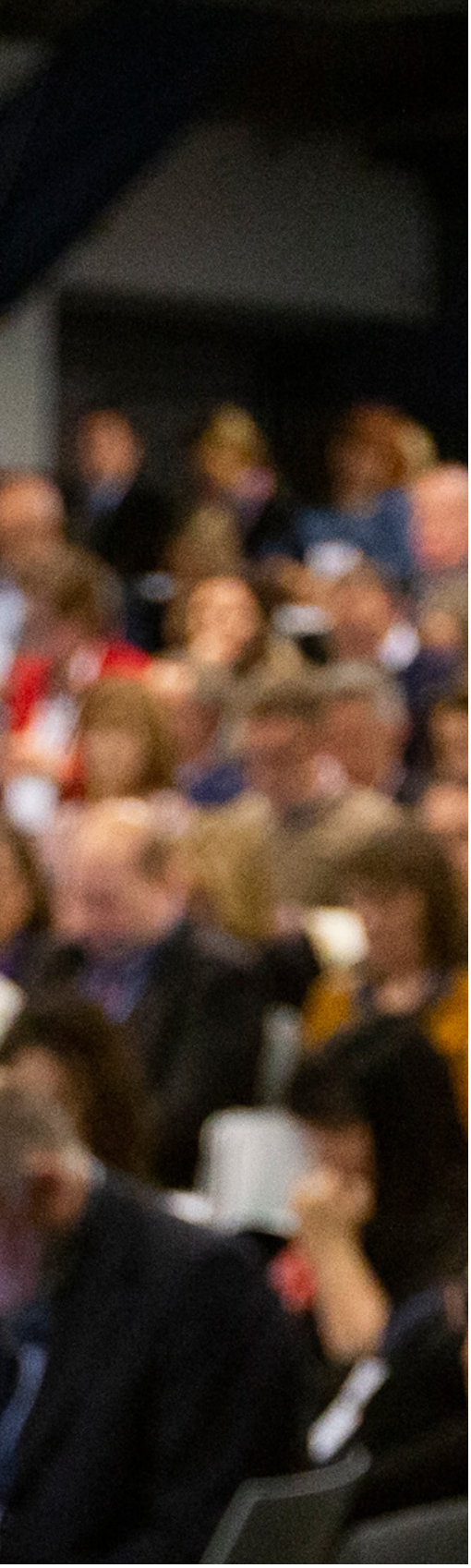

# Hidden Leaders

## Disability leadership in civil society

acevo
imagine, inspire, improve

Zara Todd and Ellie Munro

# Contents

**1. Summary** **2**

1.1 About the authors 3

**2. The problem** **4**

2.1 Definitions and terminology used in this report 5

2.2 About this project 7

2.3 What did we do? 8

2.4 What is still needed 9

**3. Emergent issues** **10**

3.1 Who are disabled people? 10

3.2 The dynamics of disability in civil society 12

3.3 Stigma and disclosure 14

3.4 ACEVO's offer for disabled leaders 16

3.5 Realising disability inclusion in civil society workplace 19

3.6 Learning from disabled leaders 21

3.7 Capacity and confidence 22

**4. Taking action: how can the sector support disabled leaders?** **24**

**5. Recommendations for ACEVO** **31**

**6. Conclusions and next steps** **33**

6.1 Acknowledgements 33

> We need to support the voluntary sector and its leaders so that they can bring their whole selves to work and what it means to do that if we want disclosure rates to increase.

# 1. Summary

This report explores what ACEVO and wider civil society need to consider if they want to be embedding disability inclusive practice.

Despite disabled people accounting for 20% of the workforce, data shows us that politically disabled[1] leaders are underrepresented in civil society with only 16% of sector CEOs identifying as disabled[2] and only 5.6% of ACEVO's members[3] disclosing disability.

This research carried out 10 semi structured interviews with staff and board members at ACEVO, and civil society leaders who identify as disabled both within and external to ACEVO's existing membership.

The aim of the interviews and the desk research that accompanies this report was to find out what are the barriers, what do we already know, and what do we need to know in order to build a more disability inclusive approach.

There were seven broad themes that emerged through the interviews:

- A lack of understanding and/or confusion around who is considered disabled
- How civil society understands disability, and where disabled people's organisations and disability charities sit
- Stigma around disability and how it affects disclosure and employment
- The accessibility and relevance of ACEVO's offer to disabled leaders
- Sector and societal barriers which inhibit disability inclusion in the sector
- The capacity and confidence of civil society to meet the needs of diverse leaders
- Visibility of disabled leaders and the missed opportunity to learn from them.

The recommendations are broken down into three sections based on what stage in its inclusion journey an organisation might be. These three sections are:

- Inclusive foundations
- Building good practice
- Leading the way.

Each section covers seven key building blocks for disability inclusion. These are:

1. Knowledge and data
2. Approach and ethos
3. Access
4. Policy and procedure
5. Training, learning and development
6. Representation
7. Working at the intersections

1 Full Glossary is available on page 36
2 Pay and Equalities Survey 2020, ACEVO
3 Figures taken from 770 members that have completed an equality data monitoring form.

In addition, there is a section of recommendations which are specific to ACEVO based on what emerged from the interviews.

We hope that this report will be a catalyst to civil society becoming more inclusive and that the sector becomes a place where disabled leaders can thrive.

## 1.1 About the authors

**Zara Todd** is an inclusion and equity consultant who specialises in organisational change and strategic development. Zara has worked in a wide variety of civil society organisations over the last 15 years including disabled people's organisations and small medium and large charities in England and Scotland and Europe. Zara has been on the leadership team of several organisations including European Network on Independent Living, Campaign Bootcamp and trustee level at a wide variety of third sector organisations including Inclusion London and Volunteering Matters.

In 2017 Zara carried out a Winston Churchill memorial trust fellowship looking at inclusion disability and leadership and what could be learned from Australia and New Zealand the recommendations were used to help the National Lottery Community Fund Develop a pilot funding scheme focused on supporting lived experience leadership. Zara politically identifies as a disabled person and an intersectional feminist. Zara has been active in the disability movement in the UK and internationally for which she has been profiled in the guardian newspaper in 2017.

Zara is also an experienced trainer, she has designed and delivered training on human rights, disability and inclusion related topics around the world for organisations such as ASEF, the Council of Europe and the British Council.

**Ellie Munro** is a researcher and policy professional working with voluntary sector organisations on issues that matter to them. She is an associate of consultancy organisations Merida, Koreo and the Patients Association, producing policy, research and evaluation reports for a range of clients. She also provides freelance policy and research support for clients, producing internal and external reports, guidance and qualitative data analysis. Ellie has a Masters degree in social research methods, and is currently a PhD student at the Third Sector Research Centre at the University of Birmingham, researching the historical development of the local voluntary sector field in relation to political and social change. She has 15 years experience working in policy, research and campaigning with a range of UK charities, including infrastructure organisations, children's rights, disability and women's rights charities. She has been a trustee of several organisations in similar fields.

> "I'm an expert at spinning plates but I'd like to be spinning less plates and better and I think ACEVO could support with this.

# 2. The problem

Disabled people account for between 15 and 25%[4][5] of the UK's population depending on which definition you are using.

But the profile of disabled employees in civil society is low. It is even lower for disabled leaders in the sector. There is a basic lack of data on the disabled civil society workforce; it is hard to see and, until now, there has been little incentive or drive in the sector to see it.

Something isn't working, and as a result civil society is losing out on disabled talent.

In commissioning this work ACEVO has taken a much-need leadership position in acknowledging the invisibility of disability leadership in civil society. Throughout this process talking to both staff and board members it is clear that there is an organisational will to do something and to live up to the ambition set out in the organisation's business plan.

