

Hidden Leaders: access to leadership roles for disabled people in the voluntary sector

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1 **Hidden Leaders: access to leadership roles for disabled people in the voluntary**
2 **sector**

3

4 **Introduction**

5 This paper discusses the findings of a research project commissioned by the
6 Association of Chief Executives of Voluntary Organisations (ACEVO) into disability
7 and leadership in the voluntary sector. The work was commissioned in early 2020, and
8 its final reports, main report *Hidden Leaders* and accompanying literature review
9 *Accessing Leadership*, were published in 2021 (Todd and Munro, 2021). The small-
10 scale study looked to guide improvements of practice to better support disabled
11 leaders and future leaders. It was commissioned as part of a wider portfolio of work
12 including reports on the experience of Black, Asian and other minority ethnic leaders
13 in the voluntary sector, and on cultures of bullying in voluntary organisations (ACEVO,
14 2021). This paper summarises the findings of these two reports, but introduces a
15 broader context in the form of academic literature on disability and leadership across
16 different workforce sectors, and in the context of voluntary sector studies. As such, it
17 addresses broader issues of equity in workforce development as detailed in the
18 scholarship than the original reports. It also raises more fundamental questions about
19 the nature of voluntary action, the voluntary sector and how we understand ‘diversity
20 and inclusion’ in that context.

21

22 The paper contributes to what is currently a limited literature on disability and
23 leadership (Boucher, 2017). While a growing body of literature addresses the subject
24 in other workforce sectors, little has been written in academic or practice literature on
25 the experience of disabled leaders in voluntary organisations, in terms of career

1 trajectories, barriers and enablers or their experience in leadership positions. There is
2 also a lack of literature considering employees at the intersections of identities of
3 disability and race (Bell, 2016; Erevelles and Minear, 2016; Berghs and Dyson, 2020).
4 In terms of data from the voluntary sector itself, the 2021 and 2022 NCVO Civil Society
5 Data Almanacs reported on the percentage of the overall voluntary sector workforce
6 that identifies as disabled (static at around 23% since 2020), but there is no further
7 analysis (Martin et al., 2021; Chan et al., 2022). A 2017 report into low pay in the
8 voluntary sector acknowledged that it did not have sufficient data to consider disabled
9 workers' pay (Living Wage Foundation, 2017). Voluntary sector research tends to
10 focus on disabled people as beneficiaries, rather than people building careers in the
11 sector (eg Warwick-Booth et al., 2020; Cullingworth et al., 2022), or mentions disability
12 briefly in the context of wider equity and discrimination narratives (eg Lough, 2021;
13 Dale and Breeze, 2022). This is, of course, valuable research, but the other dimension
14 of experience – namely disabled people building careers in the voluntary sector - is
15 missing, and deserves further examination.

16

17 The paper opens by considering existing literature, then describes findings from
18 interviews with disabled leaders in voluntary organisations. It provides an important
19 addition to existing literature on leadership and disability, and on the disabled
20 workforce in the voluntary sector.

21

22 **Disability and leadership: barriers and enablers from across sectors**

23 It is important first to establish what we mean by 'disability'. Different 'models' of
24 disability emphasise different aspects of impairment and/or societal barriers disabled

1 people face. Much of the debate around models and terms is around the balance of
2 this emphasis. This paper and research primarily adopted a 'social model' of disability
3 (Oliver, 2013; Martin, 2020) which is common to rights-based work in the voluntary
4 sector in this area. This sees disability as a social construction, rather than as a matter
5 of individual incapacity: it is caused by barriers in society, which disable an individual
6 with an impairment. The model sets itself firstly against the medical model, with its
7 focus on treatments, cures and individual responsibility. Secondly, it rejects the charity
8 model, particularly pertinent to this journal, which prioritises non-disabled experts and
9 so-called protectors over disabled voices, perpetuating concepts of vulnerability and
10 helplessness. This second model can be seen in some historical and contemporary
11 charity-led services and institutions for disabled people, and, as highlighted by Hevey
12 and, in more contemporary examples, Waltz, oppressive images of disability in charity
13 advertising (Hevey, 1992; Waltz, 2012).

14

15 The social model is also not without critique (Shakespeare, 2014; Wendell, 2016). For
16 instance, some have argued that it downplays the role of impairment and personal
17 experience, and disabled people's right to bodily autonomy (Morris, 1991; Smith,
18 2012). Alternative models, such as the interactional model, social relational model and
19 the human rights model, have built upon the social model to encompass a greater
20 focus on policy solutions, and more discussion and acknowledgement of impairment
21 (Degener, 2016; Boucher, 2017; Lawson and Beckett, 2021; Sang, Calvard and
22 Remnant, 2021).

23

24 There is a growing body of literature relating to leadership across different sectors
25 acknowledging the social structural barriers to leadership disabled people face,

1 although little yet on the voluntary sector. There is a great deal of synergy across this
2 literature in terms of the barriers and enablers for disabled leaders, including issues
3 with disabled identities and workplace disclosure, difficulties securing adaptations and
4 adjustments, problematic attitudes and a lack of opportunity for advancement, the
5 benefits of mentoring and peer support, how policies and procedures can help to
6 embed rights and processes, and thinking on changing attitudes and norms.

