to impairment types, the Movement: 'should've, but hasn't explicitly, shown that its work is there to benefit people with hidden impairments rather than just those with visible ones. (...) I've probably been as guilty as others, when public speaking or whatever, in not preempting people's sense that I'm probably not thinking of them by making it clear that I am. We talk about transport across the board, but the fact is that if you feel like you're being overlooked you'll probably presume that discussions about transport are discussions about wheelchair access on transport rather than anything else. The front-facing element of the movement has been/

perceived as, at least from what I know of the DPM in Bristol, dominated by people with mobility or sensory impairments - especially since we lost Bristol and South Gloucestershire People First group for people with learning difficulties. So the perception that we're all about walking sticks, wheelchairs, guide dogs, etc, hasn't helped the broader community of disabled people feel sufficiently included. I think that's contributed to that greater fracturing over the last ten years'

BDEF's response to both the fracturing of disabled people's representation into different interest groups, and the fracturing of disabled people's interests from those of non-disabled people in the city, has been to present the demands of different impairment groups in regards to access and reform as positively reinforcing each other, and as being beneficial to non-disabled Bristolians if they were acted upon and granted. On regards to representing people with hidden impairments, this has taken a very concrete form in the work BDEF do:

*'When I do access work, it's not just about wheelchairs and sensory impairments; it goes down to what language you use, if there are areas where people experiencing sensory overload can go, if there're seats where people can rest, where you're placing*

*and how you're formatting signs for things you're exhibiting (where they are, what font they're in, what contrast they use, what language they use)'*

This ethos also underpins the Bristol Disabled People's Manifesto (outlined in Section 1); which sourced its content from a wide variety of disabled people in order to present a set of reforms which would allow for greater civic engagement for disabled people across the city, as well as other Bristolians experiencing inequality and disadvantage:

*'We went through all the different issues that disabled people had raised over the last 13 years and picked out the common threads from that, then consultation with Disabled people and their organisations - including face to face consultation. (...). It was comprised in that way. We wanted it to be comprehensive - that's why it covers a variety of things and areas of life. It's not all the issues - we couldn't put everything that needs to be changed in there otherwise nobody would read it! So it was picking out a bunch of 'first hits', if you like, to get the ball rolling. It's a big ask as a bunch of first hits; but if you can get meaningful inclusive education (which means meaningful curricula as well as people just being in the same physical space); if you can get meaningful employment for those who are*

*able to and would value it; if people can get around; if people actually have meaningful independent living: then even with just what's in the Manifesto, the hardest part of my job would be done. If we took on what's in the Manifesto, then they would already be in a position to be open to make future changes as things develop. If they're still closed, then they won't more than pick a couple of easy things from the Manifesto itself'*

The sheer breadth of disabled people's experience, and the fact that the conditions for disabled people directly affect their families, friends, and community, is held by BDEF to show that there is a shared interest amongst non-disabled people in securing that the Manifesto is acted upon by all arms of regional government. Using Independent Living and redesigning public space in light of environmental concerns as examples, the spokesperson explains:

*'The underlying belief of the members is that meaningful equality and inclusion of disabled people is good for everybody - that's why we say it's for the benefit of all, not just disabled people. The needs of disabled people are so broad that we didn't want to limit ourselves in what areas we were able to respond to as and when disabled people raise them with us.*

*The issue about their unpaid assistants is that the state exploits family labour in a whole variety of ways, and we believe quite strongly that more independence for disabled people is of benefit to those who support them as well - those who are unpaid in particular. They then are less exploited for their labour, they're not prevented from fulfilling their own ambitions in life, their own independence'*

*'There are other ways of doing things than the way we do them at the moment: it just takes a different way of thinking. If you're thinking about environmental pollution; you're going to need to think about transport and how to get people around, you need to think about seating in public spaces for people who can't walk long distances at a stretch - plus the advantage is that if you put seating in you make a place more of a destination and community space'*

One advantage of taking such a wide ranging approach to disability issues for BDEF is that it allows them to utilise a variety of tactics in order to pursue their goals, meaning that there is experience of antagonistic and collaborative forms of activism within the organisation which can address disabled people's concerns as they arise. So in addition to the protests and rallies mentioned in the last section:

*'Equally, we sit around the table with planners and say 'look, that doesn't look like a good idea; have you realised if you do that you'll have wasted all the money you spent on access because you won't have got it right?'*

This wideness of remit, however, risks the organisation's resources becoming stretched over a number of different areas; making it difficult to ensure organisational focus on one specific intervention or area:

*'One of the problems, as some people would see it, with the Forum is that - because it's focused on what the disabled people it's in contact with want - it's always been a very broad church. As such, it's always struggled to prioritise one area of difficulty over another. So we do a bit on most things, rather than everything on one thing.'*

Another difficulty arises in that wide consultations themselves cost money; not least when they have to be accessible to people with varying impairments. Changes to funding for the organisation can require complete reworkings of how consultations with disabled people are done, and can create delays in meeting with members or other disabled people to discuss their needs and priorities:

*‘(W)e ended up with little-to-no money or staff time to hold large, public consultations with disabled people to review it. What we do do is make sure that what we’re doing still relates to that Manifesto; and I’d say there’s little in it that I’d be confident to say had been fully achieved. (...) One of the things that changed for us is that, since we lost the funding for big public meetings, we had to look at another way to hear what it was that disabled people wanted; we had to look at a project based way of finding those things out.’*

## **Reviving the grassroots: BRIL, horizontal organising, and collective responsibility**

Unlike other organisations, which either existed (in one form or another) prior to the austerity period or stepped in to replace and rework services or forms of representation in the city for a long time, BRIL was set up to directly challenge an erosion of disabled people’s rights that occurred during the 2010s. The primary impulse for its foundation was the re-interpretation of ‘Independent Living’ it felt was being carried out by national and local government; whereby what had been a demand by disabled people for support to exercise control over their lives and take an active part in community and political life was recast as reducing

dependency on the state by decreasing the level of support available to a disabled person. As journalist John Pring (2019) notes in his coverage of the BRIL launch event:

*‘BRIL’s founders believe that phrases like “choice and control” and “independent living” are being used to justify regressive policies, such as cuts to social care, while the Care Act had not produced the promised “level playing field” across different local authorities. (...) BRIL believes that, without (...) a radical rethink on social care, the achievements fought for by the disabled people’s movement will be “worn away”’ (n.p)*

As it is local authority and NHS policies that BRIL believes are in large part responsible for the redefinition of independent living, they viewed it as impossible to publicly and coherently campaign for an alternative conception of social care while accepting funding from either source. This, in practice, means that the organisation runs with very few financial resources. The lack of core funding or contracts, however, does allow members much greater freedom to decide on how it structures itself as an organisation and how it makes decisions about what it does; allowing disabled members a direct say over the organisation’s priorities at each meeting.

As one spokesperson explained:

*'The thing about BRIL is that it's self-organised; it came from a group of disabled, neurodivergent, people who identify as (mental health - LB) service survivors. We thought there was something missing in this city and wanted to do something about it. We don't have outcome measures; we're not asking people to do surveys where they tell on a scale how their feeling today or whether this meeting meant a lot to them. We hope the meetings are meaningful in and of themselves, rather than being constructed or forced. There's no managerialism involved'*

This form of horizontal organising, without rules around what the group can do imposed from the outside by contracts (or the internal management structures necessary to monitor and administer them) has incentivised BRIL to take a proactive approach to issues members raise; engaging in action relatively quickly after making a decision to take on a project or campaign:

*'I think something we've learnt is that, instead of waiting for permission to do something or wondering whether we should contact such and such a person, we just do it. If something important is going on, or if we have a question, we just contact them*

*and ask for information or say that we want to do something. (...) (I)f you're gonna wait for permission to do stuff then nothing will ever happen. What we try to do is just get involved. It doesn't always necessarily work - over the years some of the things we got involved in became quite complicated or difficult - but that's part of the reason we've become quite well-known. Everyone in the group has different things that they bring to that as well. There's a sense that it's a collective thing, and no-one's telling you you can't do something; if someone has an issue or wants to suggest an idea, they can'*

As another BRIL spokesperson argues, the emphasis on self-activity both helps to increase disabled members ability to intervene directly on the issues that affect them most, while getting around the fact that other services that they may use have become overstretched through increased demand and funding cuts:

*'If you wait for someone else to help you, like they help in other organisations, to stand up for you or your rights or find out information for you - it's never the same as doing it for yourself. I learned through my life, what you don't do for yourself quite often doesn't get done. One of my philosophies is to try and get things done, but to get that started you have to dig in to get it off the ground and get others to*



*join in. It's much harder to get anything moving if you're just going around other organisations even if they say they're going to help. There are so many who are overworked, overstressed, and don't have enough staff or resources - they're trying to help so many people - that it's just better to try to do it yourself'*

The organisation's openness to taking on the concerns of its members almost immediately has allowed it to branch out much further than its original remit concerning independent living, into areas of work which its members believe are aligned with or reinforce the argument for disabled people's self-determination. It also allows for a convergence between the campaigning element of the organisation's work and peer support; as things which impact members are addressed both in their effect on that individual and as wider issues requiring a collective response from the group as a whole:

*'We campaign for the right for all to have enough support; including, recently, the right to take a PA into hospital with you despite ambiguous hospital guidance. BRIL also provides peer support through our online meetings, information sharing - including the provision of easy-read, and we also work in solidarity with other*

*marginalised groups and communities - most recently Black Lives Matter. At present, when any member identifies something they feel needs to be investigated, it's discussed by the full group and decided by collective responsibility - which doesn't happen in other organisations. So nobody has more control than others, and everybody is equal'*

*'Peer support was, I feel, right there from the start - we didn't feel that we had to copy from other organisations, or others who set up just to do peer support. It was very natural due to us being in the same boat; equal, trying to get our voice heard. None of us get paid - we're all voluntary, and we don't have some people who have a job representing us or doing the work who have to prove they're more essential or knowledgeable. Everyone is the same, and peer support is natural given that'*

With these advantages, and the freedom to redesign how a DPO sets its priorities and acts while many disabled people are struggling to exercise control over their lives, come the limitations associated with a lack of money to pay for staff costs or other resources which would allow the organisation to build capacity:

*'Obviously, we're independent, but it is clearly harder without any funding. The*

*benefits include not being afraid to criticise any major organisation; as we don't receive any financial support from them, we therefore don't have to worry about losing any funding. We are, however, in a bit of a catch-22 situation: although we're all volunteers, the downside is not having the funding to campaign more effectively; which in turn could be a barrier to receiving funding from any source we may wish to criticise in the future'*

As BRIL uses both social media and links with other DPOs around the country to publicise its work and stay in touch with disabled activists, it's often the case that those who contact them to raise an issue or request support don't fully understand the practicalities of running an organisation with limited resources; with the risk that more demand can arise for the group to take action on something than there is capacity in the organisation itself:

*'We've had people contact us because they've heard of us through social media; other disabled activists in other parts of the country have said to people in Bristol - particularly when there's an issue around social care, benefits assessments, or whatever - that maybe they should talk to us. One of the things that we do is loan out tape recorders for ESA and PIP*

*assessment - people don't seem to know we do that, for some reason. We quite often get emails about that. We do a lot of work with other groups around the country too. (...) Again, we're a small group and are very limited in what we can realistically do; so that's something we try to think about. The problem with social media sometimes is that you give an impression that you have more capacity to do stuff and are bigger than you actually are. The Twitter effect is very noticeable; we've got a logo so people think we're a big organisation. In reality, we're mainly unemployed people in Bristol trying to do something different.'*

BRIL spokespeople were also aware that, with any kind of open decision-making process, there is the potential for discussion and consensus building to drag out longer than the group can afford if it wishes to take action on an urgent issue. One BRIL spokesperson explains how they attempt to avoid this:

*'I think it (the way BRIL takes decisions - LB) is organic; but that isn't to say that the group's not organised - because we have to be organised. Some of the things we've done - particularly campaigns or working with legal firms - are very practical, material things for which we have to be very organised. They're time limited, we've next to no money to do anything with. Some of*

*the people in the group are very organised - the way they think and the way they are is very focused and organised. For some of us, that's not their skills. So what we're trying to do is combine all that stuff - so you've got creative thinkers alongside those who are more lateral and organised - whatever those things mean. The organic aspect is the learning, the doing is very organised'*

BRIL are still a very young group, formed in September 2019. It remains to be seen how well their form of horizontal organising scales up if and when the core membership of the group grows larger - with BRIL spokespeople indicating that many members' involvement has been prevented or reduced by the pandemic, and that planned outreach to grow their membership has faced a number of obstacles during this time. Increases in membership entail a wider variety of views on strategy and priorities within an organisation, and can lead to consensus based decision making becoming more time consuming or fractious as time goes on. As I argue elsewhere (Beesley: 2019), a model of decentralised and horizontal decision making in a DPO exists to some degree in the form of Disabled People Against Cuts (DPAC); and it's likely that there is similarity between the strategic orientation of BRIL and that of the local DPAC branch - although we were unable

to investigate this further during our research. BRIL is also unique in Bristol in its refusal to even compete for public or charity sector funding; with all other DPOs either directly applying for grants and contracts from local government or an NHS body directly, or (as with the Survivors' Network in relation to BIMHN) being a member of a larger organisation which does.