> "Willingness is there but we don't seem to be able to move forward, intentions need to be turned into actions.

ACEVO began collecting data around disability within its membership in 2018 through its member application and renewal process. As of March 2020 only 5.4% answered yes to the question 'Are you a Disabled person?' 72% said they were not and 22.2% preferred not to say. This is considerably less than the number that identified as having a disability in the latest Pay and Equalities Survey (2020)[6] which found 16% of respondents identified as having a disability or health condition. According to 2019 data published by ACEVO none of the organisation staff team (n=15) nor its Board of Trustees (n=11) identifies as disabled.

The world has changed dramatically since this work was commissioned in January 2020. Both the death of George Floyd and the subsequent resurgence of the Black Lives Matter movement, and the COVID-19 pandemic have brought civil society to a crossroads. We have the opportunity to consider what we want and need the values and actions of the sector to be, moving forwards. Over the months that this research and report has been being compiled there has been much rhetoric in society about "building back better"; as you will see from what we have found in this research it is essential that building back better is disability inclusive.

> "The voluntary sector does not walk the talk of disability inclusion.

4 https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability
5 https://www.worldbank.org/en/topic/disability
6 Question asked in the Pay and Equalities Survey is: **'Do you consider yourself to have a disability, learning difference or health condition?'**

A recurring issue raised throughout the research interviews was the gap between words and actions; numerous interviewees spoke of disability inclusion within civil society as aspired to but rarely delivered.

> Civil society is aspirational as a sector. We want to be as accessible as possible but there is disconnect with the reality and we think we're special {exempt from work} because we are not-for-profit.

This report aims to provide a roadmap for ACEVO and civil society to begin to bridge this disconnect so that disabled leaders are seen and valued, and that the skills, experience and talents that disabled people bring to the workplace can be harnessed by civil society.

> We need spaces where we can share knowledge and build the next generation pipelines into DPOs [Disabled people's organisations] so that young leaders see them as attractive places to work.

This is not the end of the journey or job done, but rather the first toe in the water; this report, the accompanying literature review and its recommendations indicate that we are just at the tip of the iceberg of understanding the dynamics of disability leadership and civil society. Stigma and misunderstanding of disability and disabled people mean that some disabled staff will not yet feel safe to disclose their disability, or to share the discrimination and ableism they face in the workplace. Others are put in a position of being the voice for the entire disabled workforce, because their impairments are visible, and they are expected by non-disabled leaders and colleagues to provide this role. As such, this report can only be a snapshot of disabled leaders' experience in the sector.

> We are not delivering for members if we are not accessible.

We welcome ACEVO's openness to address some of the most pertinent and uncomfortable issues facing civil society. As we start planning for the future, we hope that this report will complement and speak to the recent **Home Truths** report and contribute to the momentum for change in the sector. We believe that ACEVO and its membership are key allies and advocates for moving this agenda forward in part because this is not just about an immediate solution but a long-term approach to shape and create the next generation of civil society leaders.

## 2.1 Definitions and terminology used in this report

The research, and therefore this report, follow the social model of disability in their approach. This is a conscious decision as the social model is the preferred understanding of disability by disability activists and disabled people's organisations in the UK.

> The voluntary sector reflects society ... it has no understanding of barriers. Frequently people talk about equality of opportunity rather than systemic oppression; most organisations' senior management lacked knowledge of the social model of disability and inclusion.

## The social model of disability

The social model of disability is the philosophical and theoretical approach which dominates how the disability sector in the UK understands disability and how disability fits into society. The social model of disability was developed by disabled people in the UK as a means of explaining the discrimination and barriers that they faced without blaming themselves.

Traditionally in the UK disability was understood from a medical perspective, meaning that disabled people were seen as the problem that needed to be fixed and were expected to normalise themselves via medical intervention in order to be able to access society.

Due to the disadvantages disabled people faced in UK society in the late nineteenth and early twentieth century the country saw a boom in charitable trusts and organisations set up to support disabled people in recognition of the obstacles they encountered. These organisations traditionally focused on disabled people as objects of pity in order to get donations from the public to run their services and interventions. Within the charity model of disability non-disabled people were seen as the experts in disability.

The social model of disability sees disability as a social construction which is caused by barriers in society which disable an individual with an impairment. These barriers fall into three broad categories:

- Environmental
- Attitudinal
- Institutional

Under the social model of disability everyone in society has a responsibility to remove barriers in order to achieve equality for disabled people. The social model of disability sees disabled people as having the same right to have a say in their lives as non-disabled people.

*taken from Todd (2018) Developing Inclusive Leadership in the Disability Movement: Lessons and Learning from Australia and New Zealand.

We are using the term civil society to cover charities, not-for-profit organisations, non-governmental organisations, social enterprise, user-led organisations and disabled people's organisations. Later in the report we will discuss the consequences of this definition in relation to disabled people's organisations. It is important to stress that disabled people do not necessarily work for, or want to work for, disability or health-related organisations. The findings and recommendations of this report are designed to encourage the **whole** sector to recognise, support and develop its disabled leaders and future leaders.

> "You end up being typecast as to where you are and where you should be as a disabled CEO... At the start of my career I looked outside the disability space for work but didn't get anywhere... As a disabled leader you are not seen as a whole person.

We use the Equality Act 2010 definition and the United Nations Convention on the Rights of Persons with Disabilities preamble to understand who is covered by the term 'disabled person'. Knowledge and understanding of these definitions vary massively. To support the research process, where needed we provided interviewees with these definitions. They are not without issue as definitions: however, they are commonly understood in the UK. The ways in which civil society defines disability will be explored further in the findings of this report.

## Disability definitions

### Equality Act 2010

'a physical or mental impairment which has a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities.'

### UN Convention of the Rights of Persons with Disabilities 2008

'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.'

Finally, we acknowledge that leadership, as a concept, has multiple and complex meanings and definitions. For the purposes of this report and for the research that we carried out to support it we are referring to leadership in the specific sense of governance and senior executive leadership positions, such as chief executive officers (CEOs) or directors in civil society. This makes sense for ACEVO, given its remit and role in supporting civil society chief executives. However, we also recognise that leadership happens at different levels across an organisation; this is one reason why initiatives to support and develop disabled employees need to be embedded throughout those organisations.

## 2.2 About this project

We were commissioned by ACEVO to help it understand how it could become more disability inclusive as an organisation. We also looked at what ACEVO could do to support disabled leaders, and the organisation's potential role in supporting wider civil society to be more disability inclusive.

> "What do we need to do to empower people to call out inaccessibility?

The organisation had already identified the lack of disabled leaders within its membership, staff team and board, and a desire to understand what the issues facing disabled leaders are.

It became very clear to us that to understand the issues we needed to talk to ACEVO staff and trustees, ACEVO members and disabled CEOs - both members and non-members of ACEVO.

Originally as part of the research we had anticipated also providing an anonymous survey, due to the known issues around disability disclosure in employment. However, world events meant that we were aware of both survey fatigue, and the very real trauma marginalised people are living with in the wake of both COVID-19 and recent murders of Black people in the US.

The purpose of this research is to provide ACEVO with a roadmap of how to become a disability inclusive organisation and a leading ally within civil society for disabled leaders. We also hope that this report will support a wider conversation about disability leadership in civil society and be the significant moment in recognising the existence and contribution that disabled leaders make to the sector.

This report has 3 sections:

- Emerging issues
- Taking action
- Recommendations for ACEVO

This document is also supported by a literature review exploring disability leadership in the voluntary and other sectors available **here**.

## 2.3 What did we do?

At the start of this project we set out to understand what was already out there in relation to this topic, explored through a literature review.

