

Accessing Leadership: supporting disabled leaders and future leaders in the voluntary sector

Part One: Scoping Review

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Foreword: Zara Todd & Ellie Munro

As Shakespeare wrote in Twelfth Night, 'some are born great; some achieve greatness and some have greatness thrust upon them.' For many disabled leaders, their leadership journey is a mixture of all these origin points. Very few of the disabled leaders that we have spoken to over the last five years ever started out wanting to be a leader and, for many of us, the title of leader is still an uncomfortable one. When you combine this with the skills, experience and qualities needed to lead voluntary sector organisation in the 21st century it is unsurprising that, outside of the disability field, most disabled leaders are invisible.

This does not mean that lived experience of disability does not shape and the impact people's leadership styles and approaches. However, it does mean that positive disability leadership assets such as adaptability, creativity and problem-solving are not always celebrated, and that many disabled leaders feel that they need to hide their impairments in order to be accepted as a leader.

We are excited that ACEVO has created this project, and begun to ask serious questions about how we support disabled leaders and future leaders in charities and voluntary organisations. We know this sector offers amazing opportunities for developing careers that people are passionate about; we want to make sure that everyone is able to access these.

The project has only just begun, and creating change, where needed, will be a long process. What we are finding so far is that this is an area where we desperately need more research, better data and an understanding of the experience of disabled staff throughout the voluntary sector. While organisations are rightly starting to report on, and make efforts to tackle, gender pay gaps and opportunities for Black, Asian and other minoritised staff, work to understand and support disabled employees (including disabled staff who are multiply marginalised) is much more limited for most charities.

This interim report, on existing research and approaches in the field, is only one part of the project. Alongside this we are talking to current disabled leaders about the challenges they have faced in their careers, and the things that have helped them. What we are hearing from disabled leaders so far is that they don't know what support and career development opportunities are out there to help them in their role. Disabled People's Organisations (DPOs) do not necessarily see themselves as part of a wider charity sector, and face some unique challenges. Non-disabled stakeholders also tell us they aren't aware of any disabled leaders, or that they are unsure what 'counts' as disability – for instance, seeing mental ill-health as a separate concern.

The COVID-19 crisis has brought greater attention to some difficulties faced by disabled people who want to develop their careers. Inflexible working policies have suddenly been overturned, allowing people to work and attend meetings from home, and to work around caring and other commitments. This has opened up more informal professional networks as well; conversations are happening online, rather than in the tearoom, between meetings. It has also led to stark realisations for some that they are, in fact, disabled, when they have been included in shielding or high-risk health categories, or faced new challenges under lockdown.

So-called new ways of working have not always worked for disabled people, however; long online meetings organised without breaks, without captions or signing, and even without considering some disabled people's lack of access to information technology, bely a response designed, again, without disabled colleagues in mind.

It is important that the system does not return to 'normal'. That normal was not one designed for disabled staff. As the voluntary sector begins to consider how it builds back up, in the face, as is so often the case, of falling funds and rising demand, it must do so in a way that empowers, develops and makes the most of talented and ambitious disabled people. Too often, charities define disabled people only as beneficiaries, rather than talented potential leaders. The values and ethos of the work they do needs to be reflected in the way they support their workforce, including their disabled workforce, to develop.

Introduction

The Institute of Leadership and Management (ILM) describes the disabled community as an ‘untapped talent pool’. Disability too often goes unmentioned in conversations about equality, diversity and inclusion, and almost half of disabled people worry about disclosing their disability to their employer.⁽¹⁾

We don’t currently know much about how the voluntary sector makes the most of talented disabled leaders and future leaders, but we think it needs to do better. This project, created and funded by ACEVO, seeks to start that conversation.

About our project

ACEVO has started this project as part of their wider programme of work on equality, diversity and workplace cultures in the voluntary sector. Their 2020 report, [Home Truths: Undoing racism and delivering real diversity in the charity sector](#), looks at whether the sector has a problem with ‘race’ equity, and how to address this. Earlier reports have looked at [bullying within charities](#) and [creating safe organisational cultures](#). This project now turns to disability and disabled leaders in the voluntary sector.

The project has two components:

- A scoping review: what do we already know about disabled voluntary sector leaders?
- Interviews with current disabled voluntary sector leaders to understand their leadership journeys: what has helped, and what more needs to be done?

We intend to use findings from these components to draw together a road map to help ACEVO and the wider voluntary sector start to address some of the barriers that exist for disabled leaders and future leaders.

We know this will be a long process, and many charities and organisations will be right at the beginning of it. We want to focus on the attitudes, behaviours and systems that will help foster and encourage disabled leaders and future leaders, and to make best use of their talent.