7

8 For instance, previous research highlights how leadership norms – the way we see
9 and talk about leaders – exclude disabled people, and so disabled people can find
10 they are passed over for leadership and development opportunities, that would help
11 them to become leaders (Wilson-Kovacs et al., 2008; Darcy, Taylor and Green, 2016;
12 Procknow, Rocco and Munn, 2017). Additionally, disabled people reported barriers in
13 moving upwards or sideways in organisations, including a fear of losing already-
14 negotiated adjustments and acceptance from colleagues (Roulstone and Williams,
15 2014; Ware, Singal and Groce, 2021). People at the intersections of identities of
16 ethnicity and disability can be seen as even further away from the constructed ‘ideal’
17 of the leader (Garland-Thomson, 2016; Brewster et al., 2017; Berghs and Dyson,
18 2020). Disabled leaders can find themselves having to over-perform in their roles,
19 presenting as a ‘supercrip’, and being positioned as ‘inspiration’ for both disabled and
20 non-disabled people (McGonagle and Hamblin, 2014; Boucher, 2017; Lourens, 2020).

21

22 Table 1 presents common barriers and enablers to accessing leadership identified in
23 global research from across different sectors of employment and activity, including the
24 public sector, the private sector, higher education, the arts and disability activism.

25

1 Table 1: cross-cutting barriers and enablers to accessing leadership across sectors

Barriers (selected references)	Specific issues
<u>Disabled identities and disclosure</u> (Bevan, 2014; Boucher, 2017; Martin, 2017; Lourens, 2020; Berghs and Dyson, 2020)	<ul style="list-style-type: none"> • Anticipation of discrimination • Avoiding perceptions of being 'demanding' or 'a problem' • Internalised ableism and stigma • 'Passing', compensating for and concealing disability • Performing as the 'supercrip'.
<u>Adaptations and adjustments</u> (Inckle, 2018; Brown and Leigh, 2020; Ware, Singal and Groce, 2021)	<ul style="list-style-type: none"> • Being refused • Requiring lengthy argument and justification • Requiring additional unpaid labour • Need to account for pace and volume of work • Dependent on supportive line managers • Not protected by policy • Lack of awareness of systems and benefits like Access to Work.
<u>Attitudes</u> (Procknow, Rocco and Munn, 2017; Sang, Calvard and Remnant, 2021)	<ul style="list-style-type: none"> • Norms of leadership incompatible with disabled minds and bodies • Incompatibility enhanced at intersection with race and ethnicity • Lack of belief that disabled people can be professionals or leaders • Lack of disabled role models • Tokenism.
<u>Opportunities</u> (Boucher, 2017; Roulstone and Williams, 2014; Wilson-Kovacs <i>et al.</i> , 2008)	<ul style="list-style-type: none"> • Disincentive to take up opportunities because of need to renegotiate disclosure and adjustments from the start • Problems with Access to Work state benefit for self-employed people and those starting new roles • Being passed over for opportunities • Limited external views of capability • Unrealised potential • Lack of leadership development for disabled people, and lack of new leaders.
Enablers (selected references)	Specific issues
<u>Mentoring and peer support</u> (Parker Harris, Renko and Caldwell, 2014; Todd, 2016; Dennissen, Benschop and Brink, M. C. L. van den, 2019)	<ul style="list-style-type: none"> • Mentors across all roles and sectors • Peer networks and networking opportunities • Role models

<u>Policies and procedures</u> (Mellifont <i>et al.</i> , 2019; Chan <i>et al.</i> , 2020; Hale <i>et al.</i> , 2021)	<ul style="list-style-type: none"> • Embedding and protecting disabled people’s rights and good practice around recruitment, employment and retention at policy level in organisations • ‘Mainstreaming’ adaptations and adjustments, e.g. assistive technology, physical access notes for events
<u>Changing attitudes</u> (Foster-Fishman <i>et al.</i> , 2007; Nash, 2014; Emira <i>et al.</i> , 2018; Lewis, 2020; Aspis, 2021)	<ul style="list-style-type: none"> • Creating inclusive environments for disclosure • Rethinking leadership norms • Challenging the perceived ‘hierarchy of impairment’

1

2 While there is some writing on disabled leaders within Disabled People’s Movements
3 and similar around the globe (Maijet and Africa, 2015; Kim, 2010; Todd, 2018; Aspis,
4 2021), these social movements are arguably sometimes neglected by voluntary action
5 scholarship. In addition, there remains limited research or writing on disabled leaders
6 in formal charities and voluntary organisations, especially those working outside of
7 disability and health spheres. The lack of visibility may be explained by a range of
8 factors, including the perceived need on the part of disabled people to ‘pass’, or to
9 ‘mask’ disability, due to ableist societal perceptions of the ‘ideal’ leader (Boucher,
10 2017).

11

12 This review provided a backdrop for our own research, which found significant cross-
13 over with issues across private, government, higher education and other sectors. Our
14 research also highlighted some unique challenges for disabled leaders in the voluntary
15 sector, particularly in relation to whether they feel part of the voluntary sector in the
16 first place, or part of a separate liberation-based field. This raises important questions
17 of how to support current and future leaders, and the role of voluntary sector
18 infrastructure organisations in doing so.