In addition, we sought to understand what are the key issues that affect how ACEVO and the sector address the underrepresentation of disabled people in leadership roles and staff structures. Our aim was to devise and develop tangible recommendations to bring about change.

In order to do this, we carried out semi structured interviews with leaders and staff at different levels, including:

- Key staff and board members at ACEVO
- ACEVO members who expressed interest in this project
- Civil society leaders who publicly identify as disabled, and are not members of ACEVO.

Interviews with internal staff were designed to help us understand the current situation within the organisation, and its own understanding of issues related to disability leadership and inclusion. ACEVO staff helped us to identify members who were interested in the project, as well as suggesting those who were not members. In selecting interviewees, efforts were made to ensure, where possible, a range of organisational types, geographical distribution and representation of intersecting identities of race and gender.

Over the space of five and a half months from March 2020 - August 2020 researcher Zara Todd conducted 10 anonymous interviews. All interviewees were asked to speak from their experience and to avoid hypothesising on behalf of others. While some interviewees were intentionally selected because they identify publicly as disabled CEOs, we chose not to require disclosure of impairments as part of the interview process in an acknowledgement of the societal stigma associated with disability, and reflecting the reality that many disabled CEOs and other staff do not disclose their disability status.

## 2.4 What is still needed

The lack of sector specific data around disability and employment is stark, both across the sector and within individual organisations. The **literature review** accompanying this report found that, from the 25 largest civil society organisations in England, publicly available information or reference to disability within the workforce was scant at best. Even organisations who had signed up to the government's Disability Confident scheme did not always publish comprehensive disability workforce data.

This clear data gap makes it extremely hard to tell even the basic size of the disabled civil society workforce, let alone issues of retention, career progression and effective programmes for staff development. Organisations should be encouraged to report on disability disclosure rates within their workforce, in the same way that they are compelled to report on gender-based statistics, and many are beginning to report on proportions and experiences of staff from Black, Asian and other minoritised ethnic groups. There is also a need for sector-wide data; the National Council for Voluntary Organisation's (NCVO) annual Civil Society Almanac reports on some protected characteristics of the sector's workforce, but disability is not one of them.

Official statistics may be able to help fill this national data gap, to some extent. However, a wider, anonymous workforce survey will be essential for developing a full understanding of how many and where disabled people are within the sector.

The anecdotal evidence gathered through the interviews suggests that disabled staff at all levels are hidden by the stigma and limited perceived benefit of disclosure. It is important that any data that begins to be collected does not just look at current leaders but also those at earlier stages in their leadership journey, because if there are limited numbers of disabled employees entering the sector the likelihood of addressing representation at leadership level is dramatically decreased.

> "Although I identify as disabled it is not something I would lead with as I don't want to be defined by it... I am going to get unfairly judged because people's perception of me will change and I have to think before disclosing: 'Do I risk it?'

Many of the interviewees raised the philosophical question of whether the lack of disability representation within ACEVO structures was reflective of the lack of disabled CEOs, a lack of disclosure or evidence that disabled leaders are deterred from engaging with, or unaware of, ACEVO. This is a question that will need further probing as future work develops.

> "[Disabled people as part of ACEVO's membership] "Is it because {disabled leaders} are few and far between in the sector, or are they not engaging with our service, or is it because we are seen as not a network for them?

Currently the corporate sector, through initiatives like Valuable 500 and Purple Space, is being more proactive and transparent about its ambitions for disabled staff than civil society. If charities and other organisations do not aspire to more with regards to disability inclusion, the sector will lose out on disability talent.

> "There is a lack of opportunities to link up with other CEOs.

# 3. Emergent issues

Across the interviews there were seven emergent issues that reoccurred, although perspective varied depending on the interviewees' personal experience of the issues shared. These issues provide us with key insights on entry points into the challenges of disability inclusion for ACEVO, civil society and disabled leaders themselves.

The seven key issues were as follows:

- A lack of understanding and/or confusion around who is considered disabled
- How civil society understands disability, and where disabled people's organisations and disability charities sit
- Stigma around disability and how it affects disclosure and employment
- The accessibility and relevance of ACEVO's offer to disabled leaders
- Sector and societal barriers which inhibit disability inclusion in the sector
- The capacity and confidence of civil society to meet the needs of diverse leaders
- Visibility of disabled leaders and the missed opportunity to learn from them.

## 3.1 Who are disabled people?

Although there are the legal definitions of both the Equality Act 2010 and the United Nations Convention on the Rights of Persons with Disabilities, discussions about this project and during the interview process have demonstrated that there is still widespread confusion and misunderstanding around who can use and may be covered by the term disabled.

Many people are unaware of the use of the word disabled as a political identity and still conceive it negatively to do with limitation. This confusion leads to underreporting and under disclosure which means many disabled leaders don't realise their rights or reach out for support.

The confusion around who are disabled people also leads to a distinction between disability and mental health which exists in wider society and while there are distinct challenges for those with mental health impairments/conditions the distinction also makes it harder for many to understand the legal protections they have.

> "We don't have a good idea of what disability is beyond a wheelchair user, in the sector we don't connect mental health and disability.

During the interviews it became apparent that the lack of understanding of who is covered by the term disabled person - both by individuals who could identify, organisationally and in the sector - is detrimental to challenging the underrepresentation and inequality that exists. In addition, the confusion over who is covered by disability as a protected characteristic has inadvertently led to the perpetuating of hierarchies of impairment (see box on page 11).

The uncertainty around who is covered has consequences for the disclosure of needs and the understanding of who the population of disabled leaders are. Many leaders with hidden impairments are driven to either assimilate - to the detriment to their well-being - or feel obligated to justify and explain needs to a greater degree than their visibly disabled peers. It also presents challenges for the sector around ensuring that access needs are met; it is easy to see if a wheelchair user can't get into an event, however if the leader is in chronic pain because appropriate seating has not been provided that can often be hidden.

> "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.

During the interview process the confusion surrounding who are disabled people led to a dominance of leaders with visible impairments and adjustments being disproportionately named. This does not help the disclosure of disability or celebration of disabled leaders in the sector, as statistics suggest that 70% of disabled people have hidden or non-visible impairments.[7] Very few of the leaders named during this research project had hidden impairments, and people's understanding of needs was disproportionately weighted to physical interventions. This may be also indicative of lack of knowledge and understanding of what reasonable adjustments might be for those with hidden impairments; for example the provision of quiet rooms, microphones and seating. The fixation on disability as a visible thing can also pigeonhole visibly disabled leaders into only being asked to talk about disability.

## The hierarchy of impairment

The hierarchy of impairment is a social construction which operates consciously and subconsciously to place different impairments in opposition to one another in a hierarchical structure. In simple terms, this might look like someone being judged as 'more disabled', or 'not disabled enough', when compared to others. The hierarchy of impairment has no basis in lived experience and does not reflect the day-to-day reality of any individual. However its existence is used to exclude certain groups from accessing support and can lead to internalised oppression around someone's right to support.

The hierarchy of impairment perpetuates negative stereotypes, dependency and exclusion from support. The hierarchy of impairment also feeds into negative stereotypes that appear in 'inspiration porn' style communications: those which emphasise the individual overcoming adversity, rather than the structural barriers created by an ableist society.

Traditionally people with so-called 'high status' impairments - such as visible mobility needs, being deaf or being blind - are considered to be disabled and heavily impacted in their day-to-day lives. People with so-called 'low status' impairments – such as hidden disabilities, chronic pain, mental illness or neurodivergence - often have their disability status questioned or undermined.

