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

Introduction

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

The paper contributes to what is currently a limited literature on disability and leadership (Boucher, 2017). While a growing body of literature addresses the subject in other workforce sectors, little has been written in academic or practice literature on the experience of disabled leaders in voluntary organisations, in terms of career
trajectories, barriers and enablers or their experience in leadership positions. There is also a lack of literature considering employees at the intersections of identities of disability and race (Bell, 2016; Erevelles and Minear, 2016; Berghs and Dyson, 2020).

In terms of data from the voluntary sector itself, the 2021 and 2022 NCVO Civil Society Data Almanacs reported on the percentage of the overall voluntary sector workforce that identifies as disabled (static at around 23% since 2020), but there is no further analysis (Martin et al., 2021; Chan et al., 2022). A 2017 report into low pay in the voluntary sector acknowledged that it did not have sufficient data to consider disabled workers’ pay (Living Wage Foundation, 2017). Voluntary sector research tends to focus on disabled people as beneficiaries, rather than people building careers in the sector (eg Warwick-Booth et al., 2020; Cullingworth et al., 2022), or mentions disability briefly in the context of wider equity and discrimination narratives (eg Lough, 2021; Dale and Breeze, 2022). This is, of course, valuable research, but the other dimension of experience – namely disabled people building careers in the voluntary sector - is missing, and deserves further examination.

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

Disability and leadership: barriers and enablers from across sectors

It is important first to establish what we mean by ‘disability’. Different ‘models’ of disability emphasise different aspects of impairment and/or societal barriers disabled
people face. Much of the debate around models and terms is around the balance of
this emphasis. This paper and research primarily adopted a ‘social model’ of disability
(Oliver, 2013; Martin, 2020) which is common to rights-based work in the voluntary
sector in this area. This sees disability as a social construction, rather than as a matter
of individual incapacity: it is caused by barriers in society, which disable an individual
with an impairment. The model sets itself firstly against the medical model, with its
focus on treatments, cures and individual responsibility. Secondly, it rejects the charity
model, particularly pertinent to this journal, which prioritises non-disabled experts and
so-called protectors over disabled voices, perpetuating concepts of vulnerability and
helplessness. This second model can be seen in some historical and contemporary
charity-led services and institutions for disabled people, and, as highlighted by Hevey
and, in more contemporary examples, Waltz, oppressive images of disability in charity
advertising (Hevey, 1992; Waltz, 2012).

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

There is a growing body of literature relating to leadership across different sectors
acknowledging the social structural barriers to leadership disabled people face,
although little yet on the voluntary sector. There is a great deal of synergy across this literature in terms of the barriers and enablers for disabled leaders, including issues with disabled identities and workplace disclosure, difficulties securing adaptations and adjustments, problematic attitudes and a lack of opportunity for advancement, the benefits of mentoring and peer support, how policies and procedures can help to embed rights and processes, and thinking on changing attitudes and norms.

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

Table 1 presents common barriers and enablers to accessing leadership identified in global research from across different sectors of employment and activity, including the public sector, the private sector, higher education, the arts and disability activism.
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<thead>
<tr>
<th><strong>Barriers</strong> (selected references)</th>
<th><strong>Specific issues</strong></th>
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| Disabled identities and disclosure (Bevan, 2014; Boucher, 2017; Martin, 2017; Lourens, 2020; Berghs and Dyson, 2020) | • 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’. |
| Adaptations and adjustments (Inckle, 2018; Brown and Leigh, 2020; Ware, Singal and Groce, 2021) | • 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. |
| Attitudes (Procknow, Rocco and Munn, 2017; Sang, Calvard and Remnant, 2021) | • 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. |
| Opportunities (Boucher, 2017; Roulstone and Williams, 2014; Wilson-Kovacs et al., 2008) | • 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. |

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<th><strong>Enablers</strong> (selected references)</th>
<th><strong>Specific issues</strong></th>
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| Mentoring and peer support (Parker Harris, Renko and Caldwell, 2014; Todd, 2016; Dennissen, Benschop and Brink, M. C. L. van den, 2019) | • Mentors across all roles and sectors  
• Peer networks and networking opportunities  
• Role models |
### Policies and procedures (Mellifont *et al.*, 2019; Chan *et al.*, 2020; Hale *et al.*, 2021)
- 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

### Changing attitudes (Foster-Fishman *et al.*, 2007; Nash, 2014; Emira *et al.*, 2018; Lewis, 2020; Aspis, 2021)
- Creating inclusive environments for disclosure
- Rethinking leadership norms
- Challenging the perceived ‘hierarchy of impairment’

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

This review provided a backdrop for our own research, which found significant cross-over with issues across private, government, higher education and other sectors. Our research also highlighted some unique challenges for disabled leaders in the voluntary sector, particularly in relation to whether they feel part of the voluntary sector in the first place, or part of a separate liberation-based field. This raises important questions of how to support current and future leaders, and the role of voluntary sector infrastructure organisations in doing so.
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.
We delayed the project in light of the crisis and, when resumed, focused on generating insights through interviews with already-established disabled leaders. We recruited ten interviewees from three groups for semi-structured interviews, through pre-existing contacts and guidance from ACEVO. Semi-structured interviews allowed us to guide conversations in ways that served ACEVO’s needs and our central research question on the experience and support needs of disabled leaders in the voluntary sector, but also allowed participants to have a degree of direction in terms of what they felt was most important to communicate about their experience (Brinkmann, 2014).