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Methodology

As noted, the research and this paper adopts a ‘social model’ approach to disability, although acknowledging that this is a critically contested subject. This informed the study from the design phase to the final report.

We were engaged by ACEVO as independent researchers. There were no formal institutional ethics procedures to complete as a result, but still ethical issues to respond to. Participants were provided with participant information and consent sheets regarding the purpose of the study and the way in which data would be used, and that anonymised data would form the basis of public reports. Additional permission was secured by the researchers from ACEVO at an early stage to try and secure academic publication on the basis of the research.

We were mindful of both the potential for revisiting trauma when researching discrimination and ableism, and of the very specific context of the unfolding COVID-19 pandemic at the time of the project. The initial design of the research, proposed before the pandemic had reached the UK, included an extensive survey of disabled people working in the voluntary sector. This was halted on the basis that disabled people were already being asked to contribute to a number of large surveys, and were trying to navigate dangers, restrictions and grief during the first UK lockdown. We thus did not think it appropriate or ethical to request their time and focus for a project about, potentially, current and past traumas experienced in the workplace.

1 We delayed the project in light of the crisis and, when resumed, focused on generating
2 insights through interviews with already-established disabled leaders. We recruited
3 ten interviewees from three groups for semi-structured interviews, through pre-existing
4 contacts and guidance from ACEVO. Semi-structured interviews allowed us to guide
5 conversations in ways that served ACEVO's needs and our central research question
6 on the experience and support needs of disabled leaders in the voluntary sector, but
7 also allowed participants to have a degree of direction in terms of what they felt was
8 most important to communicate about their experience (Brinkmann, 2014).
9 Interviewees included:

- 10 • Staff and board members at ACEVO
- 11 • ACEVO members who expressed interest in this project
- 12 • Voluntary sector leaders who publicly identify as disabled, and are not members
13 of ACEVO.

14 Ten interviews were conducted in total by Todd, between March 2020 - August 2020,
15 using a topic guide developed based on the client's research needs and our scoping
16 literature review. We reviewed interview transcripts together and identified key
17 common themes.

18

19 The small number of interviewees, coupled with the lack of survey findings, mean this
20 study has clear limitations of scope and generalisability. It is only a snapshot of the
21 experiences of a small number of current voluntary sector leaders who openly identify
22 as disabled. A larger study and anonymous survey would capture a wider range of
23 experiences, including possibly those from people who do not openly identify as

1 disabled at work. As such, this study is a starting point, and we hope further research
2 on the subject may be conducted.

3

4 **Disability and leadership in the voluntary sector: key findings**

5 Disabled identities and disclosures

6 Voluntary sector interviewees highlighted a sense of confusion and misunderstanding
7 around who is covered by the term 'disabled', including a lack of awareness about
8 mental ill health as disability, and hidden impairments. Disabled interviewees also
9 identified a related reluctance to disclose their impairments, out of concern they will
10 not be understood:

11 *I have powered through inaccessibility to make it seem like there's no problem,*
12 *masking and accommodating inaccessibility to the detriment of my own well-*
13 *being.*

14

15 Relatedly, the issue of stigma, discrimination and ableism came up in all interviews.
16 Interviewees described how stigma could make it harder to disclose disability, which
17 in turn added to difficulties securing adjustments. Fear of disclosure can have a very
18 real impact on individuals' career trajectories, as one interviewee described:

19 *I didn't feel comfortable disclosing my needs for a long time which*
20 *meant that my career was held back but I wasn't in a position to*
21 *advocate as I didn't identify.*

1 One interviewee described how the pressure to over-perform as a Chief
2 Executive made them reluctant to disclose their impairment or identify as
3 disabled, because this was perceived not to 'fit' with the over-performing
4 image they were expected to present:

5 *It's incredibly difficult [to disclose disability] because as a Chief*
6 *Executive and leader you are expected to be superhuman and*
7 *disability doesn't fit with the image... I made the decision at the start*
8 *of my career not to disclose my disability and being a CEO makes it*
9 *difficult to change that decision.*

10 As a direct consequence of these stereotypes, a number of our interviewees identified
11 not being taken seriously outside of the disability space and not having their skills as
12 leaders valued or recognised. Interviewees were frustrated that they had to keep their
13 expertise in a 'separate box', and did not get invited to discuss issues of charity
14 management, human relations, finance and so on, because others perceived their
15 expertise as only lying in issues of disability:

16 *Society doesn't value disabled talent. We are only ever asked about*
17 *disability, not things that relate to being a CEO like managing staff*
18 *and finances.*

19 Disabled leaders identified the impact of early career experiences in shaping how they
20 understood their identity and career options. Interviewees spoke of feeling impostor
21 syndrome, expectations of failure and taking longer to understand their own leadership
22 value because there were no mentors or leaders like themselves in the space. This

1 feeling was particularly pronounced for disabled leaders of colour where they were
2 dealing with multiple and intersectional oppressions:

3 *There is an absence of Black disabled leaders - as a result I never saw myself*
4 *in the leadership role.*

5 The capacity and confidence of the voluntary sector to meet the needs of disabled
6 leaders

7 Currently, according to interviewees, the opportunities in the voluntary sector for non-
8 disabled leaders to learn from disabled leaders, and disabled leaders to learn from
9 each other, are limited. Interviewees noted the value in having a protected space for
10 disabled leaders, and leaders from diverse backgrounds more broadly, to get peer
11 support from one another and share learning, chiming with findings from other sectors
12 (Martin, 2017; Todd, 2018; Ware, Singal and Groce, 2021). There was enthusiasm
13 from interviewees for the possibility of leadership support tailored specifically to the
14 needs of disabled leaders. Disabled leaders felt that they could benefit from being in
15 contact with other leaders in order to share experiences and find solutions.