7 https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/brookes-NUJ-Hidden-disabilities-Report-plus-Lena.pdf

## 3.2 The dynamics of disability in civil society

Disability and serving the needs of disabled people is a dominant theme in civil society and has been part of many organisations' charitable purposes. For many people who grow up with or acquire impairments charity can be quite a dominant force in their lives. There are a lot of reasons for this which are beyond the scope of this report; however the dynamics of charity and its relationship to disabled people have significant consequences for disability leadership in civil society and how disabled leaders in the sector see themselves.

### The charity model of disability

This is one of the more traditional approaches to viewing and approaching impairment and disability. The charity model of disability gets its name from the way in which charitable interventions traditionally perpetuated the concepts of vulnerability and helplessness, and have perpetuated the negative perception of impairment in society. The charity model of disability prioritises non-disabled experts, protectors and decision-makers over disabled people's lived experience.

Historically, often using pity and perpetuating negative stereotypes in order to raise funds, or service delivery models that have sidelined the views and wishes of their service users, or in the worst cases perpetuated harmful systems and approaches, charitable models have not seen disabled people as actors in their own lives. This has led to the dominance of non-disabled people speaking on behalf of disabled people.

This is not to say charity doesn't play an important role in disabled people's lives. However, many disabled activists in the contemporary context feel that charities are doing the work of and covering the deficit of the state's inability to meet disabled people's basic rights, instead of campaigning for them to do so.

Additionally, many disability activists see charities as benefiting from disabled people's oppression and therefore not necessarily working for the benefit of disabled people, but for the perpetuation of their own existence. This criticism may be particularly levelled at charities taking on government service delivery contracts.

Currently the vast majority of 'out' disabled leaders in civil society are associated with disability focused charities or disabled people's organisations. As part of this research we tried to identify disabled leaders in civil society who were not associated with disability work and we struggled. A number of the disabled leaders we spoke to, both those 'out' and those who do not publicly identify as disabled, spoke of the frustration of being pigeonholed in disability-related roles and organisations, and not having the same career options within the sector.

Simultaneously, for many disabled leaders, civil society is something they choose to dissociate from because of the problematic history of power between disability focused charities and disabled people. The charitable model of disability is widely rejected by the disability community because of its ability to perpetuate oppressive attitudes and structures that many disabled people experience. The rejection of the charitable model of disability by politicised disabled people creates tension and friction when trying to group disabled people's organisations in the category with organisations that they see themselves as being in opposition to.

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

This is further complicated by the ambiguity and inconsistency with which the term 'user-led' has been applied within civil society. The phrase is sometimes used to refer to the group directly affected by an issue. It is also sometimes used in a way that is inclusive of those who are affected by association, such as parents, carers and family members, which fails to recognise the distinct voice of the affected individual. In some cases, this can reproduce paternalistic structures that disabled people have consistently fought against; the views and opinions of parents, carers and others are taken to represent the views and opinions of those more directly affected. While carers and others face their own unique challenges and issues that should be represented clearly, this cannot substitute for the voice of disabled people themselves.

Taking these complex issues together, this means disabled people's organisations tend to see themselves as distinct from the voluntary sector while simultaneously being viewed externally as being part of it. 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.

This presents a challenge for infrastructure bodies such as ACEVO in trying to be open and accessible to disabled leaders who are turned off automatically by the language inherent in voluntary sector spaces.

> I have worked in DPOs [disabled people's organisations], not charities or the voluntary sector.

Disabled people's organisations by their very nature tend to be run by politically identifying disabled leaders. There isn't a consistent understanding within the community of what constitutes a disabled people's organisation beyond "an organisation run and controlled by disabled people". Furthermore, there is disagreement both in the UK and internationally, as to what percentages are required to achieve the definition. For example, some organisations will describe themselves as disabled people's organisations when they have 70% of the board and 50% of the staff politically identifying as disabled people; others define a disabled person's organisation as 100% of the board and 50% of staff; and there are numerous definitions in between this.

> I wouldn't be in my role if I didn't politically identify as disabled - as a CEO I am advocating for my community and systems change ...

As mentioned at the start of this section, disabled leaders in civil society disproportionately tend to be associated with disability-related organisations. However, it is worth noting that DPOs themselves struggle with finding chief executives and directors who identify as disabled and have the requisite skills to keep organisations running. This will be touched on further in sections on disability inclusion in the wider context, and capacity and confidence. Disabled people's organisations could really benefit from the sector as a whole supporting and developing disabled leaders and the support available for professional development through infrastructure bodies such as ACEVO.

> If the culture of CPD [continuing professional development] is not embedded, you don't think about what support you need as the CEO.

The consciousness that is currently being raised in civil society through campaigns such as Charity So White and the need for and effectiveness of organisations led by people of colour has the potential to offer some learning. This also potentially offers a more comfortable space for disabled people's organisations to sit alongside organisations led by other systematically oppressed groups. This could also encourage recognition of intersecting oppression, and the specific, often unheard voices of Black disabled people. As highlighted by the Home Truths report, issues of racism and representation in civil society are only just beginning to be acknowledged. However the route forged by this work may support the development of a sector which is more inclusive of disability – and people who are multiply marginalised - as well.

Many of the disabled leaders we spoke to were excited at the prospect of working at the intersections and learning from the progress that Black and brown-led organisations have been making in this space. A number of the leaders spoken to as part of this project identified as Black or brown as well as disabled and reflected on how the experience of this intersection heavily impacted their experience as disabled leaders. Although co-operation and collaboration between lived experience-led organisations is viewed as beneficial by many, it is important to acknowledge and address the racism that exists within the disability movement and within disability-focused organisations at the outset of this collaboration.

> COVID and the Black Lives Matter movement show the need for inequality groups to support each other.

This desire to work intersectionally presents infrastructure bodies such as ACEVO with an opportunity to play a supportive role in this kind of collaboration, due to their reach.

## 3.3 Stigma and disclosure

Lack of disclosure and its relationship to stigma around disability came up in almost every interview. As mentioned at the start of this report there is a considerable gap between the prevalence of disability in society and what we know about representation of disabled people in the workforce of civil society.

> It can be impossible to disclose disability because it feels so risky in a sector where there are very few visible leaders.

As highlighted in the literature review, disclosure of disability as a protected characteristic is a significant issue across employment regardless of sector. Underreporting is endemic and, in and of itself, continues to perpetuate the problem. If you do not see people like yourself in your workplace or in the leadership team, how do you know you will be accepted for who you are and what you need? Given the negative perception of disability in society and the systemic discrimination faced by disabled people, workplaces need to make significant, visible efforts to ensure employees feel safe to be their whole self. Simultaneously, for those who cannot hide the disclosure because of visible impairments, how workplaces speak about and respond (or fail to respond) to their needs is often an indicator of whether it is safe or of benefit to disclose to those with hidden impairments.

> 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.

Munro's 2019 **blog series** around diversity in the charity sector is an indication that the sector is struggling to be inclusive, nurturing and respectful to many marginalised staff, including disabled staff. The prevalence of stereotypes around what impairment means for productivity and capability in the workplace, combined with stereotypes and expectations around civil society chief executives somehow being 'superhuman', can make disclosure even harder.

> 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.

In order to increase disclosure, more needs to be done to challenge the societal view of disability and impairment as solely a deficit identity. If the person is presented as the problem rather than societal factors, individuals will not choose to engage in any negative construction of themselves. The social model of disability which places the emphasis on society to change rather than the individual is key to increasing disclosure because it reframes why someone is disclosing. Rather than to highlight potential deficits, negative impacts or needs, disclosure becomes about having needs met so that you can excel in your job.

> There is a hidden versus visible impairment difference to disclosure. When you have visible impairment, you don't have a choice about disclosure but that puts pressure on you because you don't want to look like a failure.