### The DPO as a source of knowledge: WECIL, the search for efficient systems, and the restructuring of service provision

Founded in 1995, WECIL has been one of the (and occasionally the) largest disabled person- led service providers in Britain since the early 2000s (Barnes & Mercer: 2006, p 98). Heavily dependent on external funding, particularly that provided through local government contracts, in order to maintain its range of activities; WECIL was acutely affected by both reductions in the amount of cash and other resources distributed to fulfil service contracts, and changes in the way that contract outcomes were designed by commissioning bodies. The combination of reduced financing and a more restrictive definition of what the

organisation was being contracted to do (allowing WECIL service planners less say over how to conduct the services themselves) raised real concerns about how the organisation could maintain a high level of quality in its delivery to disabled people, and how it could tailor its activities to emerging areas of need amongst the disabled population of Bristol. As WECIL's former CEO noted in the organisation's 2015 strategy plan Hear Our Voice:

'It is clear that the need for WECIL services will continue to grow over the coming years, and as we are still in a time of reduced funding, we cannot rely on our income increasing in line with that need. Neither can we continue to focus on reducing running costs and offering more for less, as we would have to do so by compromising on our values and the quality of support we offer. For us, this is not an option. (...) In this time of austerity, services are often viewed in isolation, they are measured by their direct delivery costs and the wider reaching benefits are overlooked. (...) (A) monetary value is placed on wider social improvements rather than specific sector outcomes, such as health or health & social care' (p 7-8)

The organisation's initial response

to the change of climate within commissioning bodies, adopted in 2012, was to reassess and reconfigure its own internal processes to better fit with new criteria for spot purchases and contracts adopted by commissioning bodies, while attempting to diversify its sources of income to reduce its dependence on public sector funding (ibid, p 6). In 2015, this strategy was expanded, with the more ambitious aim of making WECIL the 'go to organisation for queries relating to disabled people in the South West' (p 11); requiring a rapid expansion of membership over a four year period and a greater engagement with younger disabled people (pp 10, 14), the provision of reliable data on disabled people in Bristol and disabled staff and volunteers able to co-produce policy or projects to other organisations (p 11), and the extension of its payroll services to those using personal assistants to include support planning and recruitment services - some of which was to be administered by volunteers to reduce administration costs (p 12). Simultaneously, WECIL was to boost its status as the voice of disabled people in the South West and an organisation providing social value by combining awareness raising campaigns and accessibility audits to external organisations (p 11) with measurement

tools which capture the added value produced by investing in WECIL while remaining compatible with how local authorities measure contract success (14).

Perhaps the most visible effect of this strategy was WECIL's acquisition of a number of smaller organisations providing services for disabled people; allowing it to both extend the range of services it offers to cover wider areas of disabled people's lives, while bringing activities which previously had been governed by non-disabled people under the framework of a DPO. In this process, WECIL's reach was extended into employment related training, services for disabled children and young people, and later access audits through Bristol Physical Access Chain (previously an all-disabled people committee of the Council) joining the organisation. Alongside this expansion of services, engagement with the wider disabled community was promoted through launching a new and looser form of organisational membership; with 'Community Members' engaged in consultations over WECIL service design and receiving updates from the organisation, but without formal voting rights at its Annual General Meeting (AGM) or the ability to stand for election

as a trustee.

At the time of writing, WECIL is yet to publish its new strategy plan; with delays to consultations with members caused by the pandemic and lockdown. It would not be appropriate to second guess what that document will contain - which depends largely on the input of a wide range of WECIL members who have not been interviewed for this report. Discussions with WECIL spokespeople carried out for this document, however, allow us to indicate where those working within the organisation feel that there is room for development, and what they perceive to be the role of a large service providing DPO at this juncture. There emerged from the interviews conducted for this project three key areas where spokespeople felt the organisations' efforts needed to be concentrated: in using WECIL's knowledge of disabled people's needs and aspirations to alter the way that services are designed and commissioned in Bristol, in increasing local disabled people's influence over how WECIL operates, and in a broader project of integrating disability equality and disabled people's concerns into the city's culture and governance. All of these activities are represented by spokespeople as related to WECIL's unique position in service production in



Bristol; where it's governance by those who use disability services, alongside the experience of those delivering services, may be used to create new forms of knowledge and practice which improve systems of provision and promote self-empowerment amongst disabled Bristolians.

The extent of the inefficient mismatch between the stated aims of disability services and how they operate was indicated by one WECIL spokesperson in relation to the organisation's Direct Payments (DP) service, which provides payroll and recruitment assistance to disabled people who employ their own personal assistants:

*'If the DP support service was to work well; someone would be assessed as having support needs, DP would be identified as a way for the person to have control over how those support needs are met, someone from WECIL would be able to advocate, advise, and support somebody to do that, and money would come in to meet the objectives that person set. When we studied that system and how it works in reality; essentially what happens is that someone is assessed as having care needs and there is a policy that everyone should be on DPs cause it's cheaper and 'it's what the Care Act says'.*

This person undergoes an assessment, and the only possible outcome of that is the prescription of units of care - hours per week - regardless of what that person identifies as their objectives and what ideas they have about how to achieve them. Those units are prescribed, and they're told they have a choice of providers to help with that. In reality(...) the person just gets advised of whichever one the social worker has heard of. So when we get involved, the first thing we do is look at their care package, ask them what they want to get out of life, find the two things don't meet. We challenge it, and they go back for re-assessment. We mapped this between a citizen undergoing a major life event which means that they have new unmet care needs and final support from WECIL; we counted seven times over that process that a person has to tell their story, and five additional times that a professional retells that story' This process absorbs considerable resources in both the commissioning organisation and the end service provider, with the relationship between the service required by the end user and that actually commissioned becoming more tangential as information is re-stated, re-interpreted, and re-applied to fit eligibility and operational criteria at different levels of various organisations. What emerges from such

a process is suboptimal for all involved; with regular needs to appeal decisions causing unacceptable delays to the user receiving the services they need (not to mention that the discomfort and distress caused by consistently deferring decisions makes a huge difference for someone's control over their life), and extensive resource drains on both commissioners and providers:

*'You then have a 27 step process; that's the number of meetings required to go through and retell their story for various panels to make decisions, and have those challenged - there are a few stages which assess and certify that person's needs are eligible; how is that compliant with the Care Act? There's so much waste. Our role, historically, has been to try and undo some of that damage and try and make an imperfect system fit the user as best as possible. That really is what I saw as the significant weakness, not just of WECIL but the system it operates in'*

One obvious solution to problems of bureaucratic over-extension in service planning, for this spokesperson, is an orientation in service planning towards what disabled people say they require from services which operate in the city, rather than simply what contract planners have decided would be desirable and affordable:

*'(T)he opportunity to redesign those systems without waste can only come by it being entirely person-centred. So it is about giving greater choice and control to the citizen - the user, the member of WECIL; because it's only by delivering what a person wants, and getting that right first time that we design out waste. (...) The presumption is that if you make a commitment to delivering exactly what a person wants, costs will inevitably go up. What we find time after time is, however, that when you concentrate on delivering on what somebody wants exactly and only that, your costs go down incredibly; because you're not delivering services that were never needed in the first place, and you're not picking up the cost of rectifying that those services were not what was needed for that individual'*

As an organisation controlled by its users, WECIL is in a privileged position to both provide the information about existing needs necessary to carry out such a rationalisation, as well as operational insights about how services could be administered to ensure that those (and only those) needs are addressed by commissioned interventions:

*'WECIL as an organisation has that knowledge. But more than that, WECIL is*

*the vehicle and the forum for an individual citizen to share their knowledge and experience; articulate for themselves 'what I want for me as an individual'. That is the fundamental leap'*

The position of the organisation as both a source of vital knowledge and a vehicle for change relies on disabled Bristolians continuing to have direct control over the organisation's policies and strategy, and on expanding their practical experience of engaging with different areas of community life in the city in order to strengthen the organisation's knowledge and capabilities. While two of the three spokespeople interviewed indicated that simplifying WECIL's internal democracy was necessary to extend members' influence in all areas of its work; all interviewees argued that this was not in and of itself sufficient to maintain or expand WECIL's ability to enact change. One spokesperson argues that this can only be assured by an increased focus on community development - a process of supporting disabled people's engagement in decision-making processes and civic activism by providing skills training, promoting disabled people's involvement at each level of decision making in the city, and providing analytic frameworks which promote a shared understanding of disability as a social phenomenon:

*'(I)t's largely that the development work isn't happening, when we had lots of people doing peer-advocacy that would be the obvious way of channeling them into being trustees. We also have a shadow-board now, which is young people we're hoping to learn to act as a board and eventually join us.(...) I think it [community development] is a key prong, but you need a governance structure where there's something to fit into. You can do a load of work to get people geed up, but there isn't a place where they fit into governance and have a way to say anything'*

Another framed it as a need to expand and restate WECIL's role as an organisation promoting the voice of disabled people; rather than simply as an organisation providing services to them. In so doing, the organisation proactively seeks out and utilises the expertise of its members in planning its own activities and representing its views to other organisations and external decision makers. Such an orientation requires that its members recognise that it is there to promote their views and ensure their concerns are addressed by other agencies in the city:

*'I think that, because people feel that their voices aren't heard at a political level, the more WECIL's begun to restate its role as*

*a voice organisation it's become less of a challenge to get people involved. It's not that we ever stopped being a campaigning organisation: we've always had projects like 'Experts by Experience', and our 'Listening Partnership' is perhaps the best example of youth participation and influence I've ever seen in this country. Our image, however, wasn't as a voice organisation for a lot of people; it was as a service delivery organisation. Therefore, we had a lot of service users who had a customer-provider relationship with us, rather than an engaged, inclusive, users' organisation relationship with us. I believe that is changing and improving every day.'*

## Strategic gaps and critiques

As we've seen, DPOs' strategic re-orientations and adjustments of their organisational priorities during the 2010s were driven largely by factors outside of their control - including reduced resources, increased demand upon services or representational capacity, and a worsening outlook for disabled members. Under these conditions, it is not surprising that some interviewees raised concerns that DPOs in Bristol, as a whole, had proved unable to undertake all of the activities required to promote and expand disability equality in the city. As we saw in the previous section, some

interviewees felt that not enough had been done to ensure that people with all impairment types were included in the Disabled People's Movement in Bristol. This was held, in part, to be a failure of representation - with DPOs and disabled activists perceived to be not proactive enough in incorporating people with some conditions or impairments into their campaigning work or developing new services needed by them. One part of this critique, however, concerned the level of access people with different communications needs had to DPOs' ongoing activities and services. As the spokesperson for the CDHH explained:

*"There was an argument, I think last year, when I was going to a disability event. I had to ask for an interpreter, someone else had to ask for a speech to text translation; and someone in the audience said: 'we should not be asking for these things, these things should be given to us. They should be there already as part of the plan. You're talking about disability and we should be part of that disability movement. You've put a ramp outside, why aren't you providing interpreters? Why do we have to ask?'. It was that argument. Now we can't say 'you need to provide interpreters every time you do something' because you don't know if someone deaf is going to turn up. So in some cases we do have to ask. In other*



*cases, it should be provided anyway. It's a national problem'*

A spokesperson from BRIL also pointed out that easy-read information is not produced consistently by DPOs in the city, meaning that much of the work carried out by DPOs in Bristol is not accessible to many people with learning difficulties:

*'We also have to challenge the lack of accessible information from other DPOs (...) Some of those organisations just claim that it's too expensive to do'*

While it is true that adapted communication is expensive, and DPOs starved of resources, the inability to produce accessible information about casework or other things going on in an organisation for disabled people who need them risks reinforcing the underrepresentation of certain groups within DPOs' activities; making it increasingly difficult to increase the engagement of people with these types of impairment, and thus harder to utilise their skills and expertise to grow the organisation itself. Such a situation may also discourage joint-working between DPOs; with organisation's representing people with different communication needs less likely to engage in projects

where their members cannot receive relevant information in a form they can use.

Another concern raised was whether DPOs' strategies allowed them sufficient independence from statutory authorities. Although often rooted in decisions taken by national government, much of the reduction in provision for disabled people in the 2010s was directly implemented by local councils: the same bodies which largely fund DPOs. One BRIL spokesperson argued that the reliance of DPO's on these bodies had allowed undesirable elements of local government and corporate culture, alongside the priorities held by commissioning bodies but not disabled people themselves, to seep into DPOs' practices without being questioned; undermining DPOs' ability to re-think their relationship to their members or engage in the antagonistic lobbying sometimes necessary in representing a marginalised population:

*'One of the motivations for forming BRIL was that, when you look at the organisations that came out of the Coalition or from mental health activism in the 70s and 80s, they'd all become service providers. Some of them do incredibly important work which is totally necessary; but along the line they've adopted and*

*absorbed the language and practices of business; competition, managerialism, hierarchical methods of working - and they've kinda lost their way'*

One WECIL spokesperson, while not going as far in their conclusion, acknowledged that reliance on local authority contracts has had negative impacts on what DPOs have been able to do to represent their members' interests in some cases. They linked this to the unique, and uniquely challenging, structural position DPO service providers occupy relative to local government and the delivery of public services:

*'There have been vagaries over time, I think because of the way WECIL (and all CILs) have had to shift and follow different modelling - largely based on growth. My reading is that, in many ways, the unique proposition of being a user-led organisation became somewhat compromised by the success of the movement. In more advanced and sophisticated ways than other rights movements, CILs and other DPOs got a seat at the table with influential national and local policy makers; and that grew quite rapidly into an expansion of public service delivery. Whereas CILs have their roots in Direct Payments support - quite a uniquely crafted, partly supportive, partly oppositional, relationship to local*

*authorities - as a movement it moved quite quickly to take on other public sector contracts. As such, I think there was a rapid professionalisation of the sector which - while trying to be honest and delicate with the wording here - gives validity to some of the criticisms from outside of CILs that some of their activism has been compromised by the larger contracts the movement has become reliant on in order to survive'*

Other interviewees expressed regret at what they saw as a retreat by DPOs from the broad political critique inherent in the social model of disability - which argues that disabled people's exclusion is the result of society wide practices and structures, and not simply individual attitudes and local factors. Reflecting on their own organisation, one WECIL spokesperson reported that this element of its analysis had been overlooked at points in the organisation's development:

*'I think WECIL did have that edge in the early years. There was always the issue of what is and what is not campaigning, and we weren't supposed to campaign; but we co- chaired the Disability Advisory Subcommittee of the council and that was totally having a go. We were very active in the Inclusive Education Steering Group where we were hugely critical of schools*

*and segregation. So we were proactively speaking against the council and the government during that time, but we said we weren't campaigning and just framed it as standing up for better services and disability rights. It was set up as a political organisation in my view, but much of that political emphasis got lost over the years'*

This worry was echoed by Liz Crow, who argued that the absence of the political critique in disability activism in recent years has weakened the strategic coherence of the Disabled People's Movement around the country; leaving it often unable to protect its previous gains or organise around its basic principles when disabled people's rights are under attack. Pointing to the need to articulate a political and social narrative, namely that of the social model, in order to make change sustainable, she argues:

*'So you take the change we've made over the last 30 years, and you bring in an austerity program like we've had for the last ten years, and the practical and structural changes made are shown to be very fragile because there hasn't been the kind of cultural change that embeds it. You have legislation, and people are required to an extent to comply with legislation, but it's just compliance. It's not 'I get why I'm doing this, it aligns with my values'; it's 'I've got*

*to put a bloody ramp on the door because I don't want to be sued'. So when it's tested, actually it isn't sufficiently embedded for people to do that of their own volition. It's about discourse change, ultimately; if you look at the really profound change from social movements the ones that stick around are the ones where their ideas and values become the common currency.'*


## Conclusion

DPOs operating in Bristol have been extremely flexible and innovative in their responses to the austerity period, and have utilised a range of methods to not only survive where many comparable organisations around the country folded, but in many cases to extend their influence and range of activities. This speaks to the resilience and resourcefulness of the sector locally, and indicates a wide range of expertise and practical skills amongst disabled activists in Bristol. Despite this evident strength, significant concerns have been raised regarding the ability of Bristolian DPOs to fully operationalise the principles underlying the Disabled People's Movement - that disability is caused by the way society is run, that the social exclusion of people with impairments or other health conditions

can be overcome by profound social change, and that this project requires the unity of disabled people and their organisations (regardless of impairment types) around a shared analysis and goals. Some of the obstacles to building that unity are rooted in DPOs' limited access to financial resources and the sources of their funding, however others are seen as either cultural or political in nature. If these are not addressed, then there is a risk that the 'fracturing' of the Disabled People's Movement lamented by a BDEF spokesperson in the previous chapter becomes a permanent feature of disability activism.