16

17 Disabled interviewees commonly turned to peer support for help around disability
18 inclusion and inclusive practice. However, many also identified having to learn on-the-
19 job rather than having access to learning and support on the topic. For non-disabled
20 interviewees it was apparent that it was very challenging to find support and guidance
21 around how to be disability inclusive. Several interviewees spoke about the fear of
22 doing the 'wrong thing', or not wanting to do things that could lead disabled employees
23 to leave. In some instances, not having access to explicit support around disability

1 inclusion had led to organisations losing disabled talent, which led one interviewee to
2 reflect:

3 *If we want to see more disabled leaders in the voluntary sector, we need to*
4 *support non-disabled leaders to support the development and progression of*
5 *disabled staff.*

6

7 Interviewees also noted that the additional labour necessary- to navigate disabling
8 workplace environments, policies and practices, in addition to performing their job role,
9 leaves disabled employees with limited time to engage in standard continuing
10 professional development (CPD). This means disabled leaders and future leaders will
11 likely have to work harder than non-disabled colleagues to progress in their careers.

12

13 Disabled People’s Organisations, disability charities and their place in the voluntary
14 sector

15 One issue specific to disabled leaders in disabled people’s organisations (DPOs), as
16 opposed to disability- or health-focussed charities historically led by non-disabled
17 people, is the extent to which they see themselves as part of the voluntary sector,
18 whether the sector includes them and their organisations, or alternatively whether they
19 function as a distinct organisational field.¹ This has implications for support
20 organisations like ACEVO, for voluntary sector organisations working across linked
21 policy areas, and also for voluntary sector research both in terms of the understanding
22 of the disabled people’s movement and disabled people’s varied perceptions of charity

¹ See Inclusion London for a definition of what constitutes a deaf and disabled people’s organisation (Inclusion London, 2023).

1 that must underpin our research when working in this area, and in terms of who is
2 inside our scope and who is not.

3

4 Some disabled leaders we interviewed choose to dissociate themselves from the
5 voluntary sector because of the problematic history of power imbalances between
6 disability-focused charities and disabled people. This rejection of charity clearly
7 creates tension when trying to group disabled people's organisations (DPOs) in a
8 category of 'voluntary sector', with organisations that they see themselves as being in
9 opposition to. Some regard DPOs as within a separate sector entirely:

10 *Do they understand our sector... No because DPOs [are] about liberation not*
11 *charity.*

12

13 While DPOs can see themselves as distinct from voluntary sector, they can
14 simultaneously be viewed externally as being part of it. The commissioning of this
15 study by a prominent voluntary sector infrastructure organisation is one indication of
16 this. In fact, during the interviews a number of interviewees objected to being asked
17 about their careers in the voluntary sector because as far as they were concerned,
18 they had not worked in the voluntary sector:

19 *I have worked in DPOs, not charities or the voluntary sector.*

20

21 There are also specific challenges faced by leaders of DPOs. Interviewees highlighted
22 how DPOs tend to be lean structures due to limited organisational funding. This means

1 there are even more pressures on disabled leaders' time and fewer progression routes
2 for aspiring leaders:

3 *Disabled people's organisations tend to be narrow, small and flat - there's*
4 *nowhere to go if you want to gain experience to become the CEO or leader.*

5 **Discussion, implications for practice and conclusion**

6 This final section draws out some of the implications both for practice and for our
7 understanding of disabled leadership in the voluntary sector. The *Hidden Leaders*
8 report proposes a road map for organisations to introduce policies and practice that
9 support disabled employees and foster disabled talent (Todd and Munro, 2021). The
10 conclusions here are broader, but provide the background understanding for why
11 voluntary sector practitioners should act.

12 Fighting stereotypes and making disclosure possible

13 Findings highlighted confusion in understanding what does and does not constitute
14 'disabled'. This could perpetuate an existing 'hierarchy of impairment', whereby both
15 non-disabled and disabled people, and those with impairments who do not identify as
16 disabled, see some as 'more disabled' than others, or holding more legitimate right to
17 the identity of disabled (Deal, 2003). For disabled leaders and future leaders, this has
18 consequences for the disclosure of needs: if they feel those needs will not be
19 understood or appreciated, they are less likely to disclose them. It presents challenges
20 for the sector around ensuring that access needs are met, where impairments are
21 hidden.