Interviewees included:

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

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

The small number of interviewees, coupled with the lack of survey findings, mean this study has clear limitations of scope and generalisability. It is only a snapshot of the experiences of a small number of current voluntary sector leaders who openly identify as disabled. A larger study and anonymous survey would capture a wider range of experiences, including possibly those from people who do not openly identify as
disabled at work. As such, this study is a starting point, and we hope further research on the subject may be conducted.

Disability and leadership in the voluntary sector: key findings

Disabled identities and disclosures

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

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

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

I didn’t feel comfortable disclosing my needs for a long time which meant that my career was held back but I wasn’t in a position to advocate as I didn’t identify.
One interviewee described how the pressure to over-perform as a Chief Executive made them reluctant to disclose their impairment or identify as disabled, because this was perceived not to ‘fit’ with the over-performing image they were expected to present:

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

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

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

Disabled leaders identified the impact of early career experiences in shaping how they understood their identity and career options. Interviewees spoke of feeling impostor syndrome, expectations of failure and taking longer to understand their own leadership value because there were no mentors or leaders like themselves in the space. This
feeling was particularly pronounced for disabled leaders of colour where they were dealing with multiple and intersectional oppressions:

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

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

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

Disabled interviewees commonly turned to peer support for help around disability inclusion and inclusive practice. However, many also identified having to learn on-the-job rather than having access to learning and support on the topic. For non-disabled interviewees it was apparent that it was very challenging to find support and guidance around how to be disability inclusive. Several interviewees spoke about the fear of doing the ‘wrong thing’, or not wanting to do things that could lead disabled employees to leave. In some instances, not having access to explicit support around disability
inclusion had led to organisations losing disabled talent, which led one interviewee to reflect:

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

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

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

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

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

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

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

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

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

There are also specific challenges faced by leaders of DPOs. Interviewees highlighted
how DPOs tend to be lean structures due to limited organisational funding. This means
there are even more pressures on disabled leaders’ time and fewer progression routes for aspiring leaders:

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

**Discussion, implications for practice and conclusion**

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

**Fighting stereotypes and making disclosure possible**

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

The prevalence of stereotypes around what impairment means for productivity and capability in the workplace can make disclosure even harder. There can be an
expectation that voluntary sector chief executives have to be ‘superhuman’, heroic leaders. Ableism leads to beliefs that disabled bodies and minds are too far from the ‘ideal’ norm to perform in these roles. This is something which is further compounded for disabled people who are Black or hold other minoritised identities (Morris, 1991; Bell, 2016; Ervelles and Minear, 2016; Berghs and Dyson, 2019).

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

For disabled leaders, there are additional issues around ‘superhuman’ performance. Additionally, the literature highlights the trope of the superhuman or ‘supercrip’ disabled person. This sometimes refers to media representations, including
representations in some charity communications, of disabled people, which present them as extra strong, talented, brave, and so on, and which perpetuate ableist attitudes and medical-model perceptions of disabled people. These superhuman individuals perform despite their impairment, and are an exception to the general disabled population, by this account, able to rise above through individual talent and grit. This denies the lived reality of many who are disabled by environments, systems and attitudes, and are prevented from succeeding. Ideas of super-humanness or super-cripness also refer to the related perception whereby a disabled person feels they have to perform above and beyond the level of a non-disabled person in order to make others believe in their ability to perform their role, because of societal prejudice that suggests disabled people are not, normally, able to perform to the same degree as their non-disabled counterparts (Boucher, 2017; Lourens, 2020).

Voluntary organisations must maintain and implement policies and principles that actively challenge ableist conceptions of disabled people. This includes ensuring all staff understand the social model approach to disability, and recognise that not all impairments are visible. It also relates to how charities communicate with the general public. As noted, the ‘charitable model’ of disability is widely rejected by the disability community because it is perceived to reflect oppressive attitudes and structures that many disabled people experience. Hevey, for instance, described in 1992 how charity advertising across the 1980s and early 1990s reinforced ableist and medical images of impairment, and ran counter to disabled activists’ demand for independence, by inserting charity into their lives as service providers, continuing to locate impairment as the ‘site of the issue’ and charity as the solution (Hevey, 1992, pp.39-40). It is important to note that disabled people are not a homogenous group, and there will
undoubtedly be varied opinions of the role of disability and health charities in disabled people's lives. However, as cited above (Waltz, 2012), and as evident in a range of more contemporary charity imagery examples and disabled activists’ writings, these are views that persist and are strongly held.2

Supporting disabled talent

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

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

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

Tension in voluntary action fields

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

The rest of the voluntary sector could play a fundamental role in helping strengthening capacity and building DPOs by providing career opportunities or secondments for aspiring disabled leaders where structures are less flat. This would also assist the wider voluntary sector by creating more connection points with DPOs that often do not
have the capacity or access needs met to attend networking events, which may help
to build understanding of disabled people’s lives, leadership potential and needs.

Conclusion

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

Our small-scale study begins to look at these issues. It highlights experiences common
to other sectors, including a perceived need to ‘mask’ impairments, and to over-
perform both as a leader and more specifically as a disabled leader; a lack of support
and guidance both to develop one’s skills as a disabled leader, and to support and
meet the needs of disabled workers; and an appetite for peer support and shared
learning. It also highlights issues more specific to a voluntary sector setting: the need
to support and develop current and future disabled leaders outside of health- and
disability-related organisations, and tensions between DPOs, disability activism and
the history and concept of charity. We hope future research can help further our
understanding of the experience of disabled employees across the voluntary sector, their career trajectories and how their talent can best be developed.
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