# Section 4: DPOs' experience of Collaboration and Co-production Across Bristol

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## Ambiguities of the co-production framework

One of the more promising recent developments for disabled people's aspirations to social inclusion and self-determination has been the pivot by statutory authorities and central government towards the principles of collaboration and partnership in social care service design and delivery. This is most clearly instantiated in the case of 'co-production'; once an experimental and innovative approach to integrating users into each decision-making stage of a service adopted by a dispersed group of local councils and third sector bodies, which became official government guidance to all local authorities in

relation to their obligations under the 2014 Care Act (Department of Health: 2014, p 17). Under this rubric, those who use social care services are recognised as having expertise in their own right to define the types and levels of need in a local area, how services should be implemented in order to meet these needs, and what forms of delivery should be available to allow users to make the most comprehensive use of the services at their disposal. As this expertise is equally important to the planning of good services as that held by professional service planners and providers, service users should have an equal say to their professional counterparts in how and what services are made available to them (SCIE: 2015, pp 8-9).

The co-production paradigm should be unequivocally positive for DPOs; which centralise the expertise of populations which use social care services in their membership and networks, and whose organisational structures provide infrastructure to engage disabled people consistently in the planning and delivery stages of a project. Co-production has, however, proved very difficult to define beyond the rhetoric of partnership and expertise, and the slipperiness of the term risks the framework being applied inconsistently; with any failure to fully include service users in later stages of service delivery and evaluation likely to undermine its transformative potential (ibid, p 5-6). An additional limitation stems from the fact that the language of co-production has often not extended beyond statutory bodies or areas of health and social care. As shown in the last Section, the importance of transforming social care to the projects of many DPOs does not entail that those projects do not require collaboration or constructive working relationships with organisations involved in wider spheres of community life. The interests of disabled people, as of other citizens, are wide-ranging and touch upon all areas of activity within the city; and reductions in funding alongside prescriptive funding outcomes have made it particularly

attractive for many DPOs to collaborate with diverse agencies from the private, public, and third sectors in order to run the projects they and their members believe are necessary.

This latter point is particularly pertinent to Bristol; where collaborative policy making and decentralised decision making by private and third sector organisations has been incorporated into the city's governance through the One City Plan (OCP) - administered through the mayoralty, but decided upon by partnership boards of participating organisations. This section attempts to capture the variety of collaborative practice that DPOs have been involved with in Bristol, their experiences of positive and negative forms of partnership working, and what they see as the greatest barriers to increasing disability equality through collaboration with different agencies. It explores how well DPO spokespeople feel that disability issues have been integrated into new forms of city governance like the OCP and represented in public sector initiatives, alongside their evaluations of collaborations with private and third sector actors and, finally, the ability of DPOs to collaborate with each other in order to present a united voice in pursuit of their shared interests.

As is clear from the previous Section, each DPO in Bristol has a unique relationship with other organisations and services within the city. For some, collaborations with statutory bodies which involve funding for service provision are key to the organisation's survival, whereas for others contract or core funding through these bodies are either irrelevant or undesirable. Similarly, collaborating with private or third sector firms or organisations is a higher priority to some DPOs than it is to others. As such, there is an unavoidable asymmetry in the presentation of DPOs' concerns and hopes for partnership working; with spokespeople from an organisation often having a lot to say about one area of collaboration, but limited experience of another. I have attempted to minimise this by breaking this section into a number of issue specific subsections: covering co-production with statutory bodies, commissioning of services, devolution and policy making outside of the city council and CCG, collaboration on projects with non-statutory organisations outside of policy frameworks, and partnership working across DPOs. In each subsection, only the relevant section of all DPO spokespeople will be quoted.

## Co-production with statutory services

The impression of a number of interviewees is that Bristol's statutory bodies had a history of successfully co-producing services and policies with disabled people and their organisations in the 1990s and early 2000s, that those practices almost entirely vanished after that point, but that awareness of the need to consistently co-produce a policy or service with those affected by it was re-emerging within key areas of the local authority and CCG. As one WECIL spokesperson put it in relation to Bristol City Council:

*'Historically, Bristol has a very strong track record in empowering the Disabled People's Equality Movement, and DPOs because of that; but that is historical, and recent history does not put Bristol in as favourable a light. Currently, however, BCC as an organisation is really changing; I think there are very enlightened people in senior positions now - both within adult and children's social care.'*

Interviewees were concerned that the awareness of co-production's merits at the top of the local authority was not always apparent in interactions between DPOs, officers, or council employees on

lower pay scales. In some instances, this was attributed to a lack of commitment to the principles of co-production by some local authority staff. As the spokesperson from BPAC points out, one partner in co-production being rigid in their approach to a project and failing to engage with disabled partners can jeopardise its success and waste a good deal of work already done by DPOs:

*'We were quite heavily involved in producing a couple of guides around that time (2015-17 - LB); there was the access standards and what was supposed to be a guide to accessible Bristol. That was pretty much the brainchild of a young student working temporarily at the council. It was very much taken on by one of the equalities managers. (...) BPAC had quite a big input into it. Unfortunately, the senior equalities manager took on the design and development of it herself and completely ignored a lot of the things BPAC had said and done. So when the guide was eventually produced, most BPAC members were very unhappy about its contents. (...) It's a moot point: a lot of work went into the guide, members did a lot of things - auditing shopping centres, stations, the harbourside, heaven knows what else - but a lot of that work was just ignored'*

The spokesperson from the CDHH similarly explained that, in one project carried out with a local authority team, key decisions around project planning were made at the outset without either involving or informing the CDHH:

*'It's really hit and miss. With the dementia project, we were very much working equally on that, because it's very important to all of us. When we started, however, it was just me and the Dementia Wellbeing Team; then they went away and spoke to the DST, then spoke to the someone at the Sensory Impairment Team at the council, with the Sensory Support Service. And started bringing them in. I said 'Whoa, what are you doing here? This is meant to be a project between us'. Although we hadn't signed anything, or had an official agreement, my understanding is that if we were gonna bring other people in we should at least be discussing that together'*

Although difficulties in that particular project were ironed out early, and partnership working became productive and beneficial for all involved; the CDHH spokesperson reported that some collaborative projects appear to be structured in such a way as to resist genuine partnership working on identifying outcomes or



altering how the project runs. They explained that the council's wider community consultations, including its Voice and Influence Partnership, had failed to foster co-design or co-production and were treated with suspicion by many in the deaf community, who:

*"do turn up, and they do fight - but it's a small group who are regularly at these type of things. But they feel that they're there to check a box, so the council can say they've consulted with us; or they feel that they don't listen. We're part of the Voice and Influence project: and not one person has signed up to it. Because they think 'the council don't listen to us so why bother?'. We've been trying to think of different ways to encourage them: saying 'the council are paying for this project because they want to listen now'. And people respond 'I can appreciate they want to listen, but it's just gonna be another box ticking exercise'"*

The CDHH approached council employees running consultations with the deaf community with a set of suggestions on how to repair trust and make the process more constructive for all parties. Troublingly, their spokesperson reported that they feel these suggestions were ignored:

*'(T)hey said no. I was saying, at the end of last year, that we'd have to drop V&I*

*because nobody's interested and nobody's gonna want to sign up; but I was asked to continue and persevere. So I said 'can we approach this by another avenue?', and was told to just keep going and trying to get people to sign up. What more can I do? Do they expect me to give people cash out of my own pocket whenever a person joins up? People don't want to sign up because they don't trust you guys; they don't trust the council'*

The experience of consultation processes that feel like box-ticking exercises instead of co-production was not limited to the deaf community. Looking at the trajectory of interactions between DPOs and the local authority over the years, the BDEF spokesperson notes:

*'I think responses to co-production have been really mixed; I've been with BDEF for 17 and a half years and it's been very varied over that period. I'd say the 'need' to consult with groups of disabled people has faded over the years - there's no simple reason for that nor virtuous intention behind it.*

*Originally, after the early successes of the DPM, local authorities felt that they had to listen to equalities groups and disabled people through the DPM. How openly they listened to them is debatable, and a lot of my work was then chasing up and saying*

*'you were told this, you've not done that, why is that? Can we have someone on your working group so that what was raised can be carried through to the work you finally do?'. (...). Unfortunately, these days, it's all about the numbers responding to consultations formally and very little about meeting face to face and having a two-way conversation. That change has been led in no small part by the gross reduction in the funding of local authorities, health services, and so on'*

Similar frustrations were voiced by a BRIL spokesperson, who characterised a superficial and tokenistic approach to consulting disabled people, without giving them power over decisions that concern them, as common to both local and national government:

*'The way things operate in Bristol is that people don't have actual direct influence and power over decision making. On the national scale, we have these conversations with people on how the Government has completely failed in its duties under the UN CRPD, the Senhai convention. The government is committed to directly involving disabled people, older people, people with long term chronic illness in decision making. That hasn't happened, and it's caused relentless misery as a result. That's the core of what BRIL's about, (...) -*

*not this pretend 'involvement'. In Bristol we have this constant consultation: 'we want to hear your voice' and all that stuff. People don't want to be 'heard', they want to make the decisions'*

Some interviewees believed that much of the knowledge of equalities issues necessary to promote co-production and empowerment had gradually disappeared from the council's workforce. The spokesperson for BPAC, who were ensconced in the local authority prior to becoming part of WECIL, noted a drastic reduction in staffing in the Equalities Team during BPAC's final years at the council:

*'This is my personal opinion, and I've no evidence that it's the case, but I think the council decided to concentrate on their statutory obligations and equalities just came a long way down the list of things they might want to do. The equalities department was pretty much destroyed over a ten-year period; I don't know how many people were there at the start, but when I worked there with (...) the access officer there must have been a dozen people either full- or part-time and that reduced to one or two over the last couple of years. I would say 'of course that's a mistake', but that's because I've an interest in equalities, being disabled. (...) I don't*

*know that anybody sat down in a (senior management - LB) meeting and said 'let's not worry about equalities and spend the money on something else'; but 'by proxy' is a good way of putting it. It was quietly ignored, and if nobody brought it up it wasn't gonna be an issue'*

Another WECIL spokesperson worried that the organisational memory of collaborating with disabled people to produce services or policy had largely vanished from the operations departments of Bristol City Council; leading to a lot of confusion about what co-production involved or committed statutory bodies too:

*'We had an induction on a whole lot of issues from Social Services officers. I went along to one on co-production, thinking it would be interesting, and the senior officer was saying 'We're really good at co-production in Bristol'; the example they gave was of redesigning a website where they brought in two or three VI people to comment on it. I listened for five minutes before going ballistic - which I probably shouldn't have. I said 'this is supposed to be a briefing about co-production, what it is and how to do it, all you've talked about is some small consultation work with a handful of disabled people'. They didn't even understand the word, there was no*

*concept of working with a DPO to produce something because that hasn't happened since the early days of WECIL. We didn't call it that, but we did co-produce; we co-produced the direct payment policies for Bristol and wrote the handbook for PA employers'*

A confusion, or at the very least a lack of knowledge, around partnership working and co-production are indicated in even the more positive experiences of joint working with statutory bodies reported by interviewees. Reflecting on a successful piece of co-production with the local Clinical Commissioning Group (CCG), the BDEF spokesperson noted that disabled people's involvement at each stage of policy design was largely facilitated by a small number of enlightened and committed worker in the CCG; rather than because structures which promote co-production had already been built into the organisation's ways of working - although the interviewee hoped that the outcome of the work they had contributed to would allow that to happen in future:

*'There are, however, areas where there are individuals who are very active in big organisations who really take it*

*seriously. An example would be where we've recently worked with the CCG and co-produced their new participation policy; that policy, crudely speaking, addresses their 'triangle of engagement' - which was lots of consultation, little bit of engagement, basically no co-production. We've switched that round. In the policy now, they are supposed to have co-production wherever they can; if they can't, they should have engagement. If they can't do that, or it would be a waste of people's time, they should do consultation. I'd say that was down, as it often is, to an handful of individuals in that organisation who were prepared to drive it through that organisation - so internal allies. It's very rare that you would see an organisation, like a statutory or private sector organisation, structured to respond as a whole organisation in pushing through progress, rather than it being individuals with a passion taking that on. In this instance, I think it helped that it was someone new to that sector, who didn't carry its culture with them'*