The consequences of disclosure in the sector as it currently stands leave many disabled leaders feeling pigeonholed or trapped in working for organisations related to their identity. 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.

> 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.

Another issue that emerged in the interviews around disclosure related more to the role of CEOs as managers. This has knock-on effects for disclosure at different levels of the organisation, individuals' ability to stay in their job and to progress, and therefore disability inclusion. Many of our interviewees identified working with and managing staff with health conditions and impairments who either minimised their needs, rejected the disability identity or didn't know what they needed in the workplace to thrive. This presented considerable challenges in terms of wanting to be supportive whilst not having the tools or knowledge to manage that person and their needs. Creating and facilitating workplace cultures that recognise and value talent, support and celebrate disabled colleagues appropriately, and challenge negative stereotypes where necessary, are key steps in creating a more inclusive sector. Employees at all levels need to be supported to recognise and raise their needs without fear of stigma or discrimination, and signposted to appropriate information on what adjustments might be useful to them, rather than seeing this as a problem with that individual. While there are many reasons for non-disclosure, an unintended consequence can be depriving managers of the support they need to realise inclusion. On managing disabled staff:

> I didn't know how to support her and she didn't know what she needed. There was nowhere to go to ask for help.

This is heavily connected to the confusion that surrounds who disabled people are, because if somebody doesn't understand who is considered disabled by law, they may struggle to know whether that term applies to them in order to disclose.

One way to look at enhancing disability inclusion in the sector is to consider whether the conditionality of disclosure is really required in order to make things accessible. If we plan for and anticipate diverse leaders attending events and other engagements with the organisation, then both the need for disclosure diminishes while simultaneously supporting more people to access the space. This does not mean covering specific, technical needs even if they have not been flagged as required, but rather simple measures such as ensuring venues are accessible and including accessibility information as standard, providing quiet rooms, ensuring clear routes to entrances, exits and facilities, and including recording and closed captioning for online events as standard.

## 3.4 ACEVO's offer for disabled leaders

The majority of the interviewees for this project had some connection to ACEVO. This was inevitable given the small scale of this project and the desire to speak to staff and board members as well as members themselves. It is notable that of the six politically identifying disabled leaders interviewed in this process only two were members of ACEVO. Of the remaining four politically identifying disabled leaders interviewed, only one was fully aware of what ACEVO was and did.

> I've had next to no formal or external support [for my role as CEO], however I have had amazing peer support relationship from other leaders of DPOs.

When disabled leaders had the role and offer of ACEVO explained them, they unanimously saw the value in the organisation and the potential support the organisation could offer them as individuals both currently and throughout their leadership career.

The lack of understanding of what ACEVO does felt challenging for many disabled leaders working in organisations under great financial strain, as justifying the membership fee to your organisational governance board is hard if you don't understand what you and your organisation are going to get out of the spend. Many of the interviewees indicated that they wished there were taster options to give disabled leaders tangible experience of membership benefits so that they could justify the costs.

> As a disabled leader and being new to the role joining something like ACEVO felt like too much.

For those disabled leaders who were familiar with ACEVO or already members a key issue that was highlighted was not seeing themselves in how ACEVO communicates what it does or its working priorities. One interviewee identified having considered ACEVO to support their leadership journey and having concluded that there was no one like them to be mentored by so there wasn't any point in seeking the opportunity, because the mentor would likely not understand their reality.

> I've looked at several leadership programs including ACEVO and the mentors don't reflect my experience and therefore would lack knowledge to support my journey.

While a number of people noted recent attempts to platform disabled speakers at events, they expressed frustration that the speakers were only ever seen in relation to disability inclusion rather than wider topics where CEOs held expertise.

> It would be great if ACEVO could create space for disabled leaders to be heard.

> Platform disabled leaders talking on leadership not because they are disabled but because they are good leaders. However it is also important to recognise the skills and assets disabled leaders develop to survive.

From both staff and members there was a strong feeling that the organisation's approach to disability inclusion is reactive rather than proactive and there was a sense that things were only accessible because people asked rather than being pre-emptive. That being said, the disabled leaders who had experienced ACEVO's approach to meeting adjustments had nothing but praise for the quality and dedication the organisation showed in meeting expressed needs.

> My experience of ACEVO is they are great, they listen... For me it's about effort not perfection.

While this is perhaps to be expected given the small-scale and means of selection around this research, all interviewees familiar with ACEVO spoke of seeing disabled leaders and reasonable adjustments at organisational events. This is perhaps an area where an anonymous survey would be particularly useful in understanding if anyone is currently feeling excluded from ACEVO's activities. Some of the interviewees not familiar with ACEVO expressed a degree of trepidation around the organisation's ability to be inclusive to them which suggests that the organisation needs to work on communicating its accessibility offer and approach externally as this may increase take-up of membership by disabled leaders.

Of the ACEVO staff and board members interviewed, many struggled to identify work that ACEVO had done in this area in the main part due to the misunderstanding of where mental health conditions fit in with disability. Some staff did describe ACEVO's work around mental health and wellbeing, but did not associate this with disability.

There was excitement both from staff and disabled leaders at the possibility of what an offer opportunity within ACEVO could do if tailored specifically to the needs of disabled leaders. Many of the disabled leaders felt that they could benefit from being in contact with other leaders in order to share experiences and find solutions.

All parties emphasised that any offer needs to be based on the needs of disabled leaders, which should be established through co-production. In order for this to be achieved meaningfully and in a way that is non-exploitative, there may need to be some reimbursement of time.

> ACEVO needs to co-produce their offer with disabled leaders and they need to fund the process to ensure those leaders can be at the table.

Some of the issues that were identified as being specific to disabled leaders were

- The barriers and discrimination experienced in the sector and how that affected people's roles.
- The challenges and opportunities that come from having to manage your own access needs while leading an organisation.
- The fact that many disabled people-led organisations are small and flat with high expectations of their CEO and the functions that they are required to perform while simultaneously having limited opportunities for CPD and progression.
- The question of how you create reasonable adjustments for yourself when that is something that you hold organisationally.

The disruption caused by COVID-19, whilst negatively affecting access for many disabled people, does also present an opportunity for ACEVO and other infrastructure bodies to seriously consider what accessible engagement looks like both virtually and face-to-face. For example, when face-to-face meetings are possible again how could videoconferencing and live streaming be integrated in a way that allowed for interactive participation remotely.

## 3.5 Realising disability inclusion in civil society workplace

Leadership is not something that happens suddenly overnight. It is something that is developed over time and through experience, so when we are looking at how to support disability inclusive leadership it is essential to consider people's journey to leadership positions and how that may support or hinder future disabled leaders.

Evidence found in the literature review accompanying this report shows that civil society is making progress by having positive statements about employing disabled and diverse candidates. However, the literature review also found that there was limited information about the retention and progression of disabled staff.

> "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.

An area of inquiry in our interviews was where our interviewees got support around disability inclusion and inclusive practice. Many of the disabled leaders turned to peer support in order to negotiate this. However, many identified having to learn on-the-job rather than having access to learning and support on the topic. For the 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', with the awareness of not wanting to do things that could lead disabled employees to leave. This is challenging because not doing anything out of fear when there are considerable barriers and underrepresentation has the potential to perpetuate issues rather than solve them.

All staff in organisations should be given training and support to understand and become actors in creating more inclusive and nurturing working environments.

> "Championing disability leadership is not about a strapline on a website, but how leaders talk about disability.

In fact, a number of interviewees identified concern about instances in their career where they felt out of their depth with regards to supporting disabled staff, and they were reflective on how this affected both themselves and the staff members. In some instances, not having access to explicit support and tools around disability inclusion had led to organisations losing disabled talent.