22

23 The prevalence of stereotypes around what impairment means for productivity and
24 capability in the workplace can make disclosure even harder. There can be an

1 expectation that voluntary sector chief executives have to be 'superhuman', heroic
2 leaders. Ableism leads to beliefs that disabled bodies and minds are too far from the
3 'ideal' norm to perform in these roles. This is something which is further compounded
4 for disabled people who are Black or hold other minoritised identities (Morris, 1991;
5 Bell, 2016; Ervelles and Minear, 2016; Berghs and Dyson, 2019).

6

7 There is limited existing literature on the intersection of identities and the impact of
8 multiple oppression on leaders. Bell (2016) attributes this to a failure of theory and
9 research around disability to successfully challenge the dominant assumption of
10 whiteness. Berghs and Dyson argue that because racism often reduces Black people
11 to their bodies, and sees those bodies as worth less, it is 'difficult to frame impairment
12 in terms of a positive disabled identity' (2020, p.14). They also suggest that mutuality
13 of care-giving over life-cycles is valued higher by Black communities than white
14 disabled people, who emphasise independence. These issues present challenges for
15 representation of Black experiences within the white-dominated disability rights
16 movement which has, itself, faced criticism, alongside challenges posed by structural
17 racism in education, employment and elsewhere, which aspiring Black leaders face.
18 We can see these experiences and challenges described in Black, Asian and minority
19 ethnic leadership literature from across different sectors (Johnson, 2017; Arday, 2018;
20 Business in the Community, 2018).

21

22 For disabled leaders, there are additional issues around 'superhuman' performance.
23 additionally The literature highlights the trope of the superhuman or 'supercrip'
24 disabled person. This sometimes refers to media representations, including

1 representations in some charity communications, of disabled people, which present
2 them as extra strong, talented, brave, and so on, and which perpetuate ableist
3 attitudes and medical-model perceptions of disabled people. These superhuman
4 individuals perform *despite* their impairment, and are an exception to the general
5 disabled population, by this account, able to rise above through individual talent and
6 grit. This denies the lived reality of many who are disabled by environments, systems
7 and attitudes, and are prevented from succeeding. Ideas of super-humanness or
8 super-crippness also refer to the related perception whereby a disabled person feels
9 they have to perform above and beyond the level of a non-disabled person in order to
10 make others believe in their ability to perform their role, because of societal prejudice
11 that suggests disabled people are *not*, normally, able to perform to the same degree
12 as their non-disabled counterparts (Boucher, 2017; Lourens, 2020).

13

14 Voluntary organisations must maintain and implement policies and principles that
15 actively challenge ableist conceptions of disabled people. This includes ensuring all
16 staff understand the social model approach to disability, and recognise that not all
17 impairments are visible. It also relates to how charities communicate with the general
18 public. As noted, the 'charitable model' of disability is widely rejected by the disability
19 community because it is perceived to reflect oppressive attitudes and structures that
20 many disabled people experience. Hevey, for instance, described in 1992 how charity
21 advertising across the 1980s and early 1990s reinforced ableist and medical images
22 of impairment, and ran counter to disabled activists' demand for independence, by
23 inserting charity into their lives as service providers, continuing to locate impairment
24 as the 'site of the issue' and charity as the solution (Hevey, 1992, pp.39-40). It is
25 important to note that disabled people are not a homogenous group, and there will

1 undoubtedly be varied opinions of the role of disability and health charities in disabled
2 people's lives. However, as cited above (Waltz, 2012), and as evident in a range of
3 more contemporary charity imagery examples and disabled activists' writings, these
4 are views that persist and are strongly held.²

5

6 Supporting disabled talent

7 It is important that the additional energy that disabled staff use in order to remain in
8 their jobs is acknowledged and that disabled staff are given the opportunity to grow
9 and develop skill sets outside of basic survival. As in other sectors, disabled staff can
10 find themselves either having to assimilate into workplaces not designed for disabled
11 employees, often compromising access needs; or having to lead organisational
12 change in addition to their employment, in order to be able to do their job (Boucher,
13 2017; Lourens, 2020).

14

15 Unless more is done within the sector to build ethos and cultures that are inclusive
16 and supportive, many potential disabled leaders may not feel that they have the
17 capacity or energy to deal with both these and the additional challenges of "working
18 while disabled", a phrase that echoes overlapping liberation causes such as anti-
19 racism, and that draws attention to the clash between personal identities and
20 professional environments that can occur for many minoritised people.

21

² This is a subject that deserves more attention than there is room for here, but some interesting examples include Damien Hirst's sculpture 'Charity' and the reaction to it from disabled activists (Crawshaw, 2019), and a Guide Dogs for the Blind Association campaign called 'Shades for a Day' from the early 2000s (UK Parliament, 2002).

1 Voluntary sector infrastructure bodies are well placed to facilitate both connections
2 between leaders within the field, and opportunities for intersectional and inter-sector
3 learnings, if they were willing and resourced to take on this role.