A spokesperson from the Sight Loss Council, which has a much more positive experience of working with the local authority and NHS bodies than other organisations, reported that successful co-production and engagement in their case was largely the result of their

own initiative; with local government and health service providers open to partnership working but very unlikely to initiate it themselves during the planning stage of a project and seemingly unaware of the need to factor co-design and co-delivery into their work without prompting. As with interviewees already quoted, they thought this had a lot to do with the loss of organisational memory:

*'I know from what other disabled people say to me that they feel they're getting left out of consultations more and more, and that there isn't the consultation engagement in place there was 10 years ago. Bristol had quite a good reputation up to the early 2000s because of the hard work of disabled people's organisations, and certainly there's a general feeling things have gone backwards. All I will say is that, when I speak to officers now, they might not be thinking proactively about including disabled people but when you approach them and say they should be, they do respond positively. I don't know if there's a mismatch between proactivity and something else. The desire is there to do it, they just don't think about it most of the time. I know there've been so many changes in the council in particular, they've lost a lot of their workforce and with that the historical memory is gone. All the policies and stuff they had are*



*gone; we're having to start from scratch. For those of us who've been around for 20 years, that's irritating. I'm not sensing any hostility to talking to disabled people, though - if you go to talk to them, they will talk to you. They're just not very proactive about it'*

If the knowledge gap around disability equality and co-production that interviewees identified in statutory bodies is at the root of the problems that they've experienced, then the provision of Disability and Deaf Equalities Training (DET) within these authorities would be an obvious first step towards resolving it. DET is based on the same paradigm as anti-racism and gender equality training, and focuses on how institutions can reduce the attitudinal, organisational, and organisational barriers to disabled and deaf people's participation in social and civic life. If carried out amongst all employees who might be involved in co-production processes, it would provide them with a baseline understanding of the issues disabled people believe to be most pressing, while building their relationships with disabled trainers who could support them to initiate partnerships with disabled people in their communities. During the 1990s and early 2000s, DET was a core plank of the council's relationship with DPOs, but as

one WECIL spokesperson recounts, it has fallen entirely by the wayside:

*'We did mandatory DET training with senior managers in Bristol and Avon; it was easier in terms of relationships, and because they had a basic knowledge of what we were talking about. Even now, I bump into people who say 'my whole understanding of disability was changed by being on your training' - often I don't remember the training at all! (...)- which doesn't mean the training was brilliant, but that there's been damn all since. There's not been consistent DET in Bristol of managers for years now'*

The CDHH spokesperson reported that their own attempts to provide Deaf Equalities Training to local authority departments have been mixed; with positive responses to the training itself, but some reluctance from public sector bodies to prioritise it for their staff:

*'It's really difficult to get into those places. I have done the council in the past: two trainings in the past. It was during Deaf Awareness Week; so it was free, and they like that. It was also an open invitation, so I was just waiting in a room for people to show up. So it's hit and miss in that respect. I've been trying to work with the council to provide more intensive training for council departments: working around*

*each to give them more training. That hasn't happened; they've not been very receptive in receiving that - which is really frustrating because they need to improve their services, particularly in regard to front of house services at 1 (Victoria St - LB). It's not deaf friendly. I have people come to me and say 'I've been down there 'cause I need to talk to someone about my council tax, and they've no idea how to communicate with me'. It's difficult with how we approach the council: if you really approach them at the right time they'll say 'Yeah, let's do something about this', but...'*

While WECIL and BDEF's recent experiences point towards an overall improvement in some parts the City Council's and CCG's approach to partnership working and co-production; it's clear from other organisations that these positive changes are far from evenly spread. If statutory bodies in the city are to take advantage of both the opportunity to partner disabled people-led organisations which have proved themselves to be resilient and creative, and to use the expertise of the members and communities they represent to produce more effective policies and services, then these inconsistencies across organisational layers will need to be overcome. BDEF's involvement with the CCG's participation policy is an

important step forwards in this regard, and indicates the positive impact engagement with a DPO can have during the design of co-production policies themselves. It must be hoped that other arms of the public sector in Bristol follow suit.

## **Funding and contracts**

Drastic reductions to local government budgets around the country have altered the way that local services are commissioned in ways which are detrimental to DPOs. Not only has the money paid for services been reduced, leading to real worries from some DPOs that they will be unable to deliver a service of appropriate quality with the resources available to them, but reduced budgets has incentivised contracts to be offered to larger charities or firms capable of cross-subsidising their activities and taking advantage of economies of scale to offer services at a cost lower than any small organisation could operate on (SOL & NSUN: 2019, p 3). Nationally, those DPOs that rely on public sector monies to survive have often simply stopped surviving; with the consequent loss of their own expertise and knowledge of local communities and inclusion of those communities in service planning and delivery.

Bristol was hit particularly hard by cuts to money allocated by central government to councils; with £233 million worth of reductions in the City Council's budgets between 2010 and 2018 failing to eliminate a sizeable deficit in the local authorities funds (Ashcroft: 2019). Following the effects of the Coronavirus pandemic - entailing much higher spending by local authorities and declining income from multiple sources - the council's budget has suffered a further net loss of £86 million, with officers now warning that further cuts are 'inevitable' (Cameron: 2020). This is hardly reassuring for DPO's in Bristol who administer council-funded services, who reported that greater understanding of what kind of funding they need to provide decent and efficient services has only recently been forthcoming. As one WECIL spokesperson explained:

*'We are delivering statutory contracts which aren't based on a full costs recovery model; that's been detrimental to the sector; because it means that there are larger organisations like WECIL which struggle but are able to subsidise some contracts by having other activities. There's a very Conservative-led idea that that is the effective way of delivering*

*services; to devolve them to community organisations (so they're commissioned rather than centrally delivered), but then such community organisations should have their own means of generating profit, so that they're able to deliver services at direct costs without having to trouble the state for overheads. That understanding has been demonstrated to be false; and that is now changing, I think, in terms of commissioners' understanding of what they need to do to invest in a supply chain that will sustain. That, however, has come too late for many organisations, and we have seen a loss of a great deal of the sector - in terms of general third sector organisations closing down, especially the smaller ones' (Section in brackets interviewee's addition)).*

As with other DPOs and user-led organisations around the country, WECIL interviewees expressed concerns about their ability to provide quality services on the budgets allocated to them. As another WECIL spokesperson explained, WECIL had been forced to subsidise some services itself; but this had neither resolved the issue fully in the short term, nor provided a sustainable long term option for maintaining and improving service quality:

'Over the years funding has clearly been

affected, and I'm more worried about the quality of the services we run, rather than the range of the offer. It's very clear that there's been a gradual whittling away of the money available, increasing of the targets, and a lack of understanding of the cost of access or self-organisation that DPOs have. Some of this is due to procurement processes where equality issues are not fully addressed. We're in some contracts where what we can deliver is limited due to the nature of the contract itself. I'm more worried about that than the specific services we offer; it's the quality of the services which are impacted by austerity and by the way they do the commissioning. (...) We're aware of where we just cannot fully deliver what disabled people say they need, and there are some situations where the quality and accessibility of services will only improve if we get some more resources. We have actually put funding into some contracts or commissioned services from our reserves to try and help, when they commission with inadequate resources.'

Poorly designed commissioning processes, and a failure to clearly communicate how commissioning criteria are interpreted and applied to DPOs and other community organisations, was also a matter of concern to interviewees. As the BDEF spokesperson reported,

an inability to explain exactly how changes in commissioning would be administered, or to take the situations of bidders into account in the commissioning process, caused a drain on BDEF's capacity in the run up to significant alterations in its funding; with increasing levels of staff time committed to addressing new funding criteria that did not reflect the reality of community organisations and may not even have been implemented, and less resources free to engage in the community development work the organisation is actually for:

*'Although our funding situation in hard cash changed in 2018, the whole of the previous year was spent trying to prepare and adapt for that change. For example, when it became apparent that funding was going to be based on a contract; we had to do a lot of work bringing all the equalities forums together to figure out how we could run such a service as a partnership while retaining what we felt was essential - which is that the work of each organisation is focused on what those with lived experience want. If you've got to cover all equalities with one pot of money, there will inevitably be a lot of compromises. It took a lot of discussion, but we all got rather stymied by the commissioning rules; because each of*



*the forums were primarily funded by the council, none of them had sufficient turnover to be a lead bidder under the rules. BCC implied it would be understanding; but wouldn't actually say 'it's ok, we understand the situation, and we'll waive that in this case'. So we had to spend a whole load of time finding a lead bidder and negotiating with them - which started positively, but then went very pear shaped in my personal view. The outcome was that we ended up with little-to-no money or staff time to hold large, public consultations with disabled people to review [The Disabled People's Manifesto]'*

One WECIL spokesperson agreed that the design of contracts had caused a substantial amount of work for the organisation that had little to do with either achieving a contract's outcomes or addressing the needs of service recipients. This 'waste work', caused more often than not by a failure to meet need or allocate resources efficiently at an earlier stage in contract delivery, has a direct impact on an organisation's ability to maintain quality, or engage in other activities which could increase its impact:

*'What I found with WECIL is that there was tonnes of failure demand and tonnes of waste work. It was largely because WECIL had grown through a large number of LA*

*contracts which, in themselves, weren't sophisticated. If you wanna find systems full of waste, look at a large and complex organisation like a LA. Contracts with LAs tend to be the perceived best and most cost effective fit to what legislation demands of them; and tend not to commission person centred services. The danger of anything that's reliant on public sector contracts is that they'll focus on the targets and KPIs of ill-designed contracts, on measures that aren't person centred. If we're delivering what a commissioner demands from us rather than what a citizen expects of us, we're gonna be generating a lot of failure demand'*

The scale of waste caused by the existing contracts between the local authority and organisations administering services are, in WECIL's case at least, significant; with only a limited amount that WECIL can do to remove waste without the structure of the contract itself, and the behaviour of contract partners in their inputs into the process, altering:

*'We did a lot to design out waste in our work. I quantified how much work is waste in the DP system; it came out at about 60% waste, which isn't unusual in any sector. I then looked at the causes of that failure demand: quite often its internal systems, but a significant proportion in*

*this case is really caused by externalities - usually previous misunderstandings, missteps, or miscalculations, including by a commissioner. We were only really able to design half of that waste out of the system - that's all that it is in our gift to do'*

A JobsNetwork spokesperson indicated that the scope of projects which Bristol City Council were willing to fund (often encompassing the whole city rather than taking advantage of localised knowledge to run small targeted interventions in neighbourhoods), combined with the absence of non-cash resources like promotion and facilities offered by other local authorities, made it difficult and unattractive for them to compete for local authority funding in Bristol at all, and to prefer working with neighbouring authorities:

*'There are some issues with funding in Bristol - it can be very competitive and not always area specific. But it's not always about funding, one of the conversations we've had with South Glos is about them promoting the project we're working there. (...) What I've found in South Glos is that you can get funding and support for a small, localised, project'*

The spokesperson working in BPAC argued that, in their case, a lowered

engagement with equalities issues within the council itself had disincentivised cash-cheap investments in projects led by disabled people if these also involved input or co-ordination from local authority staff:

*'It was very much borne out of austerity. We had a contact in Equalities, but she was a part-time worker herself, and it became clear that BCC didn't really want to continue to fund BPAC - even though the funding was only about £3k a year, which isn't a lot of money in the real world. Because of the reduction in Equalities and the loss of the access officer position, BPAC had lost a lot of its contacts in BCC. There were changes within the council - of structure, with senior staff moving about and jobs being deleted. It became impossible for BPAC to operate in the way it had before. The work was drying up, it just wasn't being put through by the council, the group decided that it really needed to be looking outside of BCC, which is a decision the council embraced, shall we say'*

Two WECIL spokespeople indicated that they believe commissioners' understanding of what they can do to support small organisations deliver effective services in a way that is sustainable has markedly improved in

the recent past; leaving them hopeful that things will get better in this regard going forwards:

*‘The fix is about influencing everyone else involved - social workers, people who have spending decisions in LAs. (...) It’s taken a long time, but I think we’re now in that situation in Bristol. We’ve been able to evidence the improvements that we’ve made internally; and the datasets that shows that there are improvements needed externally to WECIL in order to make that system work for citizens. There are some enlightened people in ASC commissioning, so our relationship is evolving, I would say; from a contractor, that a commissioner is to some extent obliged to work with, to a partner with which they are genuinely enthusiastic to develop radical change with’*

*‘Suddenly, they’re talking to WECIL about having a bit of money to do co-production around Direct Payments and things with the commissioning team’*

How this understanding evolves in light of the emerging financial pressures on the local authority remains to be seen. Delays in contracts developing to take greater account of the needs of community organisations and those they represent may, however, have dramatic consequences for smaller DPOs. While

some, like JobsNetwork, may be able to take their work out of area in order to secure funding; it seems likely that other organisations whose membership ties them closely to Bristol will be forced to make very difficult decisions about the quality of the services they offer; or, in the worst case scenario (if the form in which contracts are designed does not change for some time), whether they can continue operating at all.

## **Devolution, decentralisation, and DPOs in the wider debates of the city**

As mentioned in the introductory section of this report; the governance of Bristol has changed drastically over the period this report covers; with three new layers of local and regional policy- making infrastructure emerging in the 2010s. The first of these was the Bristol Mayoralty, which adds an executive decision-making function to the traditional activities of the local council, and was established after a referendum in the city in 2012. Regional devolution was further expanded with the introduction of the West of England Combined Authority - covering Bristol, Bath and North East Somerset, and South Gloucestershire - in 2017 to administer transport, adult skills,

and economic planning responsibilities that had previously been administered by central government. Finally, in 2019, policy planning was further de-centralised in the city with the establishment of the One City Plan (OCP) by Bristol's Mayor Marvin Rees; a policy program which runs parallel to the council's activities and is constructed through partnerships of local businesses, community organisations, public sector bodies, trade unions, politicians and educational institutions - with feedback sought from the public through an online portal to inform later reformulations of policy planning (Bristol One City: 2020, pp 5, 7).