What do we mean by disability?

Disabled people might have long-term physical disabilities or health conditions, mental health conditions, learning disabilities and neurodivergence, and/or sensory impairments. They might have one condition or multiple; their condition might be fluctuating, progressive or stable; and they might not always be, or have been, disabled. The common factor is that they are prevented or hindered from participating in society on an equal basis to non-disabled people, because systems and structures have not been designed with them in mind. As such, a person is not disabled by their specific health condition, but by the fact that systems exclude them as a result. This is called the **social model of disability**, and we use this understanding in this report and the wider project. This is similar to the

definition used in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) – known as the **human rights model**. The human rights model, however, brings more of a focus on principles and values for policymaking, and the interaction between health- or condition-related impairment and structural oppression. 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.

For the most part we will use **identity-first language** in this report (i.e. disabled people, not people with disabilities). While some individuals may 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. We will also refer to D/deaf people, recognising the diversity among hearing-impaired people, some of whom identify with a Deaf community, and others who do not; and to people with learning disabilities, recognising the wishes of some to be referred to as such. There will also be references to neurodiversity and neurodivergence, 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.

Not everyone who would be considered disabled under the law will identify as disabled, for a range of reasons. Some people may see themselves more as having a temporary health condition, such as cancer; some may have struggled to get a formal diagnosis; some may not realise their mental health condition, neurodivergence or other condition are included under the banner of 'disability'; and others may feel uncomfortable with the label, because of society's negative connotations, or their own perceptions about what does and doesn't 'count'. Employees may also choose to not disclose their disability – and no one should be compelled to do so. However, employers can take steps to make their employees feel comfortable discussing their needs, and contribute to the kind of cultural and attitudinal change necessary to rethink our ideas in wider society around disability.

What do we mean by the voluntary sector?

We want to find out what it is like to be a disabled person and to work in and lead charities and voluntary organisations in the English voluntary sector. This includes organisations in the disability movement and the voluntary health sector, campaigning for disabled people's rights or condition-specific support, but also other charities and organisations where disabled people want to build careers with a social purpose within this sector.

The **disability movement** itself is made up of voluntary organisations – not all charities, and not all of whom identify with large charities – of a range of sizes, functions and leadership models. **D/deaf and Disabled People's Organisations** (DDPOs, or DPOs) are user led pan-disability groups, often small and local, offering services, advice, campaigning and advocacy to other disabled people. These fit into a traditional 'self-help' or mutual aid model of organisation. Because of their size, resource challenges, experience and understanding of the issues, and for some a need to work to different work patterns than non-disabled people, disabled leaders in these organisations may face different challenges and have different models of leading their organisations effectively and sustainably. Some of these may be common to other user-led and small organisations, while others may be unique.

Disability and health charities are not necessarily run by disabled people, are often (but not always) about a specific condition, and fit more into a traditional 'charity' model. Many of these organisations

do different types of policy and campaigning work around disabled people's employment. This does not necessarily mean they employ disabled people, or support them to develop their careers within these organisations, although there are some examples of good and developing practice.

It is important not to assume that all disabled people do, or want to, work on disability or health issues, however. It is also not solely the responsibility of the people and organisations who do to help disabled people build their careers. The **voluntary sector as a whole** needs to think about how it supports its disabled staff, how it makes sure they have access to the same opportunities for development and career advancement as their non-disabled colleagues.

About this report

This report is a scoping review that looks at what we already know about disabled leaders and future leaders in the voluntary sector.

Section 1 will start by outlining the national and international context for disabled employment. This includes internationally-recognised rights for disabled people to participate in work and employment, and national legislation that protects some of those rights.

Section 2 looks at what we know about the disabled workforce overall, what we know about disabled workers in the voluntary sector, and finally what we know about disabled leaders in charities and voluntary organisations.

Section 3 then looks at what we can learn from disabled people's experiences in other sectors.

Section 4 lists some schemes and programmes that already exist to support disabled employees, including leadership development programmes run by voluntary organisations for staff across sectors, business support, and government advice and schemes for meeting legal obligations.

Finally, **section 5** will summarise what more we need to know and do, and the next stages of the project.

There are some suggestions and examples of good practice throughout this report. However, at this stage we have not made recommendations, as we need to talk to and learn from disabled people leading and working in the sector to understand their experiences. This report is, nevertheless, a call to action. As organisations begin to return to old ways of working, or start designing new ones, in response to the COVID-19 crisis, it is imperative that they do so in a way that takes into account, and works for, disabled workers.