A number of interviewees identified uncertainty about what reasonable adjustments and being supportive of disabled colleagues meant in practice, and didn't feel like there were independent spaces to get information or advice.

> "It would be great if the [ACEVO] helpline staff were specifically trained in disability inclusion and particularly managing disabled staff.

A number of interviewees identified using ACEVO's helpline to get support around management issues but feeling uncertain as to whether ACEVO's helpline staff would have the knowledge or expertise to deal with a case with a disability dimension.

Current civil society leaders have a key role to play in realising disability inclusion in the sector; the behaviour and approach of current leaders has reverberations for decades. Many of the disabled leaders that we spoke to identified the impact of early career experiences in shaping how they understood their identity and career options. This includes seeing role models that people identify with, as well as whether disabled people find themselves offered the same opportunities as their non-disabled colleagues. Some research from other sectors, identified in the accompanying literature review, suggested this did not always happen.

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

Finding your way to leadership can be particularly intimidating if you do not see people like yourself or with your experience in leadership positions. Many of our interviewees spoke of feeling impostor syndrome, expectations of failure and taking longer to understand their own leadership value because there weren't mentors or leaders like themselves in the space. This feeling was particularly pronounced for Black and brown disabled leaders where they were dealing with multiple and intersectional oppressions.

> "When I started as the CEO most of the spaces, I went into were full of white privileged males.

Creating a culture of openness and understanding around disability takes conscious effort and tangible actions which are consistent and upheld. The publication of something like an organisational manifesto, or commitment to action, on inclusion may help in communicating both the actual and aspirational desires of organisations to include disabled leaders. A manifesto should be given to all staff, regardless of known disability status, and might cover:

- Principles which guide the organisation's work.
- How to request an adaption or adjustment.
- Transparency about how and when that will be made.
- Relevant information about organisational targets around disability inclusion.
- What disabled people can expect if interacting with the organisation or disclosing needs, including the availability of alternative communication methods and formats.

The introduction of **wellness action plans** in the workplace, to help actively support employees mental wellbeing, can also help staff understand what is available and understand how to support one another positively in the workplace.

Due to the limited number of disabled people working in civil society, especially outside of disability orientated organisations, disabled staff can find themselves having to assimilate, often compromising access needs, or having to lead organisational change, in addition to their employment, in order to be able to do their job. Both options often leave disabled employees with limited time capacity to engage in standard continuing professional development (CPD). It is important that the additional energy that

disabled staff use in order to remain within civil society is acknowledged and that disabled staff are given the opportunity to grow and develop skill sets outside of basic survival. All of the interviewees highlighted the challenges that are inherent to being a civil society CEO; aspiring disabled leaders will not be oblivious to these challenges. However, 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.

> “There can be internalised oppression compounded by external perception that leaves you [as a disabled CEO] to wonder am I worthy of this role.

Thanks to the few trailblazing disabled leaders we do have in civil society, we are hopefully at the point where we do not have to repeat the experiences of many of the interviewees. However, for that to happen we need to have a concerted effort by the sector to acknowledge, celebrate and platform disabled leaders in all areas, not just in relation to diversity.

### Disability Justice - what is it?

Disability Justice is an approach to understanding disability which emerged from the United States in the late 2010s, developed by predominantly queer disabled people of colour at Sins Invalid.

It was developed in recognition that disability theories to date were still failing to include and acknowledge those who experienced multiple oppressions. Therefore a model centred solely around disability perpetuates inequalities within the disability community.

Disability Justice has 10 underlying principles which if followed aim to liberate people's whole selves and celebrate diversity and disability whilst embedding accessibility. While the movement is growing, it is relatively unknown in the UK currently.

## 3.6 Learning from disabled leaders

The social model of disability and the empowerment that comes from it gives many disabled leaders the opportunity to acknowledge and celebrate the additional life skills and talents that they gain from lived experience in a in a society not designed to include them. Many of the skills needed to successfully navigate life with an impairment are also transferable skills which are beneficial as leaders and CEOs, particularly in civil society. For example, the ability to problem solve, adapt and create new ways of doing things, and managing lots of people are all things that many disabled people have to do on a daily basis which also allow civil society leaders to excel. Currently, the opportunities for non-disabled leaders to learn from disabled leaders and disabled leaders to learn from each other are slim; disabled leaders are rarely asked to talk about innovation, people management or managing governance structures. Instead there is a focus on storytelling and talking about the barriers and solutions to the sector's and society's issues around diversity. In the interviews some of the disabled

leaders we spoke to felt frustrated that they weren't given opportunities to talk about financial procedures, fundraising or human resources in the context of being around other CEOs.

> [Civil society] perpetuates hierarchy of identity and [as a disabled leader if you are out and/or visible] you are forced to put disability first and put your expertise in a box.

Interestingly, when we asked interviewees to identify current civil society disabled leaders, they identified people based on being visibly present in spaces rather than because that person had done an interesting podcast or written an interesting article. It is essential that if civil society is to achieve its rhetoric around inclusion and diversity that those from diverse backgrounds are given the space to shine and share as leaders rather than being decorative diversity.

> Disabled leaders need more allies in the sector, but as allies we should not expect those who are experiencing discrimination and oppression to educate us all the time. There are already resources out there like blogs and podcasts.

Many of those that we talked to saw the value in having a protected space for disabled leaders, and lived experience leaders more broadly, to get peer support from one another and share learning. As stated earlier, organisations like ACEVO and other infrastructure bodies are well placed to facilitate both connections between leaders within the field, and opportunities for intersectional and inter sector learnings.

In addition, ACEVO's role within the sector positions it well to platform disabled leaders and provide the support many of them are desperately seeking. Working alongside disabled leaders ACEVO has the potential to create connections and promote high quality technical advice.

Finally, through celebrating disabled leaders and the diversity of skills they bring to civil society, ACEVO also has a key role in supporting the career pipelines of the next generation of disabled leaders. Research has identified the importance of relative role models for aspiring leaders; organisations like ACEVO can help to identify and promote these.

> If we want more disabled CEOs, young disabled people need to see disabled people in leadership positions.

## 3.7 Capacity and confidence

Disability inclusion cannot happen accidentally; it requires deliberate and proactive measures. Exclusion is difficult to see because it requires people to consider who is not in the room and why they might not be there. Exclusion itself places the burden of getting involved on the person being excluded, whereas inclusion is something that requires everyone's commitment to achieve. Inclusion requires communication and accountability in order to be successful but when it is achieved, not only does it benefit the individuals but also the community as a whole.

> How can you develop and empower people if you don't even have the capacity to develop yourself?

Disabled leaders, like all civil society leaders, are under great deal of pressure and their time is limited. However, as stated, an additional challenge facing disabled leaders is that the majority of disability-led organisations are flat and small due to lack of organisational funding. This means that there are even more pressures on disabled leaders' time and also less progression routes to enable more disabled leaders to progress. The rest of civil society could play a fundamental role in helping to strengthen capacity and build disabled people's organisations by providing career opportunities for potential disabled leaders where structures are less flat. This would also assist the wider civil society by creating more connection points with disability led organisations.

> 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.

Inclusion is always a learning process but civil society is not starting from a blank page; there is already good practice and experience in D/deaf and disabled people's organisations.

In addition, simple things such as statements about commitments to diversity and inclusion followed up by access need questions and named contacts demonstrate easily that you intend to carry through on your principles into action.

# 4. Taking action: how can the sector support disabled leaders?

Reflecting on what disabled and non-disabled leaders and other staff told us during this research, we recognised that organisations are at very different starting points in their journey to become an inclusive organisation. Alongside individual organisational action, we also think there are actions the sector could start to take collectively, to help break down the stigma, prejudice and poor practice which stops stop organisations being able to make the best use of talented disabled leaders.