Of these three new branches of local governance, DPO spokespeople were most keen to talk about the OCP and the advantages and barriers it created for advancing disability equality within the city. Some viewed the principle of decentralised decision making within the city to have inherent benefits, and to be indicative of a tendency to embed co-production into the culture of the city. One WECIL spokesperson reflects:

*'With the OCP, I admit I was quite dubious at first. Part of me thought 'is this a New Labour mode interpretation of the Big Society?' (...) In terms of its delivery, however, I'd say that it's showing incredible*

*promise for devolution of control, to the point that co- production is becoming a norm of how development across the city is being approached. (...) The council has relinquished itself of power in a lot of decision making by restating its own role as that of partner in these conversations instead of sole decider. I think that's a brave thing to do - and it is in the spirit of devolution and of co-production'*

An SLC spokesperson echoes this sentiment:

*'We have actively engaged with the Health and Wellbeing Board, which is one of the delivery bodies on the OCP. Initially the contact was through me, but gradually I'm getting members engaged in it to get our profile up. So, yes, we're conscious of it, yes we're aware of it, yes we're seen as a partner - we're on the mailing lists and work with it. We do think it's a useful thing, and it's a constructive way forward. (...) The Gatherings I've been to were quite refreshing for me. When I was active in the city, there would not have been an event like that which brought together the private sector and business sector. Whatever we think of the Mayoralty, it clearly has made some difference in terms of networking and bringing different aspects of the city together. There are some advantages to that'*



Despite this, even those excited by the principle of power over vast swathes of policy being devolved outside of the council had concerns about the level of awareness of disability equality issues amongst OCP partners, and the ability of DPOs to get into positions where they can influence key partners to be proactive on disability equality. This concern is backed up by the fact that the most recent iteration of the OCP only lists one DPO as a partner in developing the plan (Bristol One City: 2020, p 57). As the same spokesperson for the SLC expands:

*‘(T)he level of awareness of VI issues, as with most disability issues, is very low. So you have to put up with some fairly silly comments and statements; they don’t really get it. But you expect that’*

As the WECIL spokesperson quoted above notes; the structure of the partnership boards, and the in clarity as to how organisations or individuals are appointed to them, makes it difficult for DPOs to ensure that disabled people’s interests are represented in all of the decisions that affect them:

*‘I do wonder how democratic appointment is of the other partners in these conversations. It’s an exciting thing to watch and participate in; but I currently*

*feel that it’s a challenge to get WECIL into a lot of the places I think it needs to be in, where other doors were more easily opened. I’m saying that [someone in] one of the larger organisations of our ilk; so I think other organisations will probably feel more excluded than we do (..) It’s quite opaque as to who decides who gets to sit on which panel. I don’t know that it’s deliberately opaque, but the consequence is that it is’*

A different WECIL spokesperson was more damning of what they perceived as an exclusive and exclusionary culture of the OCP, which they believed made it more difficult for disabled people to influence local policy than it has been hitherto:

*‘It’s people from around the city, about 200 come to the City Gatherings, but they’re the ‘good and the great’ - from the universities, businesses, from churches, whatever. It’s not a diverse group, I doubt there’d be many disabled people at all. I think BDEF might get represented, and I think (another disabled activist) went to the last one; but there’s no positive action to make sure DPOs are part of that (...) I think those things actually make it harder for DPOs to have an influence in key strategic issues.’*

A similar concern was raised by the

BDEF spokesperson, who complained that the added layer of bureaucracy tied up in liaising with those planning and administering the OCP, combined with a general lack of interest in disability equality issues, increased both the complexity and the amount of work required to get disabled people's priorities integrated into policy planning:

*'The difference is, to some extent, it takes up more time; we can't stop what we were doing because we've got to get the ear of the officers doing the implementation, but you've now got this other (One City) structure imposed on top of it. So there's more work to do in terms of the sheer number of fora that you've got to engage with to exert any influence. I don't think we're listened to more than we were before, at least not in a way that necessarily leads to change. One example would be that, in housing, I've been saying from the start that there should be a commitment to accessible housing and why is it not in there? So then an iteration came out saying that all new housing would be 'adaptable and accessible'; I mean they're one thing or another, they can't be both.'*

Interviewees were also concerned that elements of the adopted plan risked setting back disability equality,

particularly in regards to access to the built environment. The emphasis on encouraging 'active travel' through a combination of cycle lanes and pedestrianised zones to reduce the city's traffic (Bristol One City: 2020, p 30) appeared ill-thought through to some interviewees campaigning for equal access to public space in the city. As the WECIL spokesperson involved with BPAC pointed out, it felt that this part of the plan had been constructed without disabled people's access needs in mind:

*'The number of cycle paths being built in the city are problematic if you're disabled; so there's a problem there where sustainability may run head on into what disabled people may need. A lot of disabled people need to travel around by car, for example; whilst that may not be the way forward for the climate, but for some people it's just a necessary issue. I don't think those kinds of issues are being tackled by the OCP; but we're engaging and I hope there will be wins (as well as losses) along the way. (...) A lot of the OCP stuff is really good; and we desperately need to fight climate change, get cars off the road, cut down air transport, and lots of other things that are in the OCP. While we're doing that, we also need to recognise that there are*

*people who, for no fault of their own, can't fully engage in that. If you're a wheelchair user and get around the city in an adapted car, there's little point putting in some cycle lanes and telling them to cycle'*

As the BDEF spokesperson explained, plans to reorganise the centre of the city on principles adopted in the OCP were already showing a lack of understanding of many disabled people's access needs:

*'(I)t's all very well to talk about 'active travel'; but what does that mean for disabled people? It's always been spoken about in terms of non-disabled people's active travel. So it's not just about which roads are closed and how disabled people get to them - although that's very important - it's also about where people are placed within that 'active travel environment'. It's about what services haven't been thought of that might be needed to allow disabled people to take advantage of that.(...) (T)he problem at the moment is that there are only three places in the North-North East section of the area where disabled people are going to be able to park, on the edge of the pedestrianised area, in order to get into it. Anywhere from the South to the North East; there's nothing. Take Corn St for example – a very long road for many a disabled person. You can't have people having to get off at the*

*Registry Office as the only way of shopping in that Old City area, without it becoming inaccessible'*

Attitudes towards WECA, although only expressed by two of the interviewees, were entirely negative; with the authority seen to be uninterested in including disabled people's voices in their operations, and as complicating the process of DPOs influencing local policy. As the BDEF spokesperson recounted, even when some issues had been satisfactorily addressed within decision-making fora in Bristol, these could be substantially delayed by inaction by WECA without any real way to exert pressure upwards to facilitate change:

*'(A)fter some back-and-forth I got them (council officers - LB) to put a commitment that 10% of all affordable housing will be accessible into the Local Plan - which has legal status, whereas the OCP doesn't. What I then discovered is that, after all of that, they'd held a review of, and updated, the Local Plan when they couldn't implement any changes anyway. This is because WECA still don't have approval for the Spatial Plan; and until there's an approved Spatial Plan, the Local Plan doesn't have a legally enforceable status. (...) (W)e've got a sub-regional authority in WECA who don't want to listen to*

*anybody from outside the private sector or local authorities. When it comes to having regular equalities input and all of that; they aren't interested at all'*

A WECIL spokesperson was very disappointed by the lack of engagement by WECA with disabled people's organisations, especially given its remit covers matters of significant interests to disabled people in the region:

*'(A)s far as I know there's no involvement of DPOs anywhere in that WECA structure, nobody knows how to get involved, and the whole WECA thing is inaccessible. The main areas they're funding are transport and adult skills; both of which should have a strong disabled people's input and there isn't at all. The whole thing is a nightmare, I would say'*

While there exists some good will towards the principles of devolution of powers within the city and region, DPO spokespeople have expressed serious concerns about how well disabled people and disability equality issues are represented within new governance structures. At the level of the city and the One City Plan; it's felt that a lack of knowledge of disability equality presents obstacles to disabled people's interests being represented

cohesively within the plan, while the opacity of how partnership boards are constructed makes it difficult for them to exert influence over decisions which affect disabled people. At the level of the subregional authority, some DPO activists reported that they were not consulted at all on decisions being made on services which directly affect disabled people in Bristol and its surrounding areas.

## **Partnership working with private and third sector organisations**

Interviewees' experience of working with firms, charities, or other non-governmental bodies outside of the OCP varied widely depending on the structure and strategy of the DPO in question, the type of organisation they were partnering or collaborating with, and the extent to which the latter take their responsibilities as partners seriously. For the Sight Loss Council, which do not rely on any partnership outside of the Thomas Pocklington Trust for funding and who have a small team of skilled members, collaborations with the private sector have gone very positively; with both spokespeople reporting that they were very pleased with responses of firms across economic

sectors to their approaches to discuss equal access for VI people to goods and services:

*‘On transport, I’ve been working with the trains and the bus company. First Bus have been brilliant, we’ve done loads of work with them and last November we had a ‘Meet the bus’ event, which was an opportunity for visually impaired people to go to a local bus depot and go onto buses basically: to talk to some drivers, even management turned up to that, and to get on the buses and see how the layout, the seats, the cab where the driver sits, and get a feel of what it’s like without it being an active bus with other passengers onboard already. That was brilliant and there’ll be another one but obviously that’s been put on hold (due to coronavirus - LB). With the trains, there’s lots of work going on with the front of temple meads station to improve access; we’ve been heavily involved with that to make sure that the access works for VI people as well. There’s training videos out there with First Bus and the trains on how best to support VI people. So lots of big stuff. On Arts and Leisure as well, SLC members have talked to theatres and concert venues about how to make their services more accessible - things about access and audio description. Really good stuff’*

*‘First Bus have produced a video aimed at everyone about the social distancing measures on buses; but when we saw it, it was completely inaccessible to people with VI. So we worked with them to do a script for the video explaining it in words and text. That video has now gone out nationally to all of the First Bus network and has the SLC logo all over it, because they’re treating it as a genuine piece of partnership work with the SLC. The SLCs in Bristol and Gloucester have worked together to produce a series of leaflets on the impact of social distancing on people with VI; so we’ve got ones for health, buses, taxis, trains, shopping and public buildings. All of those have gone out to all the relevant organisations saying there’s something that you can do. (...) So they’ve all come back and thanked us and said it’s useful’*

Similarly, both interviewees reported a generally positive working relationship with the local organisations for VI people which aren’t user-led; most particularly Vision West of England, who run the VI Forum through which the SLC conducts consultation with local VI people and seeks feedback on its ongoing work. Excepting their frustrations with an occasional tendency to ‘be a bit territorial’ by project workers in some blind charities, and with how slowly local higher education institutions respond to



SLC prompting, SLC spokespeople were generally satisfied and optimistic with the partnerships they'd already formed, and with the possibility of extending its partnerships in future. Limitations were more obvious for interviewees working with actors in the construction sector; where high production costs and multiple priorities can lead to the access issues raised by DPO partners taking a back seat in the management of a building project. The interviewee working with BPAC reports:

*'South Bristol Hospital had some very pretty steps up to the front door when we first got involved. We asked them why, and the architect just said he thought it looked nice. So you've got this issue where people have no real grasp of what disabled people require from a building. More importantly, you have a problem where you say to them 'we need a lift this size by that size, with a mirror at the back, and it can't be at the top of a stairwell' etc; and as the project goes on and starts to go over budget they start to cut corners. Equalities are the first corners to get cut; because they don't think those are particularly important. I always say that if we give you ten points and you do seven, that's probably a win.'*

In this interviewee's view, this situation is compounded by an ignorance of disabled people's needs by both those who

commission, plan, and design building projects, and those members of the public who will use the building and have certain demands of it that developers are called upon to meet:

*'(G)enerally, there's a lack of interest. When you see a new building design, most people look at it and see what they like or don't like about the design; very few people think 'how would I get in there if I used a wheelchair?'. That's what we need to tackle. There needs to be better public awareness of things like that. My local pub, for instance; there's no way you can get in or out if you use a wheelchair. They were gonna redevelop it about twelve years ago, and we had the senior South West Manager come down; I asked him whether they were gonna do anything to make it more accessible and make sure you can get a wheelchair in and out. He said they'd done some tests and discovered that disabled people don't spend a lot of money in bars. Well, yeah; but that's 'cause they can't get in! It's that sort of thing where you need people to be thinking about disabled people's access; it needs to be on people's agendas more than it is'*

In relation to housing, the BDEF spokesperson explained that they are currently trying to encourage a greater

awareness among housebuilders of the benefits of adopting elements of universal design to their projects, and of the need to ensure that a wider variety of disabled people are consulted throughout the process of building new homes. This intervention is, however, at an early stage:

*'I sit on the homes' board and one of our ambitions is to make house builders and providers understand that, if they looked ahead a bit more in how they construct the homes, they could save a lot of money by ending up with a home a disabled person could actually live in; and also in that it would be much cheaper to retrofit when people need it. Alongside that, we say you should always have a reference panel of disabled people with different impairments that you use from the beginning of the designs, right through to the occupation of the building. It doesn't matter how many BDEFs or BPACs or whoever that you employ to have a look at your plans; the fact remains that, while we have a certain amount of expertise and we can do a certain amount of representation, in the end you have to be looking at a wide spectrum of disabled people and checking that it works for them (...) This kind of change towards looking at co-production as positive for everybody is very new'*

For the CDHH, engagement from private partners has generally been beneficial to both parties; with particular success noted in their Smart Meter Project, and in the provision of Deaf Equality Training in private workplaces where a deaf person has been newly employed. Collaborations with other third sector or charitable bodies have been much more of a mixed bag, however; with the spokesperson reporting both genuinely constructive joint working arrangements, and others which did not feel like partnerships at all. Positive examples of collaboration were characterised by the CDHH spokesperson as having a clear understanding by all parties of what they could expect from each other:

*'We've had some success: I was part of working with Linkage - they've merged with another organisation for older people now, but we had a really good relationship with them. They told us they wanted to work with us more closely because a lot of their users had hearing loss and they wanted to improve that aspect of their communication. We provided them with information and guidance, and they invited us to networking things and gave us an opportunity to promote our work. So it was a two-way thing: we gave something to them and they gave something to us. We gave information, they gave us opportunities to network with people we wouldn't have thought of or not had the opportunity to. So*