1. What does the law say about supporting disabled staff?

International treaties and national legal duties set out the rights and expectations of disabled people, and the requirements of their employers. This section briefly explains these. Some more information and sources of support are available in section 4 of this report.

We want to empower and develop leaders across the voluntary sector. Getting the basic legal requirements in place, including making changes to the way we work, is the first step to ensuring disabled future leaders have the same opportunities to build their careers as non-disabled colleagues. It will also help organisations make the most of their workforce, and benefit from the talent and skills all their employees hold.

International rights for disabled people

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was ratified by the UK in 2009. Broadly, this means the UK agrees to protect and promote the human rights of disabled people, including:

- Eliminating disability discrimination
- Enabling disabled people to live independently
- Ensuring inclusive education
- Protecting disabled people from exploitation, violence and abuse⁽²⁾

The Convention does not explicitly define disability. It adopts a **human rights model**, which recognises both the impact of impairments on an individual and the societal barriers that exist. It also underlines the principle that an impairment does not remove or invalidate a person's human rights. It states that:

"Disability is an evolving concept and [it] results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others."

Article 1 also specifies that disabled people include those with '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.'

Article 27 of the Convention is about work and employment. It states that governments should recognise disabled people's right to work on an equal basis to non-disabled people. This means States should take steps to prevent discrimination in employment on the basis of disability, ensure just and favourable conditions of work equal to those of other employees, have access to training, employment opportunities and career advancement, and provide reasonable accommodations or adjustments.⁽³⁾

The UN examines countries who have ratified different conventions every few years; the last examination in relation to the UNCRPD was in 2017. Among many other findings and recommendations, the UN Committee found that:

- Organisations representing disabled people, including those representing disabled women, children and intersex people, did not have enough support to be actively involved in implementing the Convention, or in the design and implementation of strategic government policies for disabled people
- Government should identify and address gaps in terms of accessibility standards including the design of affordable and accessible physical environments, housing, information and communications technology, information formats and transport infrastructure
- It should adopt a plan of action to eliminate the perception that disabled people do not have 'a good and decent life', of equal worth to non-disabled people
- The employment and pay gap for disabled people was persistent, especially for disabled women, neurodivergent people and those with a learning disability, and blind and partially sighted people. Government should develop employment policy to support all disabled people to find decent work, with equal pay for work of equal value
- There was insufficient provision of reasonable adjustments for disabled people to access employment. The Committee recommended ensuring accommodations were provided to all who needed them, that regular training for employers and employees should be provided, and that effective sanctions should be introduced to prevent employers denying reasonable requests
- Government needed to improve its collection of reliable data, publicly available and broken down by different protected characteristics.⁽⁴⁾

While the Committee's recommendations are for the State, often in partnership or consultation with representative organisations, there are clearly some actions that individual organisations could take to model best practice. This might include demonstrating through practice the equal worth and value of disabled people's lives through enabling them to make the most of their talent and skills, ensuring disabled employees are paid the same as non-disabled employees and that this is measured and reported on, and doing as much as possible to make reasonable adjustments and findings solutions to enable disabled people to enjoy a healthy, accessible and supportive work environment.

There are also many findings and recommendations that align with targets of the global **Sustainable Development Goals**. This set of 17 interconnected goals was agreed by the UN in 2015. It requires all stakeholders – governments, businesses and civil society organisations – to play a part in achieving these goals by 2030. There are specific references to disabled people in terms of access to education (Goal 4), promoting inclusive economic growth and access to the job market (Goal 8), including disabled people in social, economic and political life (Goal 10), creating accessible cities and public spaces (Goal 11) and collecting reliable data (Goal 17). These are all areas where voluntary organisations can, and should, contribute.^(5,6)

The Equality Act 2010

The **Equality Act 2010** defines disabled in the following way:

You're disabled under the Equality Act 2010 if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities.

Substantial means it might take longer to complete daily tasks, and long-term means 12 months or more, either continuously or cumulatively, or if it is expected to affect someone for the rest of their life. In some cases, such as people with HIV, multiple sclerosis or cancer, they are legally counted as disabled from the day of diagnosis.

The Act covers different types of discrimination disabled people might face:

- **Direct discrimination:** where someone is treated less favourably than someone else because they are disabled
- **Discrimination arising from a disability:** a disabled person is treated unfavourably because of something connected with their disability (eg a physical symptom of a medical condition), and the unfavourable treatment cannot be justified
- **Indirect discrimination:** where a rule, policy or practice applied to everyone has a particular negative impact on disabled people, which cannot be justified as a fair and reasonable approach to achieving a legitimate aim
- **Discrimination by association:** where someone is discriminated against because they are linked to or associated with a disabled person (e.g. because they are a carer)
- **Discrimination by perception:** where someone is discriminated against because they are perceived to be disabled, chronically ill or neurodiverse when they are not
- **Harassment:** unwanted behaviour related to disability that has the purpose or effect of creating an intimidating, hostile, degrading, humiliating or offensive environment for them
- **Victimisation:** where someone is treated badly because they have made a complaint, or supported someone else to make a complaint, under the Act. This also applies if they haven't made a complaint, but the service provider or employer thinks they have.