> “It’s worse for CEO roles to disclose disability...you don’t want to be tokenised as the disabled leader.

> “There is no culture of take-up of CPD in disabled people’s organisations and until you try you don’t know the value of it.

With this in mind, we have produced a series of actions individual organisations can take, which over time can add up to sector-wide change. We know that this change won’t happen overnight, and that some organisations will have to get some essential building blocks in place first. We are mindful of the resources necessary to achieve this change too. Many of them will take significant investments of time and money. Creating a sector that values, supports and develops disabled leaders is long-term work, which will need to address and overcome decades of entrenched ableism, and the actions reflect this. However, many of the actions are not resource-intensive, and a more inclusive sector will bring considerable benefits to the workforce as a whole.

The actions begin with building the basics, including understanding what the disabled workforce looks like. They then look at actions and needs for the wider sector, and for future disabled leaders. We have split actions into three progressive changes, to help organisations think about building an inclusive organisation as a journey. These stages are:

1. Inclusive foundations
2. Building good practice
3. Leading the way

The tables below cover seven areas of an organisation, and can be used as a light-touch audit tool to assess what stage the organisation is at, and what more it might need to do.

The number of actions we have suggested reflect the early stage we believe the majority of the sector is at. Some organisations will not be ready to take all of the actions below, but can build up to them once they have the basics for supporting disabled leaders in place. Some organisations, particularly those with low numbers of employees, may also find that it is impractical or inappropriate to engage

in some of the monitoring processes described below. These actions provide a guide, rather than a prescription; there are actions all organisations can take to play their part in improving the sector as a whole. What is important is that action is taken in order to create real change.

> As a leader I need to look outside my organisation [to get support on disability inclusion]. I need a safe space to explore and understand disability and what it means to be inclusive.

| 1. Inclusive Foundations | | Is this in place yet? | What more do we need to do? |
|---|---|---|---|
| Knowledge and data | • Have clear information available for staff around reasonable adjustments and the Access to Work programme, including at recruitment, induction and appraisal stages. | | |
| | • For larger organisations, collect data about rates of disability disclosure, retention and job satisfaction, to understand the size of the internal disabled workforce, and to flag any early issues. | | |
| Approach and ethos | • Adopt the social model of disability/ human rights model of disability into organisational practice and make this clear in relevant internal and external communications. | | |
| | • Create an organisational disability inclusion and accessibility manifesto or statement of commitments and promote to all staff. | | |
| Access | • When running events for civil society provide all attendees with access information about the event and an opportunity to share their access needs. | | |
| | • Where access adjustments have been invested in and can be shared without detriment to the requesting person, for example the provision of quiet rooms at events, share with all event attendees or service users, rather than just the requester, so that disclosure of access needs is not always necessary in order to benefit from the adjustment. | | |
| Policy and procedure | • Conduct a policy review to ensure that all policies and procedures in the organisation are anti-oppressive, non-exploitative and supportive of disabled people. For example, if you have a social media policy make it mandatory to make social media content accessible. In addition, have a clear and transparent:<br>a. Reasonable adjustment policy<br>b. Disability leave policy<br>c. An induction policy and process that provides explicit space for employees and board members to share access needs and reasonable adjustment requests | | |

| | | | |
|---|---|---|---|
| Policy and procedure (cont) | • Target and design recruitment materials to disabled candidates, with explicit mention of reasonable adjustments, flexible working and wanting a representative workforce. | | |
| | • Consider the adoption of workplace wellness action plans [8] | | |
| Training, learning and development | • Provide disability equality training for all staff and board members and ensure that it is part of any new staff member's induction. | | |
| Representation | • Ensure that all materials, including the website, reflect the diversity of the organisation's membership or service users, including disability. | | |
| | • Ensure materials produced have basic accessibility features such alt text, plaintext, transcription and closed captioning. | | |
| | • Produce materials and stories which show civil society as a viable place to succeed as a disabled person. | | |
| Working at the intersections | • Ensure that an intersectional approach is taken to support offers, and avoid conflicts that require individuals to prioritise an identity - for example, not holding a black caucus at the same time as a disabled caucus. | | |

8 https://www.mind.org.uk/workplace/mental-health-at-work/taking-care-of-your-staff/employer-resources/wellness-action-plan-download/

| 2. Building Good Practice | | Is this in place yet? | What more do we need to do? |
|---|---|---|---|
| Knowledge and data | • Develop a standard expectation that disability data will be shared in annual reports by all large civil society organisations. | | |
| | • Actively engage the workforce and beneficiaries in discussions around reasonable adjustments and adaptations, especially in induction processes. | | |
| Approach and ethos | • Review what it would take to move your organisational practice from a social model approach to a disability justice approach. | | |
| | • Have measurable targets as part of an organisational inclusion and accessibility manifesto or strategy, and carry out annual reviews around implementation. | | |
| Access | • Carry out access audits of activities and venues and have a basic minimum access standard which all of your activities adhere to. | | |
| Policy and procedure | • Annually review all policies and procedures to ensure that they align with current best practice around access and inclusion. | | |
| | • Operate a guaranteed interview scheme for candidates who meet the essential criteria of jobs who identify as disabled. | | |
| | • Have established policies and procedures in place for reasonable adjustments, which support requests and include deadlines for implementation. | | |
| Training, learning and development | • Annually set aside staff development time to explore issues around disability inclusion. | | |
| Representation | • Ensure there is disability representation in all events, and that representation is not tokenistic and representative of the diversity of the disabled community. | | |
| | • Develop leadership potential pipelines that recognise and harness the skills gained by lived experience. This includes mentoring from those with lived experience. | | |
| Working at the intersections | • Run activities that are aimed at disabled people who have additional protected characteristics such as events or forums for disabled people of colour or disabled women. | | |

| 3. Leading the Way | | Is this in place yet? | What more do we need to do? |
|---|---|---|---|
| Knowledge and data | • Large organisations should produce dedicated annual workforce diversity reports that explore employment issues for disabled employees, identify any problems and include action plans for improvement | | |
| | • Create and engage in cross-sector discussion and learning groups to learn and promote best practice for inclusive employment from business, the public sector and civil society. | | |
| Approach and ethos | • Develop and monitor an organisation-wide strategy for embedding Disability Justice as an intersectional approach. | | |
| Access | • Choose venues and activities based on accessibility as a key criteria | | |
| | • Where venues and activities fail to meet your criteria engage in dialogue to improve access and, if partners are unwilling, cease using services. | | |
| Policy and procedure | • Commission independent reviews of policies and procedures to ensure they are promoting disability equity | | |
| | • Go beyond the minimal legal requirements around reasonable adjustments and work with staff and other stakeholders to define organisational adjustments which are available without disclosure. | | |
| Training, learning and development | • Include actionable objectives around disability inclusion for consideration in appraisals and performance reviews. For example for a manager an objective might be to inform all staff about the access to work scheme and the organisation's reasonable adjustment policy, or if a member of staff is working on communications, ensure all content has alt text and captioning. | | |

| | | | |
|---|---|---|---|
| Training, learning and development (cont) | • Invest in developing the skills and experience of disabled staff including additional continuing professional development opportunities in acknowledgement of the systemic barriers disabled people face in accessing learning opportunities. | | |
| Representation | • Ensure that disabled leaders are visible in activities and events - particularly on issues not related to disability | | |
| | • Employ and retain disabled leaders at the forefront of the organisation both in staff and board. | | |
| Working at the intersections | • Embed an intersectional approach to organisational working through policy and procedure, and measure and report on intersectional grounds | | |

# 5. Recommendations for ACEVO

This report was commissioned by ACEVO, with recognition that ACEVO itself can and should be a part of creating a more inclusive civil society sector. To this end, we have produced a number of recommendations specifically for the organisation based on the interviews conducted with disabled leaders for this project. These include ways to change ACEVO's own working, and opportunities to promote new initiatives or better practice in the wider sector. ACEVO can also use the tables above to assess its own internal practice.