*there's give and take there'*

This reciprocity is not always the case however; and the spokesperson reported that there have been occasions where the CDHH has been asked to provide support to other organisations' bids for contracts for services for deaf and hard of hearing people, only to find themselves frozen out of the actual service arrangement when funding is secured:

*'Other projects we've been part of; one with an older people's organisation going for a bid. It was for quite a lot of money, but it had to be for a collaboration. We got together with five other organisations, and we put in five bids - two of them won. As soon as they got the money, we got dropped. We got no money out of it'*

On other occasions, the CDHH spokesperson felt that other organisations had attempted to source substantial advice and information services from the CDHH, without being prepared to offer anything in return to support the organisation; creating a clear drain on capacity:

*'I don't like it when organisations come to us for a bit of advice, go away, then come back with 'oh, what about this?'. Hang on a minute! I've given you some advice for free;*

*but now you're asking us to rewrite your communication plan! We would usually charge you for that, you need to be clear what you're gonna give us for all this information'*

A contribution from one of the SLC spokespeople indicates such requests from the private and third sector to organisations of people with sensory impairments are not uncommon. While they raised no concerns about the SLC's current partnership working, they reported that, historically, they and other VI people had been expected to provide free information and training services which would normally cost a firm or charity a significant amount of money:

*'I think there's a bit of a resistance from the VI community in Bristol when we sometimes get asked to do stuff - major things, including pretty heavy training. Organisations have always been able to access training for their staff around VI, but it's always costed them. A lot of the time they are coming to VI people to do stuff on a voluntary basis. Now, I'm happy to do things, and the SLC is obviously happy to do stuff like that to some extent - as we are with the GP surgeries. But going and talking to people about how things can be improved is different*

*from putting together an entire training program and implementing it for free. That leaves something of a bad taste when it's a corporate place - particularly for those of us who have been volunteering for decades. (...) (I)t does feel a little bit like exploitation sometimes. We get caught up in the idea that we're doing it for our own benefit, but if someone else did they would be paid for it'*

Given that many DPOs are currently under pressure to do more with fewer resources, expectations that disabled people should provide substantial services for other organisations without expecting anything in return are clearly unhelpful. Despite the positive experiences of collaboration indicated above, it is also concerning that some partner organisations are perceived as seeing access or equality as an optional extra, and the first thing to be sacrificed when a project runs into difficulties. From the scale of collaborations reported by interviewees, it also appears unlikely that partnership working with the private and third sector - even if designed perfectly - could replace collaboration with local government or policy making structures as a way of integrating disabled people's voice into local decision making or public life.

## Partnership and Joint Working between DPOs

As noted in previous sections, the divergence of strategies between DPOs in the city, alongside concerns that some disabled communities have been left behind as DPOs have developed, has caused friction between organisations; and, despite joint working on projects between JobsNetwork and BRIL on the Devices.Now campaign and BDEF and BPAC on city planning consultations, collaboration between DPOs has not been consistent over the time period this report covers. This situation contrasts sharply with that of the expansion of the Disabled People's Movement in Bristol (DPM) in the 1990s; during which shared personnel between organisations, and structures for cross-organisational representation within the management of larger DPOs, encouraged the joint development of organisational strategies and the overall coherence of the movement. As one WECIL spokesperson recollects:

*'I think they [DPOs] were interdependent, and they were structurally set up like that. One part of our constitution was that we needed to have reps from different DPOs on WECIL's committee - so we had a rep from the Coalition, a rep from Dial-a-Ride, a rep from People First, Shopmobility,*

*etc. We did that specifically so we all were interdependent and also to get good trustees - if someone is on the management committee of another organisation, they're likely to be useful on yours. I think it was crucial. So, the Coalition would be pushing us on their campaign priorities and making sure we were still there in the political sphere as part of our management structure. The structure seemed to disappear about the same time as the Coalition went. (...) Thinking back, it's hard for me to remember what was the Coalition and what was WECIL because there was so much movement between the two'*

Dissolving the links between DPOs involved in different kinds of work was, in large part, carried out outside of Bristol; with the decision to fully separate service provider organisations from political or lobbying DPOs taken at the 2000 conference of the British Council of Organisations of Disabled People (Williams-Findlay: 2020, pp 322-323). Disabled activists were worried at the time about the effect that this decision would have on the ability of disabled activists to align their strategies and support each other's initiatives. As Liz Crow recalls, there were also serious concerns about the separation causing an unevenness in the movement, with funding bodies incentivised to support

the less confrontational and more professionalised arms of the social movement at the expense of the more antagonistic:

*'I was in London when the split occurred between the Coalition and the CIL and thinking 'this is a big mistake'. Why would the council give money to an organisation which is going to continue to criticise it when it can give money to a service organisation that won't bite the hand that's feeding it? I think that was the beginning of the demise of the Coalition and the expansion of WECIL - but also to WECIL's shift to becoming a far less political and far less outspoken organisation<sup>7</sup>. I think it dismantled the DPM locally to a very significant degree. (...) I think it was a strategic error that could have been predicted quite easily, but which made our organisations far more vulnerable in the face of wider political shifts'*

One BRIL spokesperson indicated that they believed austerity had intensified this uneven development, with a hostile funding environment making it harder for service providers to challenge disability discrimination by funding partners and, as such, harder to build solidarity and trust across organisations:



*'Due to the current era of austerity; many disability charities are only focused on receiving their usual funding without upsetting the apple cart by challenging the discrimination that still goes on. (...) I think something similar to that is going on generally in [DPOs] around the country'*

Another issue, highlighted by a spokesperson from JobsNetwork, was that the age-profile of DPO's management bodies had made it harder to convince them that new or innovative forms of activity belong in the Movement, and to get them to engage with new kinds of projects (particularly those related to IT or social media) which are needed by disabled people locally:

*'Generally with disability charities and DPOs; I feel like they could maybe modernise. The older generations in them like to show their pictures; but there's a new generation that promotes its work more through social media. (...) (T)here can be trustees who are senior members - and who we respect - but who don't know the difference between Facebook and Instagram'*

Interviewees felt that they had yet to recover fully from the fracturing of the sector, with the level of coordination between DPOs in the city very low prior

to the outbreak of coronavirus. This is a source of regret for many disabled activists, as another WECIL spokesperson reflects:

*'I'd say it's quite a fractured sector in Bristol. There are strong relationships between those based at the Vassal Centre, which is continuing; but there's historically been a lot of divides. We started to overcome those, but then Covid came and accelerated our work towards moving closer together - so I hope if you ask that question next year, we'll all be saying 'God, do you remember how it used to be when we were at each other's throats?' while we're all working as partners'*

Interviewees had different ideas about the form that collaboration may take in future, with some more keen on formal ties between organisations than others. Within BRIL, some argue for an umbrella organisation of DPOs and disabled activists, capable of acting as a single point of consultation and leverage for discussions with local authorities and decision makers. As one BRIL member explains:

*'(Another BRIL member) has spoken a lot about an umbrella organisation - apparently it works in Manchester and parts of London - they would be the go-*

*to for the council. Our experience of our council is to go to our council first and try to get a reaction later. We've got no say in it, and we would like a say'*

One WECIL spokesperson believed that a Disability Commission, formed within the local authority and made up of DPO representatives and other disabled people, would offer the possibility not only of uniting the sector on questions of strategy, but of ensuring that disabled people were given a say on the policy planning boards and partnerships that plan policy changes around the city:

*'In my view, the only way forward would be to have something like a Disability Commission which provides a focus for all DPOs to come together and make demands of the council. Thinking about the Commission on Race Equality and the Women's Commission in particular; they've been really effective in getting their issues onto different agendas by making sure that people from their organisations sit on different partnership boards or other boards. (...) I think there are four or five Partnership Boards with the Council now, and nobody's representing disabled people on any of them as far as I know. If you had a Commission, you could start demanding that at least one place on every board is held by a disabled person - as they're trying*

*to do with black people now. I think we need to have a focus that isn't just an organisation, but is wider, and contains people from a range of organisations - private sector, public sector, voluntary sector, whatever. Something which can identify where you can make some inroads'*

The idea for a Disability Commission recently received support from Bristol's Deputy Mayor Asher Craig, and BRIL have since formally welcomed increased support across the city for the establishment of such a body within local government (BRIL: 2020)

Another WECIL spokesperson pointed to a looser model of organisational collaboration; limited to the exertion of pressure on decision makers and community development work, without insisting on any DPO accepting a strategy or orientation outside of these areas of their work:

*'I think currently it's about having a united voice in terms of exerting pressure where it is needed on those who have legal decision-making authority over people's lives. I think it's being a united front on that. I would like to see it being more about collaborating on community organising going forward'*

At present, none of these options have been developed far enough in the local context for their strategic pros and cons to be commented on in any depth; but it is promising and heartening that there is not only regret that the sector has been so fragmented, but a variety of ideas about how partnerships between DPOs may develop in future. This commitment to collaboration between DPOs is already expressed in alliances between DPOs in Bristol and others in different parts of the country, with WECIL and BRIL in particular co-ordinating with user-led groups outside of the region; a process which has been intensified by the coronavirus pandemic. There are clear areas where collaboration may be fruitful, as the gaps in provision and representation identified by interviewees previously and the mixed responses to DPOs by decision makers and other organisations discussed here show. After a discussion of the effects of the coronavirus pandemic and government response to it, the conclusion of this report will suggest some ways in which this commitment to collaboration could be acted on in order to address specific concerns that interviewees have outlined.





# Section 5: DPO Responses to the Coronavirus Pandemic

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## A social crisis for disabled people

Research for this project began shortly after the UK government announced the first lockdown in March 2020; with citizens as a whole ordered to stay at home apart from for the most essential of tasks, and many disabled people at risk of serious ill-health or fatality if they caught Coronavirus not leaving the house entirely. The (often already frayed) tapestry of services, adjustments, and facilities which allow disabled people to take care of their welfare and take part in civic life seemed to be torn apart overnight: local authorities limited the support they provide to disabled citizens, employers of personal assistants were unable to get hold of the Personal Protective Equipment needed to keep them and their employees safe, support groups and community services closed



their doors, and even grocery shopping became perilously difficult due to increased demand for delivery slots and the inability of some stores to facilitate shopping with a guide or assistant. At the same time, advice and guidance for the general public on how to stay safe and what services they remained entitled to was often inaccessible; BSL interpretation was not provided by the government for



its daily briefings, and Easy-Read versions of government or NHS guidance were not consistently available. For those disabled people who could access the information, the guidance itself was often vague and unhelpful. In a survey of disabled people in London during the lockdown, Inclusion London (2020) found that nearly half of all respondents found it hard to make sense of public health advice or guidance; while 40% had experienced difficulty accessing support they were entitled to through a care package, and a staggering 60% had struggled to access food, medicine, or necessities (pp 6-7).

According to the Office for National Statistics (ONS) 27,534 disabled people in England and Wales died from coronavirus between the 2nd of March and the 14th of July 2020, accounting for 59% of all Covid-19 casualties (ONS: 2020): making disabled people one of the hardest hit groups in the pandemic, alongside those from Black & Minority Ethnicity groups (Centre for Evidence Based Medicine: 2020). Many respondents to the Inclusion London survey reported that they were deeply worried about their access to medical care and their right to life; with several reporting that they had been asked to sign Do Not Attempt Resuscitation forms

by primary care providers (2020: p 7), and others frightened by triage advice to doctors from the National Institute for Health and Care Excellence which would have prevented some disabled people from receiving life saving care if a legal challenge had not been launched by a disabled person and their family (ibid, p 8). The slogan of the Disabled People's Movement - 'nothing about us without us' - appeared to have been forgotten by the mainstream world; with decisions over what treatment, what support, and what information disabled people needed during the pandemic taken out of their hands. For some interviewees, the fact this had been allowed to happen and had largely gone unchallenged was evidence that disabled people's lives are not valued by social institutions or many people in wider society. Liz Crow, reflecting on the trajectory of attitudes towards disabled people since the start of the Disabled People's Movement, argues:

*'With disability, we feel we've created some discourse change over that time; but actually? One of the things that I've noticed is that when we started out as a movement; a lot of the response I and others would have got at that time was pity, at the point we got legislation though - deeply flawed as it was - a lot of people responded 'you got what you wanted, now shut up'. Pity has*

*turned to resentment and hostility; it's been a real sea change. For me that just says, this isn't the discourse change we've been going for. People as a society haven't got it, and you can see that in the pandemic. What's one of the first groups to be sacrificed? That tells you all you need to know'*

For a Sight Loss Council spokesperson, the response to the lockdown from charities designed to support VI people, the state, and private firms was deeply disappointing, with delays to addressing problems that were urgent for blind and partially sighted people undermining trust that these organisations saw VI people as of equal worth to non-disabled citizens:

*'Sadly, for me, C-19 highlighted that, when it goes horribly wrong for able-bodied (sic) people things can be done and can be done quickly; but when it's a problem for minority groups the people in power don't push for actions to be taken that quickly. I don't know the exact actions taken by other organisations to deal with the supermarket issue; I do know that I had conversations with people from those organisations that weren't always very helpful. I felt they didn't always understand; a lot of those organisations are run by sighted people rather than VI people; so it wasn't a direct problem for them. (...) I mean the organisations for VI people. It wasn't*

*a direct problem for them, but for their clients. I'm not saying that means that they didn't care, but I wonder if it took away from the urgency to resolve the problem. I know people who, at times, only had a box of cereal at home because they couldn't get anything else in and had no one to bring it in for them. It's sad that, where most of us thought massive improvements had been made in regards to equality and accessibility, some of that wasn't reflected in the worst parts of C-19 where it felt that we weren't important again; that we didn't matter and our needs didn't matter. I personally struggled with that'*