4

5 Tension in voluntary action fields

6 Our interviews highlighted how some disabled leaders identify as part of the Disabled
7 People's Movement, running DPOs. This separate field of liberation-based
8 organisations clearly overlaps with a more broadly constituted voluntary sector field. If
9 DPOs are registered charities, community interest companies or similar legal forms,
10 they will face the same legal responsibilities and constraints as voluntary sector
11 organisations. They may be constituted in the same way with the same forms of
12 governance, and they may pursue the same forms and sources of funding (or, they
13 may not). They may also have many of the same training and support needs, and
14 benefit from policy advocacy on the same issues. However there are also clear
15 tensions, including in both contemporary and historical practice. This presents a
16 challenge for generalist infrastructure bodies in trying to be open and accessible to
17 disabled leaders who reject the language and practice of organisations in voluntary
18 sector spaces.

19

20 The rest of the voluntary sector could play a fundamental role in helping strengthening
21 capacity and building DPOs by providing career opportunities or secondments for
22 aspiring disabled leaders where structures are less flat. This would also assist the
23 wider voluntary sector by creating more connection points with DPOs that often do not

1 have the capacity or access needs met to attend networking events, which may help
2 to build understanding of disabled people's lives, leadership potential and needs.

3

4 Conclusion

5 While many – although not all - of our disabled interviewees came from working in and
6 leading DPOs, it is important to restate that disabled people do not necessarily *want*
7 to work for disability-related organisations, whether DPOs or health-related charities.
8 It is perhaps symptomatic of a lack of openly disabled leaders in other charities that
9 this has been our focus, although also a product of a slimmed-down research process
10 in response to the COVID-19 pandemic. In either case, there is a clear need for further
11 research into the experience of the disabled workforce, including existing and aspiring
12 leaders, in the UK voluntary sector. There is also a need for more voluntary sector
13 data and practice literature exploring the workforce and experiences of disabled
14 workers in the sector.

15

16 Our small-scale study begins to look at these issues. It highlights experiences common
17 to other sectors, including a perceived need to 'mask' impairments, and to over-
18 perform both as a leader and more specifically as a disabled leader; a lack of support
19 and guidance both to develop one's skills as a disabled leader, and to support and
20 meet the needs of disabled workers; and an appetite for peer support and shared
21 learning. It also highlights issues more specific to a voluntary sector setting: the need
22 to support and develop current and future disabled leaders outside of health- and
23 disability-related organisations, and tensions between DPOs, disability activism and
24 the history and concept of charity. We hope future research can help further our

- 1 understanding of the experience of disabled employees across the voluntary sector,
- 2 their career trajectories and how their talent can best be developed.
- 3

1 **References**

- 2 ACEVO (2021). *Diversity in the charity sector*. London: ACEVO. Available at:
3 <https://www.acevo.org.uk/advocacy/diversity-in-the-charity-sector/> (accessed:
4 09/07/21)
- 5 Arday, J. (2018). 'Understanding race and educational leadership in higher education:
6 Exploring the Black and ethnic minority (BME) experience', *Management in Education*,
7 32(4), pp.192-200.
- 8 Aspis, S. (2021) 'Why are disabled people with learning difficulties being prevented
9 from leading campaigns, projects and initiatives?', *Disability & Society*, pp. 1-6.
- 10 Bell, C. (2016) 'Is Disability Studies Actually White Disability Studies?', in Davis, L.J.
11 (ed.) *The Disability Studies Reader*, Oxford: Routledge, pp. 406-415.
- 12 Berghs, M. and Dyson, S.M. (2020) 'Intersectionality and employment in the United
13 Kingdom: Where are all the Black disabled people?', *Disability & Society*, pp. 1-24.
- 14 Bevan, J. (2014) 'Disabled occupational therapists – asset, liability ... or 'watering
15 down' the profession?', *Disability & Society*, 29(4), pp. 583-596.
- 16 Boucher, C. (2017) 'The Roles of Power, Passing, and Surface Acting in the
17 Workplace Relationships of Female Leaders With Disability', *Business & Society*,
18 56(7), pp. 1004-1032.
- 19 Brewster, S., Duncan, N., Emira, M. and Clifford, A. (2017) 'Personal sacrifice and
20 corporate cultures: career progression for disabled staff in higher education'. *Disability
21 & Society*, 32(7), pp. 1027-1042.

1 Brinkmann, S. (2014). 'Unstructured and Semi-Structured Interviewing'. In P. Leavy
2 (Ed.). *The Oxford Handbook of Qualitative Research*, Oxford: Oxford University Press,
3 pp. 277-299.

4 Brown, N. and Leigh, J. (2020) *Ableism in Academia*. London: UCL Press.

5 Business in the Community (2020). *The Race at Work Black Voices Report*. London:
6 BITC.

7 Chan, F., Tansey, T.N., Iwanaga, K., Bezyak, J., Wehman, P., Phillips, B.N., Strauser,
8 D.R. and Anderson, C. (2020) 'Company Characteristics, Disability Inclusion
9 Practices, and Employment of People with Disabilities in the Post COVID-19 Job
10 Economy: A Cross Sectional Survey Study', *Journal of occupational rehabilitation*, pp.
11 1-11.

12 Chan, O., Fern, B., Martin, A., Tabassum, N. (2022). *UK Civil Society Data Almanac*.
13 London: NCVO. Available: [https://www.ncvo.org.uk/news-and-insights/news-
14 index/uk-civil-society-almanac-2022/#/](https://www.ncvo.org.uk/news-and-insights/news-index/uk-civil-society-almanac-2022/#/) (accessed: 06/03/23).