These recommendations are split into three sections. The first section offers suggestions as to how ACEVO can build a more diverse and representative membership base. The second looks at ways in which ACEVO can support its membership to develop inclusive practice. The final section - strengthening the sector – recognises ACEVO's role in influencing and shaping civil society as a whole.

As above, the number of recommendations reflects how early we are in this conversation. But it is clear that organisations, including ACEVO, need to take decisive action, to collectively build a sector that supports all leaders adequately.

This does not mean doing everything right all at once. Indeed, change needs planning, resourcing and discussion with others, all of which takes time. This is long-term work requiring a sustained commitment, that will bring considerable benefit to civil society.

### Increasing disabled membership of ACEVO

- Carry out marketing activities targeted at increasing disabled leaders' membership, including ensuring that all recruitment material is available in a variety of accessible formats.
- Provide free time limited access to certain member benefits, to leaders with protected characteristics to enable them to understand what the organisation's offer is and to communicate that to their own board.
- Consider offering an enhanced associate membership for aspiring leaders with protected characteristics, including disability.
- Create a specific offer for disabled CEOs, and ensure it is possible to access elements of the offer confidentially or without disclosure, while also normalising disclosure.
  This might include:
    - Co-producing an ACEVO disabled leaders offer with disabled CEOs, ensuring that they are remunerated in a way that facilitates participation - for example offering a certain number of months' free membership, payment or free CPD opportunities
    - Creating a network for grassroots leaders from marginalised backgrounds to come together to support each other
    - Incentives or benefits such as discounted membership to encourage disclosure of disability by ACEVO members.
- Check annually with ACEVO members to give them the opportunity to update their data and access needs.

## Supporting ACEVO's membership to be more disability inclusive

- Produce or promote existing materials and resources which support CEOs, leadership teams and human resources departments to understand what is meant and required in law under reasonable adjustments.
- Ensure that all helpline staff are trained to respond to disability-related queries or, as a minimum, are able to signpost to appropriate alternative support.
- Provide templates so that organisations can develop their own access and inclusion manifestos, and capture and share appropriate disability workforce data.
- Produce materials for members on how to avoid tokenism and 'inspiration porn' when recognising and celebrating disabled staff.
- Support the sector to develop an understanding of the transferable skills which are developed as a direct result of disability so they can acknowledge, support and recruit candidates and staff with potential and skills developed through non-traditional means - for example, the skills that come from managing a care support package.

## Strengthening the sector

- Carry out an anonymous survey of disabled employees' experience to understand how big the issue is and what are the key push and pull points that drive disabled staff in and out of civil society.
- Carry out more in-depth research into the barriers faced by disabled leaders. This might include:
    - Disability disclosure
    - Knowledge and understanding of the benefit of ACEVO membership amongst disabled leaders
    - Access to continuing professional development opportunities for disabled leaders.
- Work with other sector infrastructure bodies to establish a State of the Sector's Workforce report annually for the next five years, including capturing quantitative and qualitative data on the experience of marginalised employees.
- Work with other infrastructure bodies and experts to consider how disability and other protected characteristics can be represented in existing civil society workforce research and data, such as the Civil Society Almanac.
- Produce materials with user-led organisations to help the sector and society understand the difference between user-led organisations and 'organisations for' disabled people.
- Produce case studies, interviews and podcasts which feature and celebrate disabled leaders in civil society, including material on management issues not related to disability or other identities.
- Develop materials that help aspiring and future disabled leaders progress their careers.

# 6. Conclusions and next steps

The findings from interviews and further research generated from this work show that there is still a long way to go for civil society around both disability leadership and disability inclusion in general. The lack of quantitative data available shows that we need more data, research and discussion if we are going to help civil society live up to its values and benefit from the expertise of disabled people.

The actions for civil society in this report aim to provide the foundations for the sector to grow and become more inclusive, but also providing the skills and information to truly hold the sector to account for the gap between its values and its practice. The recommendations for ACEVO recognise the central role it can play in helping disabled leaders to flourish.

We have heard and seen that ACEVO's offer and ability to connect and share learning has great potential in supporting and developing disabled leaders. The existing work should be capitalised upon so that that more people understand both ACEVO's offer and disabled leaders' potential.

At the outset of this project COVID-19 was a virtually unknown term. We have seen during the progression of this project that the impact of the pandemic on civil society is going to be shaping things for a long time to come. However, the inability to carry on business as normal is an opportunity to build back better, in a way that supports and learns from disabled people's leadership. ACEVO has an opportunity to be at the forefront of this effort.

## 6.1 Acknowledgements

Thank you to all of the disabled leaders and ACEVO staff and trustees who gave their time to share their stories and ideas for this research. Thank you particularly to Kristiana Wrixon and Maisie Hubert for their ongoing support, advice and suggestions, and to ACEVO for commissioning this work.

# Glossary

**Access to Work** – A government employment support programme that aims to help more Disabled people start or stay in work. Includes grant scheme that can help with the cost of reasonable adjustments (see **https://www.gov.uk/government/publications/access-to-work-factsheet/access-to-work-factsheet-for-customers**)

**Charity model of disability** - The charity model of disability gets its name from the way in which charitable interventions traditionally perpetuated the concepts of vulnerability and helplessness and have perpetuated the negative perception of impairment in society. The charity model of disability prioritises non-disabled experts, protectors and decision-makers over disabled people's lived experience.

**Deaf and Disabled people's organisations (DDPOs or DPOs)** – these organisations are run by and for Deaf and Disabled people, and have either a board made up of 75% or more Deaf and Disabled people, or a staff team of 50% or more Deaf and Disabled people, or both (source: Inclusion London).

**D/deaf people** – this recognises diversity among the hearing impaired, some who identify with a Deaf community and, others who do not.

**Disability** – is the social consequence of having an impairment. People with impairments are disabled by society and social constructs (see social model of disability).

**Disability Justice** - Disability Justice originated in the US and has 10 underlying principles which if followed aim to liberate people's whole selves and celebrate diversity and disability whilst embedding accessibility. While the movement is growing, it is relatively unknown in the UK currently.

**Hidden impairments** – a hidden impairment is one where it is not outwardly obvious that a person has a physical, sensory or cognitive difference – for example dyslexia, experiencing depression or some long-term health conditions like Crohn's disease.

**Identity-first language** – i.e disabled people rather than people with disabilities. While some individuals prefer people-first language, identity-first better reflects the social model, whereby people are disabled by conditions and design of society, structures and services, rather than because they have a medical condition.

**Impairment** - an individual's physical, sensory or cognitive difference.

**Medical model of disability** - The medical model of disability defines disability in relation to people's health or other conditions, focusing on treatments, cures and individual responsibility, rather than barriers within the system.

**Politically disabled** – the term 'Disabled people' is a political term that people with impairments use to emphasise the social cause and nature of exclusion and discrimintation faced by people with impairments who are disabled by society.

**Reasonable adjustments** –changes employer's must make to remove or reduce barriers that disadvantage Disabled people in the workplace.

**Social model of disability** - the social model, whereby people are disabled by conditions and design of society, structures and services, rather than because they have a medical condition. A social model interpretation of neurological and learning disabilities such as autistic spectrum disorders, dyspraxia, dyslexia and dyscalculia, attention deficit disorders and other similar conditions, rejecting medical approaches that seek to 'cure' individuals.

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**Published: February 2021**