The increasing level of need amongst disabled people for the most basic forms of support, the withdrawal of practical and representative support from other sources, and the very real fear amongst disabled people that they would not survive the pandemic created a wave of new work for many DPOs; which tried the best they could with their limited resources to plug the widening gaps in provision for disabled people, and to persuade other agencies to adapt their Covid policies to address the position that disabled people now found themselves in. At the same time, DPOs had to alter entirely the ways in which they worked: forgoing all face-to-face contact between members, physical community

outreach, and use of shared office spaces or facilities. Steps towards moving contact between people online, common to many responses to coronavirus by companies and charities, were not always possible for organisations working with disabled people - who make up the majority of non-internet users in the UK (Sanders: 2020) and whose internet access is believed to have declined throughout the pandemic itself due to increasing day-to-day making internet access financially unviable for some (Burgess: 2020). Smaller DPOs, such as the Bristol Epilepsy Network which primarily works as a peer support group, were forced to cease operating when the pandemic struck. For those that were able to carry on, as a BRIL spokesperson explains, the work that needed to be done often seemed overwhelming:

*'It's absolutely relentless. Going back to some of the things we said earlier; possibly one problem is that, because our remit is so broad, we get asked to get involved in a lot of things. The thing everyone knows is that the Covid pandemic has uncovered what was already happening; it's highlighted the vast inequalities, disablism, and racism of this country. It feels utterly relentless - locally and nationally. Part of our remit is fighting for independent living as envisioned by people; not by the state, not by people*

*in power. That is completely at the core of it all: what's happened to disabled people, autistic people, people in the mental health system is absolutely inseparable from the way Covid has been used to punish people. One of the difficulties is that because that is so close to what we're about, we feel a responsibility to constantly keep doing stuff even when it's almost overwhelming'*

Despite the quantity and variety of challenges posed by the pandemic, and the fact that their traditional ways of working had become impossible in many instances; DPOs in Bristol varied and expanded their activities during the pandemic to represent the interests of disabled people at a time of great uncertainty, and to provide for new needs created or intensified by the lockdown and public policy response. As we'll see, the flexibility of DPOs responses to the crisis was not cost free; with many having to delay or alter their plans for expansion and organisational development because of the lockdown. Despite what was clearly a stressful, difficult, and sometimes distressing period for disabled activists and DPO staff; our interviewees reported that the hard work undertaken during the pandemic had built solidarity across and within their organisations, and

had allowed them to demonstrate just how important independent, disabled people-led organisations are to advancing equality. In this Section, the activities of each participating DPO during the first spike of the pandemic are briefly described, followed by a summary of the challenges and opportunities interviewees identified for development of the Disabled People's Movement in future.

## Organisational responses to the pandemic

### JobsNetwork

Having run the majority of their training courses from public and community facilities before the pandemic, JobsNetwork were forced to completely change the way that they provided their services. They were able to move some of their provision online, running weekly workshops over Zoom so that learners with IT equipment and internet access could continue to access training. In addition to this, JobsNetwork linked up with a scheme to provide IT equipment for people at risk of social isolation during lockdown, and argued within it for greater

awareness of disabled people's needs to communication technology:

*'During lockdown we took part in the devices.now campaign. We received several small tablets and provided them to different people who were entitled to them. We also put forward some issues ourselves; the eligibility for these tablets were for people without internet, and also we argued that we felt they could do more to help disabled people. For instance, we've had one person who was shielding - who did have internet - but they were glad that we purchased the tablet for them so that they could use it in the garden instead of just being stressed in the house'*

### WECIL

As the largest DPO in Bristol, and the provider of the most extensive services, WECIL's operations were significantly inconvenienced by the closure of its office spaces in North Bristol, and the cancellation of its drop ins, community meetings, and home visits. The organisation, however, managed to keep all of its services running throughout the pandemic - utilising telephone calls, online conference software, and in some cases drones in order to make sure it kept in contact with service users and continue its support to them. In addition,



WECIL launched three new local services during the lockdown: an online drop in for disabled people to meet together and discuss how the pandemic is affecting them, a telefriending service to support disabled people at risk of social isolation during lockdown, and a 'Navigator' helpline to for disabled Bristolians to access guidance, advice, and support in accessing the services they are entitled to. Towards the end of the first lockdown, WECIL staff and volunteers conducted a number of access audits on cultural venues in Bristol to ensure that their reopening could facilitate both disabled people's access needs and the social distancing measures required to keep patrons safe.

WECIL's conception of itself as both a unique source of expertise on the needs of disabled people in the South West and a vehicle for social change was expressed clearly through strategic actions it has taken during the pandemic. In collaboration with Irwin Mitchell LLP solicitors, the organisation produced *My Rights and the Coronavirus Act*; an information resource for disabled people on how their rights had been affected by emergency legislation enacted in March 2020, and which drew on both Irwin Mitchell's legal expertise and WECIL's understanding of how disabled

people had accessed their rights and the barriers facing them before the pandemic. This document was distributed nationally by Disability Rights UK. Alongside this provision of specialist information to disabled people around the country; WECIL used its expertise on service delivery and disabled people's needs to inform local social care policy, encouraging councils to understand and proactively address challenges to providing personal assistance services during the pandemic so that disabled people are not deprived of the support and materials they need to manage their day-to-day life. As one WECIL spokesperson explains:

*'(A)t the outset of the first lockdown WECIL pushed most of its human resources to analysis of the risks to deliverability of all care packages which are resourced by Direct Payments across Bristol (and South Gloucestershire and B&NES) – whether or not the individual was a WECIL customer - and created service-level and individual-level reports for the commissioners. This work was fundamental to the protection of many disabled people from significant harm. In the case of BCC, they counted 400 of these one-to-one calls as evidence of completion of their own welfare checks. WECIL were also responsible for*

*supporting BCC by collecting demand for PPE and distributing PPE to DP recipients across the city and were recognised by the council(s) as having the only resource of reliable data on and relationships with DP recipients in the area'*

As this WECIL spokesperson goes on to explain; representing the needs, rights, and desires of disabled people to local government during a period of profound crisis and stretched budgets was not always easy, and required the organisation to take an uncompromising stance on issues which matter most to disabled people, and to build alliances with other DPOs in the process to increase disabled people's ability to prevent policies or decisions which would impact them negatively:

*'(We) challenged, very publicly, BCC's use of the powers to enact 'easements' to the Care Act that were given to them by the Coronavirus Act. The success of this challenging and campaigning, which was achievable due to our presence at the table with commissioners, is what led to the formation of the [Covid-19] specific Adult Social Care Equalities Scrutiny group which now meets regularly to hold the council to account in any changes made to how care is resourced and delivered in Bristol. This group*

*includes the majority of the DPOs contacted for this paper. (...) Feathers were well and truly ruffled in this challenge but WECIL were unflinching and this resulted in real change, scrutiny and genuine engagement of DPOs in decision making'*

In addition to these local activities, WECIL has been taking part in a policy discussion forum of CILs and other DPO groups around the country, facilitated by Disability Rights UK. This group, initially set up to discuss shared challenges that have arisen during the pandemic and co-ordinate DPOs' responses, has agreed that it will continue to meet indefinitely and to collaborate on issues beyond the scope of the pandemic. During the pandemic, WECIL has also joined the Reclaiming Our Futures Alliance - a group for disabled people and DPOs in England to coordinate grassroots campaigns nationally and internationally -, and the DPO Forum - a collection of DPOs which meet with representatives of the Disability Unit and the Minister of State at the Department of Work and Pensions in order to influence central government policy.

## BDEF

BDEF responded to the onset of lockdown by increasing its peer support activities, intensifying its lobbying of local and national government, and collating accessible information and guidance for disabled people in the city. It's 'Making Change Happen' project, a peer support initiative for disabled people to identify issues affecting them and plan campaigns to address them, began to meet every weekday on Zoom in order to prevent social isolation and support members to respond immediately to the rapidly changing situation. For disabled people without access to the internet or IT equipment, BDEF volunteers have been making welfare phone calls to find out what challenges they are facing during the pandemic and to signpost them to relevant services. BDEF members campaigned successfully for Bristol City Council to provide a dedicated response team for people who use Direct Payments to employ their own PAs - who had been left out of other schemes designed to provide Personal Protective Equipment and guidance to social care settings - and to include PAs in the council's own schemes to support key workers during the pandemic. BDEF called strongly on central government and CCGs to end discharges of patients

with Covid symptoms into care settings, and to improve the quality and accessibility of the information and guidance around coronavirus that disabled people require. BDEF also ran a survey of disabled Bristolians' experience of the lockdown, and have liaised with performance art and archival projects to ensure that disabled people's concerns, thoughts, and feelings during the pandemic are captured for posterity.

## CDHH

As with WECIL, CDHH was forced to close its office space and arrange for remote delivery of its services at the beginning of lockdown - managing to keep its equipment service in operation, and hosting its coffee mornings via Zoom without significant decline in attendance. Accessible information and guidance was a particular problem for the communities CDHH works with; with the government's failure to provide a BSL interpreter for the daily Coronavirus Briefing and the initial lack of a BSL interface on local helplines leaving many deaf Bristolians unable to access the information they needed. CDHH were able to convince the local authority to implement a sign video option on their helpline; although their spokesperson remained frustrated that

this had not been promoted beyond the council's website, noting that many deaf and hard of hearing people had a lower level of internet access than the general population. CDHH also took part in the national campaign for the government to include BSL translation for all public addresses and statements on the pandemic and changes in government advice.

## SLC

For an organisation which focuses its work on liaising and consulting with the executives of diverse organisations; it became imperative for the SLC in Bristol to influence its partners' policies as they developed, as rectifying practices which exclude VI people after the fact would take time to filter down to providers' operations. As one SLC spokesperson expressed it:

*'Things are changing so quickly, we're just trying to keep up with that and make sure we're involved as the changes happen rather than coming in afterwards and saying 'this isn't right'. That's our main focus'*

To this end, the SLC produced a series of leaflets on the effects of social distancing on VI people's access to services in each of its work areas. These were sent out to

relevant officers in the local authority and large service providers shortly after the government announced its guidance for businesses re-opening. In addition, the SLC initiated a weekly (and later bi-weekly) co-ordinating group of organisations working with VI people in order to identify challenges early and take proactive action across the city.

## BRIL

Founded officially in 2019, BRIL was barely six months old when the pandemic hit; and its members' plans for how the organisation would develop had to be rapidly rethought. BRIL started to meet three times a week, as opposed to quarterly as they had intended, and realised early on that peer support and individual case work - which is more amenable to both legal challenges to statutory authorities and online activism - were going to be a greater part of the organisation's work than they had originally envisioned. BRIL's first successful campaign during the pandemic was to cause NHS England to change their guidance around hospital visitors to allow PAs of people with communication difficulties to support discussions between patients and their medical team on hospital wards. BRIL used this campaign to further its argument for co-



production across all policy areas that affect disabled people; pointing out that this policy had been constructed without disabled people's input, and had failed to account for an access problem that would be obvious to any DPO. BRIL were additionally involved, alongside other DPOs and disability charities, in launching a legal challenge against the suspension of routine CQC inspections of care homes during the first lockdown, and in campaigns to get protective equipment distributed to Direct Payments employees.

## The effect of the pandemic on organisations

Interviewees reported that one notable impact that the pandemic has had on DPOs' plans and aspirations for the future has been its prevention of community development work - activities which encourage disabled people's involvement in wider society, help them develop skills to take greater control of their lives, and develop the relationships between DPOs and disabled citizens. While DPOs have kept some of their community development work going through expanding their peer support activities online and developing new advice

services, one BRIL spokesperson reports that some disabled people have dropped out of contact during the pandemic, and that planned work with those who are often missed by community organisations has had to be jettisoned:

*'There's people who got involved at the beginning that haven't been involved so much recently - there's a lot of reasons for that, especially the pandemic, or health or impairment reasons, or other stuff they've got going on in life. (...) What we really tried to do in the early days of BRIL (...) is get other people involved and put a lot of effort into doing things differently and reaching out to different groups of people. For example, people in supported living environments, people at the day centres, and people with learning difficulties in Bristol very often seem to get left out. Covid's made that really difficult, we've lost touch with a lot of people'*

For WECIL, the pandemic had delayed a thorough strategic review of the organisation: to be carried out in consultation with its members and the disabled people who provide feedback on its services. Such a review was intended to strengthen disabled people's influence over each element of what the organisation does, to set its priorities for the coming five years,

to increase its accountability to groups underrepresented in its governance, and to identify how disabled people in the area want the organisation to engage with them and their lives. This processes will not only structure WECIL's activities for the next five years, but will allow it a greater understanding of the demands of the community it serves and help it to represent and promote their interests in its work with other organisations:

*'I think in order to be truly a user-led organisation in terms of governance; it's important that there is a trustee co-ordinated, user produced strategy that we're all working towards - so that managers and teams know that any decisions they are making about development is development towards the objectives of a strategy that was set by our users. (...) (T)hat gives teams much more freedom to be creative in how they would develop new or better systems of work. It gives that confidence to go out and co-produce solutions with users without having to go back to the top of the organisation and check that that is what we would want to do; we have that clarity of our objectives in order to do that. Additionally, it's these key discussions we're having about what membership is, how people have influence, how we ensure that influence is pan-disability and not*

*favouring certain impairment groups. All of that will play into what becomes our new strategy. This summer was all about getting that done, co-produced through large scale events and lots of smaller, 1:1 engagement opportunities with users: and then Coronavirus....'*

There has been one positive exception, with additional community development by BDEF going ahead throughout the pandemic in the form of their work on a Climate Action Plan for Disabled People. This involves liaising with a wide array of disabled people to discuss how they feel the city should respond to the environmental crisis and how they believe the collective effort to prevent ecological disaster can involve them as equal partners, and is coordinated with a number of partner organisations. CDHH's plans for a project to provide comprehensive information to people with recent hearing loss, which relied on getting a number of different professionals and service providers in a room with users, had to be postponed, however; with need arising from greater levels of hearing loss across the population continuing to grow in the meantime:

*'Actually, just before Covid we had a project which was going to be launched in June, a workshop for people who're new to*

*hearing loss to provide that information: about hearing loss, about hearing aides, about mental health, about adjustment, about communication, about what equipment is available. Obviously, we can't do that now because we can't get people together; so we've had to put that to one side until we're back at work and we can meet and talk. It'll probably be next year before we can launch that again. So, that is the problem'*