The Act applies a duty to make **reasonable adjustments** for disabled people, and it is unlawful to fail to do so. For organisations providing services to people (e.g. shops and restaurants, universities and training providers, care providers, etc.), this duty is **anticipatory** – an organisation must think about what disabled people might reasonably need in advance, rather than waiting until a disabled person wants to use its services. When deciding whether an adjustment is reasonable, an organisation can consider how effective and practicable it would be, how much it costs and the organisation's relative resources and size.

Employers are also required to make reasonable adjustments for their disabled employees (or candidates, during recruitment). This duty is not anticipatory; organisations can respond to employees' needs when they arise. The duty applies where the employer knows, or could reasonably be expected to know, that an employee is disabled. An employer must make reasonable efforts to find out if employees have additional needs, without violating the dignity or privacy of the person. In addition, an employer cannot choose someone for redundancy because they are disabled, and they cannot force someone to retire if they become disabled.

There are **three requirements for employers** to support a disabled person who might otherwise be placed at a substantial disadvantage compared to non-disabled colleagues:

- **Changing the way things are done:** changing policies or standard practices that pose significant challenges for disabled colleagues, such as when and where meetings take place, where people are allowed to work and how they manage their time

- **Changing the physical workplace:** introducing, amending or changing physical features of an office or other workplace to remove physical barriers to working, such as glass doors, hearing loops or ramps
- **Providing extra equipment, aids or services:** providing equipment that will assist a disabled employee to do their job, such as specialist software, stands, rests and chairs, or an assistant to help them with work-related tasks.

Again, employers can consider the effectiveness and practicality of the proposed change when deciding whether an adjustment is reasonable, as well as its cost, the organisation's resources and size, and the availability of financial support. If an adjustment is reasonable, the employer must pay for it, although many adjustments are low- or no-cost. Leonard Cheshire reported some entrenched attitudes among employers that acted as a barrier to hiring disabled staff, including fears about the cost of workplace adjustments; 66% of employers said these would be a barrier to employing a disabled person in 2018.⁽⁷⁾ However, where adjustments do carry a cost, a government financial scheme called **Access to Work** can help with extra costs that an employer may not be able or obliged to meet. There is more detail on this in section 4.

In addition to duties under the Equality Act 2010, employers are also required to ensure the health, safety and wellbeing of all their employees, whether they have a disability or not. The main legislation in this area is the **Health and Safety at Work etc. Act 1974**. This legislation does not provide any justification for not taking on a disabled worker.⁽⁸⁻¹³⁾

Understanding this national, and global, context underpins this work, and duties must be met robustly, transparently and with the aim of supporting marginalised staff to the best of an organisation's capability. However, supporting disabled staff to achieve their full potential, to access development opportunities and to progress in their careers, takes more than meeting legal equality duties. The rest of this report will look at what we know already about disabled leaders in the voluntary sector, what we might learn from other sectors, and what we still need to find out.

2. What do we know about disabled leaders in the voluntary sector?

When we are thinking about leadership, we can think about both current and future leaders. This section will look first at what we know about the disabled workforce overall, what we can tell about the disabled workforce in the voluntary sector including future and potential leaders, and then at leaders today.

There is a significant research gap on disabled leaders overall, and even less on disabled leaders in the voluntary sector. A lot of research on work and disabled people focuses on how they can be supported to enter employment, rather than necessarily sustain it or advance their careers. The next stage of this project, gathering the views of disabled people in the voluntary sector, will be an important contribution to this area, but larger scale projects will be necessary to better understand the career journeys, success factors and barriers for disabled leaders in our sector.

The disabled workforce overall

The number of disabled people in employment has increased overall since 2013, when comparable measures began. This might be due to policy initiatives to encourage disabled people into work and a less generous and more restricted benefits regime, as well as population factors such as an increase in the working-aged population, an increase in prevalence of disability in that population, and a rising employment rate overall. 4.4 million disabled people were in employment in the last quarter of 2019 – a little over half of the total population of 8.1 million working aged disabled adults.