15 Crawshaw, Gill (2019). 'Researching Damien Hirst's "Charity"'. *Piss on Pity exhibition*,
16 available [https://pissonpityexhibition.wordpress.com/2019/11/07/researching-
17 damien-hirsts-charity/](https://pissonpityexhibition.wordpress.com/2019/11/07/researching-damien-hirsts-charity/) (accessed: 06/03/23)

18 Cullingworth, J., Watson, N., Shakespeare, T., Brunner, R., Pearson, C., Scherer, N.
19 (2022). "'They have been a saving grace in all this": the role of the third sector in
20 disabled people's experiences of COVID-19 and implications for sector-state
21 relations'. *Voluntary Sector Review*, pp.1-18.

- 1 Dale, E.J. and Breeze, B. (2022). 'Making the tea or making it to the top? How gender
2 stereotypes impact women fundraisers' careers'. *Voluntary Sector Review*, 13(1),
3 pp.19-36.
- 4 Darcy, S., Taylor, T. and Green, J. (2016) 'But I can do the job': examining disability
5 employment practice through human rights complaint cases'. *Disability & Society*,
6 31(9), pp. 1242-1274.
- 7 Deal, M. (2003) 'Disabled people's attitudes toward other impairment groups: a
8 hierarchy of impairments', *Disability & Society*, 18(7), pp. 897-910.
- 9 Degener, T. (2016) 'Disability in a Human Rights Context'. *Laws*, 5(3), pp. 1-24.
- 10 Dennissen, M.H.J., Benschop, Y.W.M. and Brink, M. C. L. van den (2019) 'Diversity
11 networks: Networking for equality?', *British journal of management*, 30(4), pp. 966-
12 980.
- 13 Emira, M., Brewster, S., Duncan, N. and Clifford, A. (2018) 'What disability? I am a
14 leader! Understanding leadership in HE from a disability perspective', *Educational
15 Management Administration & Leadership*, 46(3), pp. 457-473.
- 16 Erevelles, N. and Minear, A. (2016) 'Unspeakable Offenses: Untangling Race and
17 Disability in Discourses of Intersectionality', in Davis, L.J. (ed.) *The Disability Studies
18 Reader* Oxford: Routledge, pp. 381-395.
- 19 Foster-Fishman, P., Jimenez, T., Valenti, M. and Kelley, T. (2007) 'Building the next
20 generation of leaders in the disabilities movement', *Disability & society*, 22(4), pp. 341-
21 356.

- 1 Garland-Thomson, R. (2016) 'Integrating Disability, Transforming Feminist Theory',
2 in Davis, L.J. (ed.). *The Disability Studies Reader*, Oxford: Routledge, pp. 360-380.
- 3 Hale, C., Benstead, S., Hardy, K. and Ingold, J. (2021) "*I already have a job... getting*
4 *through the day*": *Energy limiting chronic illness (ELCI), social inclusion, employment*
5 *and social security*. Sheffield: Centre for Welfare Reform.
- 6 Hevey, David (1992). *The creatures that time forgot: photography and disability*
7 *imagery*. London: Routledge.
- 8 Inckle, K. (2018). 'Unreasonable adjustments: the additional unpaid labour of
9 academics with disabilities', *Disability & Society*, 33(8), pp. 1372-1376.
- 10 Inclusion London (2023). *What is a DDPO?*. London: Inclusion London, available:
11 <https://www.inclusionlondon.org.uk/about-us/what-is-a-ddpo/what-is-a-ddpo/>
12 (accessed 13/03/23).
- 13 Johnson, L (2017). 'The lives and identities of UK Black and South Asian head
14 teachers: Metaphors of leadership'. *Educational Management Administration &*
15 *Leadership*, 45(5), pp. 842–862.
- 16 Kim, K.M. (2010) 'The accomplishments of disabled women's advocacy organizations
17 and their future in Korea', *Disability and Society*, 25(2), pp. 219-230
- 18 Lawson, A. and Beckett, A.E. (2021) 'The social and human rights models of disability:
19 towards a complementarity thesis', *The International Journal of Human Rights*, 25(2),
20 pp. 348-379.