Despite these very real setbacks in expanding DPOs' influence and support, many interviewees indicated that Covid, despite everything, had made the case for the importance of organisations



led by disabled people for advancing equality and guiding the provision of services. As one SLC spokesperson reported, the proactive work done by their organisation during the lockdown and re-opening made them and their aims difficult to ignore:

*'(W)e're really getting out there now because we're preparing our press release and with the leaflets. I think the SLC will be much better known after C-19 than it was before'*

For one interviewee from BRIL, their activities during Covid had demonstrated to all involved how effective and important self-organisation amongst disabled people can be in even the most difficult of times; uniting disabled people around effecting change in the world and providing mutual support:

*'The good thing which has come out of it is that we've become more active in supporting our members through the pandemic by meeting several times a week. Due to that, BRIL has become more important than ever throughout the crisis; even if we can't, at the moment, campaign against government policies that affect disabled people individually and collectively'*



One WECIL spokesperson explained that they felt that historical fractures between DPOs in Bristol had begun to heal throughout 2020, as the seriousness of the situation disabled people found themselves in became clear to DPOs across old organisational and political divides. They hoped that this would bring about new, constructive relationships within the sector; facilitating a united voice on issues affecting disabled people and a more cohesive and supportive development of organisations' strategies:

*'Bristol does have a number of strong user-led organisations; WECIL is the biggest, but there are many others - those more towards the campaigning end of the spectrum, and a number of impairment specific organisations. It seems to me that, historically, divisions have grown between all of them. I think that's unfortunate; it weakens us as a sector. Without meaning to be glib; the one gift of the Coronavirus to us is that we've all suddenly faced the same existential threat and we can't but be on the same side. Bridges have really been built as a result of the response to*



*that, which gives a strong opportunity to be more collegiate and partnership orientated going forward. I think there will continue to be areas of division, but I truly believe that we are entering a new paradigm where we can openly challenge as colleagues, rather than bitterly talk behind each other's backs about how we do that wrong'*

This unity may become more important than ever; with the challenges of the second spike of coronavirus beginning to be felt as this piece of work was completed, and uncertainty about how the economic and social recovery from coronavirus will affect disabled people. Collaboration and partnership between DPOs may be the difference between them developing better ways of supporting and empowering their communities, and them being placed in an even more dire resource and funding situation than they were after the last financial crisis while disabled people across the city continue to be disadvantaged. As the same interviewee from WECIL explains, the impact of recessions on disabled people are disproportionate, and there is worrying talk already about reorganising support services in a way that would strip disabled people of choice and control: 'God knows the money is still not there. Coronavirus has now added a whole layer

of complexity to the issue - we don't know as a country how we're gonna pay off the credit card bill for everything we've done to keep the economy going, but social care users are always on the front line of trying to resolve issues like that. There's been dangerous talk recently of ASC going into the NHS budget: while I want to see ASC have some equity with healthcare in terms of things being free at the point of use, but I don't want ASC to be centralised nationally. Just look at how poorly health is managed, look at how badly the current crisis is being managed by a very centralised, command and control government; I think if you're putting those budgets into the NHS, you might as well abolish local government'



# Recommendations

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## Collaboration between DPOs

Interviewees expressed a desire for closer and more collegiate relationships between DPOs, and suggested a number of ways to achieve this. Progress in this area is already being made on the Adult Social Care Equalities Steering Group, which scrutinises local authority policy responses to Coronavirus, and in a number of accessibility projects for local infrastructure which bring together multiple DPOs. Following support from the Deputy Mayor, it appears likely that a Disability Commission to advise the mayor and monitor city-level policy decisions and implementation is a likely forum for future collaboration - although the exact form the Commission will take and the role of DPOs within it has yet to be decided. While we believe this is positive, it clearly does not address all of the issues interviewees identified as holding back the development of a coherent and unified Disabled People's Movement in Bristol - including people with certain kinds of impairments not being sufficiently included in the DPM,

difficulties with securing accessible information, and recent difficulties with community development work that all organisations see as vital. In order to supplement any future commission and build upon work already in progress, and prevent these problems from growing, we recommend:

1. That DPOs commit to forming an inclusive working group to look specifically at accessible communication; with a remit that includes securing funding for communication technologies and translation, pooling cash and knowledge resources to facilitate the effective creation and dissemination of accessible information from all DPOs involved, and investigating training for DPO staff and activists to increase communication skills within each organisation. This working group should also consider what guidance DPOs can collectively provide to statutory and private services on making their communications more accessible.
2. That DPOs undertake a joint review of their community development strategies, with the aim of reaching a shared



understanding of priorities in this area and a joint plan for future work. This review should seek to identify which groups of disabled people are currently left out of community development projects, how DPOs can alter their practice to include them, and what barriers people from this group face in engaging with the DPM locally. It should also seek to build on the work of some DPOs with disabled young people and asylum seekers to include those voices in the future development of the Disabled People's Movement. If after investigation, barriers to some groups' engagement are caused by local or national policies or the actions of other social institutions, then members should agree a joint response to the relevant decision makers.

3. Given their mixed experience of co-production (discussed further below), it is desirable that clear guidance on co-production is communicated by DPOs to their partners. In order to be comprehensive and include the priorities and concerns of all disabled-led groups in Bristol, DPOs should liaise with one another in order to produce an advisory document on the principles and practice and of co-production for circulation throughout statutory bodies and other agencies who work regularly with disabled people.

## Co-production and collaboration with statutory bodies

Interviewees reported that co-production was approached inconsistently by agents of Bristol City Council, local health services, and the West of England Combined Authority. Some interviewees did not feel that their contribution to partnerships were taken seriously, and others worried that statutory bodies do not have the relevant knowledge of disability equality within their workforce to successfully co-produce projects with DPO partners. While there are indications that knowledge and appreciation of co-production and partnership with disabled people are improving in some areas, interviewees felt that had not been enough progress in this area across the board for them to feel confident that they, their organisation's members, and the communities they service are always being valued. In order to increase the level of knowledge in BCC, WECA, the CCG and local hospital trusts, we recommend:

1. That statutory bodies commission Deaf and Disability Equality Training courses from local disabled trainers for all operational, commissioning, and

senior managers; and that this training be integrated into rolling training programs for senior staff

2. That, where this has not happened already, statutory bodies invite DPOs and their members/clients to scrutinise their co-production policies and suggest amendments. Given the real concerns expressed about disabled people's exclusion from policy responses to coronavirus by health and social care services, we believe this recommendation should be made a priority.

## Collaboration with private business, voluntary sector, and One City Partners

Collaboration and co-production of projects with organisations outside local government have grown in importance to many DPOs. Due to the implementation of the OCP, it is likely that this will become more significant for all community organisations in Bristol over the coming years. At present, however, interviewees reported a low level of understanding of disability equality amongst non-disabled people-led organisations, and a patchy and

sometimes opportunistic attitude towards partnership working. With one exception, DPO spokespeople also found that the OCP was to some extent inaccessible to their group, or was experienced as a barrier to agreeing necessary change with decision makers. Some interviewees believed that elements of the current plan, which had not had disabled people's input, actually damaged disabled people's rights to inclusion in Bristol. In order to promote partnerships between DPOs and other organisations, we urge that:

1) That positive action is taken by all OCP Partnership Boards to ensure that more disabled people and user-led organisations are invited to be OCP partners, with the aim that each Partnership Board contain a representative of a DPO or other user-led organisation and at least one disabled person by 2022.

2) That the One City Office commit to a regular meeting between its coordinators and all DPOs who wish to attend to discuss promoting disability equality in all One City Plan activities

3) That all private and voluntary organisations who work with disabled people arrange Deaf and Disability Equality training from local trainers for their senior staff.





# Bibliography

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Abberley, P (1987) 'The concept of oppression and the development of a social theory of disability' Disability, Handicap, & Society (2:1) pp 5-19

Ashcroft, E (2019) 'Bristol to lose 75p of every £1 of government funding by 2020' The Bristol Post 23/02/2018 - <https://www.bristolpost.co.uk/news/bristol-news/bristol-lose-75p-every-1-1255966>

Barnes, C & Mercer, G (2006) Independent Futures Bristol; Policy Press

Barnes, C & Oliver, M (2006) 'Disability politics and the disability movement in Britain: where did it all go wrong?' - <http://citeseerx.ist.psu.edu/viewdoc/>

Beesley, L (2019) 'From cuts, to resistance, to where?: the state and non-state actors in the strategy of Disabled People Against Cuts' The New Socialist - <https://newsocialist.org.uk/cuts-resistance-where/>

Bristol Disability Equality Forum (2016) Bristol Disabled People's Manifesto Bristol: BDEF

Bristol Reclaiming Independent Living (2020) 'BRIL's first year..... what's next?' Public Statement (16/10/2020) - [https://bril.uk/?page\\_id=11](https://bril.uk/?page_id=11)

Burgess, G (2020) 'Coronavirus has intensified the UK's digital divide' University of Cambridge Blog - <https://www.cam.ac.uk/stories/digitaldivide>

Callus, A-M (2014) 'From "for" to "of": a typology of Maltese disability organisations' Disability and Society (29:1) pp 1-15

Cameron, A (2020) 'Council will have to make spending cuts, as cost of Covid-19 passes £100 million' The Bristol Cable 03/06/2020 - <https://thebristolcable.org/2020/06/bristol-city-council-will-have-to-make-spending-cuts-as-cost-of-covid-19-could-pass-100-million/>

Centre for Evidence Based Medicine (2020) 'BAME covid-19 deaths: what do we know? Rapid data and evidence review' - <https://www.cebm.net/covid-19/bame-covid-19-deaths-what-do-we-know-rapid-data-evidence-review/>

Clifford, E (2020) *The War Against Disabled People - Capitalism, Welfare, and the Making of a Human Catastrophe* London: Zed Books

Davis, K (1993) 'On the movement' in *Disabling Barriers - Enabling Environments* (eds. Swain et al): London, SAGE pp 285-292

Department of Health (2014) *Care and Support Statutory Guidance: Issued Under the Care Act*

Finkelstein, V (2007) 'The social model of disability and the disability movement' - <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/finkelstein-The-Social-Model-of-Disability-and-the-Disability-Movement.pdf>

Gibbs, D (2005) 'Public policy and organisations of disabled people' Presentation at Centre for Disability Studies, Leeds - <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Gibbs-Leeds-0504.text.pdf>

Hunt, P (1981) 'Settling accounts with the parasite people - a critique of 'A Life Apart' by EJ Miller and GV Gwynne' *Disability Challenge!* (1) pp 37-50

Inclusion London (2020) *Abandoned, Forgotten, and Ignored London: Inclusion London* - <https://www.inclusionlondon.org.uk/wp-content/uploads/2020/06/Abandoned-Forgotten-and-Ignored-Final-1.pdf>

Jones, A, Wilson, W, Jarret, T, Kennedy & S, Powell, A (2017) *The UN Inquiry into Rights of Persons with Disabilities in the UK House of Commons Briefing Paper No.07367*

Leaman, D & Fricke, Y (1994) 'The making of a movement' *Advance: The Journal of the African Development Foundation* (5) pp 5-9

Mason, M (1981) 'Divisiveness' In *From the Cold* (1) pp 6-7

Mehta, J, Taggart, D, Clifford, E, & Speed, E (2020) "'They say jump, we say how high?": conditionality, sanctioning and incentivising disabled people into the UK labour market' *Disability and Society* (Free-standing article: DOI: 10.1080/09687599.2020.1766422)

National Survivor User's Network (2019) 'Survey results of user-led groups 2019' - <https://www.nsun.org.uk/Handlers/Download.ashx?IDMF=ad1f5671-a97f-42d8-a0f7-cee0ecb4c9c7>

(2020) 'User-led groups continue to close' - <https://www.nsun.org.uk/News/user-led-groups-continue-to-close>

Office for National Statistics (2020) 'Coronavirus related deaths by disability status, England and Wales: 2nd March - 14 July' - <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/>

Pagel, M (1988) *On Our Own Behalf - an Introduction to the Self-Organisation of Disabled People*: Manchester, Greater Manchester Coalition of Disabled People

Pring, J (2019) 'New group aims to 'reclaim the true meaning of independent living'' Disability News Service (19/09/2019) - <https://www.disabilitynewsservice.com/new-group-aims-to-reclaim-the-true-meaning-of-independent-living/>

Priestly, M (1997) 'Whose research? A personal audit' in *Doing Disability Research* (eds. Barnes & Mercer) Leeds: The Disability Press pp 88-107

Priestly, M, Waddington, L, & Bessozi, C (2010) 'Towards an agenda for disability research in Europe: learning from disabled people's organisations' *Disability*

and Society (25:6) pp 731-746

Sanders, R (2020) 'Digital inclusion, exclusion, and participation' Iriss ESSS Briefing - <https://www.iriss.org.uk/resources/esss-outlines/digital-inclusion-exclusion-and-participation>

Shaping Our Lives & National Survivor Users' Network (2020) 'The future of user-led organisations' Briefing Paper - <https://www.shapingourlives.org.uk/wp-content/uploads/2019/08/The-Future-of-User-Led-Organisations-4-April-2019-Briefing.pdf>

Social Care Institute for Excellence (SCIE) (2015) *Co-production in Social Care: What It is and How to Do It* SCIE Guide: 31

Thrive Bristol (2019) *Mental Health and Housing Working Group: Report and Recommendations* Bristol: Thrive

Union of the Physically Impaired Against Segregation (1975) *Aims and Policies* London: UPIAS  
- (1976) *Fundamental Principles of Disability* London: UPIAS  
- (1981) 'Editorial' *Disability Challenge* (1) pp 2-7

United Nations Committee on Rights  
of Persons with Disabilities (2017)  
'Concluding observations on the initial  
report of the United Kingdom of Great  
Britain and Northern Ireland' UN  
Communique: CRPD/C/GBR/CO/1

Williams-Findlay, B (2020) More Than a  
Left Foot London: Resistance Books





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