Although it has fallen slightly since 2013, the employment gap between disabled and non-disabled people was still around 28% in 2019. Disabled people were twice as likely to move out of work than non-disabled people. The employment rate gap was highest for people aged 50-64, and disabled people in this group were also twice as likely to have moved out of work than non-disabled people of the same age. This age group accounted for more than four in 10 of the working-aged disabled population overall. Disabled men and women had similar employment rates, but the employment gap was bigger between disabled men and non-disabled men compared to women.

The distribution of disabled people working in different industries in the UK was broadly the same as for non-disabled people in 2018/19, with human health and social work, retail and education in the top three employers. These accounted for 41% of the disabled workforce. However, disabled people were less likely to work in higher-skilled occupations than non-disabled colleagues. Disabled people were also more likely to be in part time work (34%) compared to non-disabled workers (23%).^(14,15)

There are some statistics on rates of pay for disabled staff compared to their non-disabled colleagues. The TUC reported, based on labour force survey statistics, that the disability pay gap was 15.5% in 2018/19. This effectively means that disabled employees get eight weeks less pay than non-disabled employees; on average, disabled workers earned £1.65 per hour less, or £3,000 per year, than non-disabled workers. The ONS, using weighted earnings data from the Annual Population Survey, found that the pay gap across the UK was 12.2% for disabled people in 2018; London (which publishes its own disability pay gap data) had the widest gap at 15.3%, and Scotland the narrowest at 8.3%. It also found that around a quarter of this difference could be accounted for by lower paid occupations and lower levels of qualification among disabled workers.^(14,16)

The ONS data found that the disability pay gap was wider for men than for women. This is consistent with a report by the Equality and Human Rights Commission on the disability pay gap. The report also looked at the intersection of disability and ethnicity, finding that where ethnic pay gaps exist, they are exacerbated by disability. However, the disability pay gap does not, on the whole, vary by ethnicity. Disabled Bangladeshi and Pakistani men were found to have particularly high pay gaps of 56% and 36% respectively, while disabled Black African men had a gap of 34% compared to White British non-disabled men. Disabled women from different ethnicities did not have significant differences in pay gaps.⁽¹⁷⁾

The voluntary sector disabled workforce

While employment statistics used here are broken down by industry, they are not broken down by sector, so we do not know how the disability employment rate compares between the voluntary, private and public sectors. Labour market statistics do report on employment in public compared to private sectors, but not on rates of disability within those figures. We do know, however, that while 20% of the organisations signed up to the **Disability Confident** employment accreditation scheme (described in more detail in section 4) are voluntary organisations, charities and social enterprises, this only represents around 2% of the sector as a whole.⁽¹⁸⁾

The National Council for Voluntary Service (NCVO) uses data from the Labour Force Survey to estimate rates of voluntary sector employment overall. However, while it reports on gender, age and ethnicity of the workforce, it does not report any data, or make any comment, on the disabled voluntary sector workforce.⁽¹⁹⁾ This represents a significant gap in our knowledge, and one that voluntary sector infrastructure bodies should be filling, either through further analysis of available data, or lobbying for better data. At the very least, this gap should be acknowledged and explained.

Reporting on the disabled workforce

Some organisations include information about the diversity of their workforce in their annual reports; most include a statement on equality, diversity and inclusion (EDI) and many present gender pay gap information. Annual reports are a way for an organisation to publicly celebrate its work and achievements, but also offer a key opportunity for transparency. This should include issues raised by workforce data and workplace culture. For those that work with and for disabled people, this also offers a good opportunity to champion and model good employment practice.

We looked at the most recent annual reports of the top 25 largest charities by latest reported income to see if they included information about their disabled employees. This included 'general charities',

according to NCVO's definition, excluding organisations such as universities, religious organisations and grant-making foundations. 10 organisations' annual reports did not mention disabled staff at all. 15 did, but of these six were limited references to legal responsibilities or general commitments. A number published data on their workforce by pay grade, gender, ethnicity and nationality, but only two reported any statistics on their disabled workforce. Of those who did not mention disabled staff, only one was not a member of the Disability Confident employment scheme; six were committed, two were employers and one was a leader. There was almost no reference to disabled leaders or career progression for disabled employees. While annual reports clearly do not cover every aspect of charities' business or necessarily translate into positive practice, and while these charities do not represent the whole sector, it is nevertheless disappointing to see a lack of explicit consideration of disabled employees in these sector leaders.

There were some good examples of charities considering or reporting on their disabled workforce. A number stated they had **representative staff networks** for disabled staff members, and some mentioned that supporting disabled workers featured in their **EDI strategies**, including monitoring through key performance indicators (KPIs).