- 1 Lewis, H. (2020) 'How Can We Develop More Deaf Christian Leaders?', *Theology*
2 *Today*, 77(2), pp. 154-164.
- 3 Living Wage Foundation (2017). *Low Pay in the Charity Sector*. London: Living Wage
4 Foundation.
- 5 Lough, B.J. (2021). 'Voluntary 'organic' leadership for community resilience'. *Voluntary*
6 *Sector Review*, 12(1), pp.81-98.
- 7 Lourens, H. (2020) 'Supercrapping the academy: the difference narrative of a disabled
8 academic', *Disability & Society*, pp. 1-16.
- 9 Majiet, S. and Africa, A. (2015) 'Women with disabilities in leadership: The challenges
10 of patriarchy', *Agenda*, 29(2), pp. 101-111.
- 11 Martin, N. (2017) *Encouraging disabled leaders in higher education: recognising*
12 *hidden talents*. London: Leadership Foundation for Higher Education.
- 13 Martin, N. (2020) 'A practical response to ableism in leadership in UK higher
14 education', in Brown, N. and Leigh, J. (eds.) *Ableism in Academia*, London: UCL
15 Press, pp. 76-102.
- 16 Martin, A., Chan, O., Lawson, M. and Goodall, C. (2021). *UK Civil Society Almanac*
17 *2021*. London: NCVO. Available: [https://www.ncvo.org.uk/news-and-insights/news-](https://www.ncvo.org.uk/news-and-insights/news-index/uk-civil-society-almanac-2021/#/)
18 [index/uk-civil-society-almanac-2021/#/](https://www.ncvo.org.uk/news-and-insights/news-index/uk-civil-society-almanac-2021/#/) (accessed 06/03/23)
- 19 McGonagle, A. and Hamblin, L. (2014) 'Proactive Responding to Anticipated
20 Discrimination Based on Chronic Illness: Double-Edged Sword?'. *Journal of business*
21 *and psychology*, 29(3), pp. 427-442.

- 1 Mellifont, D., Smith-Merry, J., Dickinson, H., Llewellyn, G., Clifton, S., Ragen, J.,
2 Raffaele, M. and Williamson, P. (2019) 'The ableism elephant in the academy: a study
3 examining academia as informed by Australian scholars with lived experience',
4 *Disability & Society*, 34(7-8), pp. 1180-1199.
- 5 Morris, J. (1991). *Pride Against Prejudice: Transforming Attitudes to Disability*.
6 London: The Women's Press.
- 7 Nash, K. (2014) *Secrets and Big News: Enabling people to be themselves at work*.
8 London: Kate Nash Associates.
- 9 Oliver, M. (2013) 'The social model of disability: thirty years on', *Disability & Society*,
10 28(7), pp. 1024-1026.
- 11 Parker Harris, S., Renko, M. and Caldwell, K. (2014) 'Social entrepreneurship as an
12 employment pathway for people with disabilities: exploring political–economic and
13 socio-cultural factors', *Disability & Society*, 29(8), pp. 1275-1290.
- 14 Procknow, G., Rocco, T.S. and Munn, S.L. (2017) '(Dis)Ableing Notions of Authentic
15 Leadership Through the Lens of Critical Disability Theory', *Advances in developing
16 human resources*, 19(4), pp. 362-377.
- 17 Roulstone, A. and Williams, J. (2014) 'Being disabled, being a manager: 'glass
18 partitions' and conditional identities in the contemporary workplace', *Disability &
19 Society*, 29(1), pp. 16-29.
- 20 Sang, K., Calvard, T. and Remnant, J. (2021) 'Disability and Academic Careers: Using
21 the Social Relational Model to Reveal the Role of Human Resource Management
22 Practices in Creating Disability', *Work, Employment and Society*, pp. 1-19.

- 1 Shakespeare, T. (2014) *Disability rights and wrongs revisited*. Second edition. London:
2 Routledge.
- 3 Smith, A. (2012). 'Hierarchy of impairment: the impact', *Ethnicity and Inequalities in*
4 *Health and Social Care*, 5(2), pp.70-71.
- 5 Todd, Z. (2016). *Developing Inclusive Leadership in the Disability Movement: Lessons*
6 *and Learning from Australia and New Zealand*. London: Winston Churchill Memorial
7 Foundation.
- 8 Todd, Z. and Munro, E. (2021). *Hidden Leaders*. London: ACEVO
- 9 UK Parliament (2002). *Shades for a Day – EDM 1599: tabled on 10 July 2002*. London:
10 UK Parliament. Available: [https://edm.parliament.uk/early-day-motion/20258/shades-](https://edm.parliament.uk/early-day-motion/20258/shades-for-a-day)
11 [for-a-day](https://edm.parliament.uk/early-day-motion/20258/shades-for-a-day) (accessed 06/03/23).
- 12 Waltz, M. (2012). 'Images and narratives of autism within charity discourses'.
13 *Disability & Society*, 27:2, pp.219-233.
- 14 Ware, H., Singal, N. and Groce, N. (2021) 'The work lives of disabled teachers:
15 revisiting inclusive education in English schools', *Disability & Society*, pp. 1-23.
- 16 Warwick-Booth, L., South, J., Giuntoli, G., Kinsella, K. and White, J. (2020). "Small
17 project, big difference': capacity building through a national volunteering fund: an
18 evaluation of the Department of Health's Health and Social Care Volunteering Fund'.
19 *Voluntary Sector Review*, 11(1), pp.21 – 40.
- 20 Wendell, S. (2016) 'Unhealthy Disabled: Treating Chronic Illnesses as Disabilities', in
21 Davis, L.J. (ed.) *The Disability Studies Reader*, Oxford: Routledge, pp. 160-172.

1 Wilson-Kovacs, D., Ryan, M.K., Haslam, S.A. and Rabinovich, A. (2008) "Just
2 because you can get a wheelchair in the building doesn't necessarily mean that you
3 can still participate': barriers to the career advancement of disabled professionals',
4 *Disability & Society*, 23(7), pp. 705-717.

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