Three organisations had more substantial sections or references to the needs of disabled workers. Mencap, which has made it a policy to directly employ people with a learning disability within the organisation, has a section on employment of people with a disability, including specific data on the size of its disabled workforce. This includes 367 staff with a declared disability, including 176 with a learning disability. The organisation has a staff inclusion group for colleagues with a learning disability. It also recognises challenges in increasing the percentage of disabled staff employed, and the uneven distribution around business areas.

St. Andrew's Healthcare does not have a specific section on disabled staff, but it does have a disabled staff support network, and expresses commitment to inclusion across different populations throughout its report. It also includes a quote from the Executive HR Director about disclosing his own disability, modelling openness and support at a senior level.

Finally, the Royal National Lifeboat Institution (RNLI) reports on its inclusion and diversity statement and staff network for disability, but it also reports on some actions taken as a result of feedback from this network. The organisation worked with its disability network, the Inclusion and Diversity Manager and colleagues in HR to develop a Passport to Wellbeing, a document designed to 'smooth the path for any employee with a specific condition or disability by enabling constructive conversations with their line manager'. This is a potentially useful way for other charities to ensure managers have the skills and confidence to have appropriate conversations about staff needs, and for staff to feel confident and supported when discussing them. While it does not report on it in the annual report, the internal staff survey includes questions on protected characteristics, and an inclusion and diversity working group has conducted a baseline diversity survey to better understand the nature of its workforce, and how it might change over coming years.

Scope, a high-profile disability charity, does not feature on this list, but it has recently begun some substantial work on better understanding its own disabled workforce, as stated in its latest annual report. Its first dedicated report on this was published in 2019, including data from staff surveys as well as HR monitoring, recognising that not all disabled staff will feel comfortable disclosing their disability to their employer. While disabled staff, representing 17% of the organisation's workforce, were more likely to say they felt appreciated and received praise than non-disabled colleagues (67% compared to

60%), a number of areas for improvement were identified. This included improving lower than desired levels of satisfaction with reasonable adjustments, where made, and high reported stress levels across the whole workforce. A quarter of employees who identified as disabled had not shared information about their disability at work, and just under 30% did not feel they were treated with fairness and respect. Scope lists some areas for action in response to its findings, and also commits to improving the information it has on its disabled workforce. This includes publishing information on pay, workplace adjustments, and length of time of employment for disabled staff, as an important measure of staff retention rates.⁽²⁰⁾

The examples above are mixed in the extent to which they engage with the nature, shape and issues faced by their disabled workforce. Large charities in particular can lead the way on better data collection, reporting and identifying the needs of their disabled staff. Disabled staff networks potentially provide a space for peer support and collective action where necessary, but the organisation as a whole needs to proactively work with them to create strategies and tools for ensuring the right support is in place. Disabled workers need to be included in EDI strategies, and these need to be practical documents that go beyond stating legal requirements. Organisations must consider recruitment practices and the size of the disabled workforce, but also the shape of it; are disabled people able to access career development opportunities, are they in management and leadership positions or fairly considered for promotion opportunities, and once employed do they stay at the organisation for a comparable length of time to their non-disabled colleagues? At the moment, many of the largest charities in England do not appear to be addressing these questions, or sharing the ways they are doing so with the public.

Disabled leaders in the voluntary sector

As stated, there is very little research on disabled leaders in the voluntary sector. This is a gap that this project intends to begin to address. During our next stage we will talk to disabled leaders from disabled people's organisations (DPOs), and from other organisations within the sector. There would also be significant value in a wider survey of disabled employees and leaders, both those who have disclosed this to their employer and those who have not, to better understand experiences of working in charities and voluntary organisations.

NCVO's 2019 review of the voluntary sector workforce as a whole did not identify data or other research on disabled voluntary sector staff and skills. However, it did highlight that a high bar of expected qualifications for staff may have a negative impact on disabled people, who are less likely to engage in higher education than the population as a whole.⁽²¹⁾ This problem may become entrenched as people try to move up the career ladder, but further research is needed to more fully understand this relationship.

There are some lessons to be learnt from other countries. A report by Zara Todd, one of the co-authors of this research, on leadership in disabled people's organisations (DPOs) in Australia and New Zealand found there were a number of key features present in organisations that had been successful in cultivating leadership, including:

- being open to new people and ideas
- creating opportunities where there are mixed levels of experience and where learning from each other is promoted
- mentoring

- giving people space to talk about their impairment experience
- consistently providing development opportunities
- seeing engagement and development as a long-term process
- expecting inclusion.

Todd's research looked at leadership within DPOs and the disability sector. It may be that there are leadership structures and models that look different within these relatively small, user-led organisations, compared to other types of organisations in the sector. Indeed, one research paper noted the tension, or 'double-bind', between leadership in DPOs – which involves wielding power - and the need for member or grassroots participation and active involvement – which involves handing power over. This requires DPO leaders to hold two sets of competencies that are sometimes at odds. (22) The next stage of this project will explore leadership experiences in DPOs in more detail.

It is important to acknowledge and celebrate disability leadership, where possible. The Shaw Trust attempts to meet this demand through its Power 100 list of the most influential disabled people in the UK. Showcasing disabled leaders across different sectors and industries, it shows what disabled leadership can look like, and offers role models for those just starting their careers. There is a section for education and the public and third sectors, featuring 25 leaders across different areas.⁽²³⁾ However, those who work for and with charities or voluntary organisations all do so within the disability sector. The work they do is extremely important, and their achievements significant, but future and potential disabled leaders need role models, and mentors, from across the voluntary sector, to show them models for career development in whatever area they are passionate about. It is also noticeable that in this category (although not the list as a whole), all of the individuals appear to be white. This may reflect additional struggles faced by Black or Asian disabled people, and those from other minoritised communities, to access the same leadership opportunities as their white colleagues, or it may be that the successes of people from these communities are less visible (or less noticed). Whatever the reason, it is important to champion, celebrate and promote the achievements of these groups too, so that Black, Asian and other multiply-marginalised disabled people are able to see people who look and identify like them in these roles, and aspire to the same for themselves.

This report is very much a starting point for exploring and understanding issues faced by disabled voluntary sector leaders and future leaders. There is a clear need to develop this further, given the lack of data on the voluntary sector disabled workforce. There are, nevertheless, a number of existing schemes and resources that recognise some of the challenges disabled employees face, and seek to nurture their leadership talent. The following section explores these.

3. What can we learn from other sectors?

There is more research, data and other material available on the disabled workforce and disabled leaders in the public and private sectors, and the higher education and creative industries fields. These are described below. Voluntary sector organisations can learn from some of these schemes and experiences; greater collaboration or ways of sharing learning across sectors may help charities understand how best to support the talent in their workforce.

The public sector

The West Midlands Combined Authority did some work in 2018 to better understand the diversity of leadership in public and private sectors in the region. It identified significant gaps in data for both sectors in terms of disabled leaders, as well as a lack of data on sexuality, class and how identities intersected. Nevertheless, it was able to conclude that disabled people were underrepresented in the public and private workforce, both as a whole and in leadership positions. Importantly, the report also explicitly recognised that it is society that disables people by failing to work in a way that allows them to make best use of their capabilities; this recognition at a senior level is a good starting point for thinking about change.

There were some barriers that cut across all groups, such as a lack of self-confidence, exclusion from informal communication networks, stereotypes about roles and abilities, and a lack of mentors and role models. The report also identified specific barriers faced by disabled people, including:

- Job security
- Personal development
- Career prospects
- Perceived capacity to lead
- Travel-to-work difficulties.

While three quarters of workplaces in the West Midlands had adopted a formal equal opportunities policy, just under 30% of these did not mention disability. Policies do not, of course, always translate into action or better systems. However, it is concerning that disabled people are not even considered across this proportion of employers; this suggests a strong need for greater understanding and embedded culture change when thinking about the disabled workforce.⁽²⁴⁾

The Civil Service also has its own DELTA (Disability Empowers Leadership Talent) scheme, launched in 2019 to encourage future leaders and create more diverse leadership teams. It seeks to do this by improving the 'collective visibility of high potential disabled civil servants', to accelerate career development and to generate a 'more diverse and robust pipeline' for senior roles. It is unclear whether this programme will be evaluated, and whether lessons from it will be shared publicly.⁽²⁵⁾

Higher education

The National Association of Disabled Staff Networks represents networks mostly within further and higher education in the UK, although it reports having a small number of public, private and voluntary sector members. While a small organisation, it gathers and represents views from across these networks, providing a collective platform to share experiences and lobby for improvements at a national policy level. Most recently, it has made a number of recommendations for higher education institutions as they begin to move back to working on site, after the COVID-19 lockdown period. Recommendations include ensuring any response is adequately equality impact assessed, instituting a no-detriment policy so that staff who cannot attend in person are not penalised, and continuing to offer a choice to both students and staff to attend lectures or meetings remotely, in a way that is inclusive for disabled people. While specific to the current higher education context, these are important considerations for all organisations.⁽²⁶⁾

Research on careers for disabled people in higher education has found that disabled academics and other staff are already involved in formal or informal leadership roles, demonstrating that, in theory, being disabled should not prevent a person from engaging in leadership as a key part of their career. However, it has also found a number of barriers to staying and progressing in these careers. Findings indicated that some participants were already engaged in leadership or aspired to such roles, and reported positive experiences. However, participants across two papers also experienced significant barriers to progression, including:

- A lack of awareness of equality and diversity among managers and colleagues
- Inadequate professional development opportunities and the competitive organisational culture of management
- Management stereotyping or making assumptions about the capabilities, or lack thereof, of disabled people
- Perceptions of being given less responsibility, or being passed over for opportunities, after disclosing a health condition or disability
- A lack of disability awareness provision, including insufficient training that didn't reach senior staff
- A lack of mentors or disabled role models across the university
- A lack of acknowledgement or reward for informal leadership roles
- A culture of long hours and poor work-life balance, with risks to health these carry, exacerbated by a perception among disabled staff that they have to work harder than their non-disabled colleagues to 'prove' their ability and counter assumptions about their lack of leadership ability
- Having to repeatedly ask for and justify a need for support, equipment and reasonable adjustments.^(27,28)

Some of these barriers are common to those identified earlier in this report, and may resonate further with disabled staff in the voluntary sector.

Creative industries

There have been a number of schemes to encourage disabled leaders in the arts and cultural industries in recent years. Some of these are run by or associated with charities, but it is a sub-sector that often works in a unique way, with unique challenges.

In 2019, Arts Council England made three grants to organisations supporting D/deaf and disabled cultural leaders at different stages of their careers. Access All Areas have been developing a career development and coaching programme for potential leaders with learning disabilities; the Shape Leadership Development Programme involves training 50 future disabled leaders with skills to succeed in the sector; and Graeae Theatre Company's National Leadership programme works to connect early and mid-career D/deaf and disabled artists with mentors, networks and pathways between artists and venues. The funding is part of the Transforming Leadership fund, and these three projects, from a total of 18, received £768,512 between them.⁽²⁹⁾

It is encouraging to see these projects emerging specifically in response to challenges Arts Council England had identified in its own practice. Its fourth annual report on equality, diversity and the creative case found that disabled workers in the National Portfolio (organisations it funds) only increased from 4% to 5% in 2017/18 compared to the beginning of the project, while the proportion remained at 4% for Major Partner Museums (museums it funds). Disabled people were underrepresented on boards of both of these institutions, and had in fact decreased from 4% to 2% in the case of Major Partner Museums. There had been small increases in the percentages of disabled chief executives (from 5% to 7%), artistic directors (5% to 8%) and chairs (from 5% to 6%) across the lifetime of the portfolio. Within its own workforce, it notes that the proportion of disabled staff (5.6%) had not increased significantly since the previous year, and that disabled staff were more likely to occupy non-managerial roles. The report adds that there is only limited data available on the disabled workforce and governance landscape across its portfolio. Even so, the fact it is taking a proactive role in better understanding diversity across the organisations it funds is one positive step to addressing some significant gaps.⁽³⁰⁾

Nevertheless, the challenges faced by disabled artists and arts organisations have been significantly increased as a result of the COVID-19 pandemic. An open letter to the Secretary of State for Culture from over 100 disabled artists and cultural leaders highlighted the way the crisis has 'magnified inequalities' for disabled people who may face long term shielding, and loss of both income and visibility as a result. A new organisation, the UK Disability Arts Alliance, has been established to fight for financial support for disabled artists, and for recovery planning that does not exclude creative disabled people.⁽³¹⁾

Research also highlights how the nature of work in creative and cultural industries – project focused and with a precarious employment system – poses challenges to disabled workers (as well as others), who were more likely to lack social capital, to struggle with income insecurities or to access alternative monetary support, and to be unable to work long, unsocial hours, often travelling across the country. One study reports that disabled workers are 'doubly disabled', first by barriers to accessing the labour market, and secondly by the labour processes of the UK film and television industry. Another study argues that mentoring and networking schemes designed to extend access to social capital in fact work inside the existing problematic structure, and make any failings to capitalise on opportunities the fault of the individual, rather than a product of structural constraints. More collective work is needed on changing cultures and perceptions of the arts and cultural work as 'for everyone'.^(32,33)

The private sector

There is more research on disabled workers in private sector workplaces than in the voluntary sector, and many of the lessons are likely to be transferrable. Studies cover issues such as condition-specific experiences of work, intersectional discrimination, sickness and productivity, and supporting talent and progression.

A report in 2019 found that while progress had been made at a leadership level on challenges of gender and ethnic diversity, disability was still absent from board level discussions in global business. 56% of global senior executives rarely or never discussed disability in their leadership agendas, and only one in 14 board-level executives identified as disabled (compared to one in seven of the world's population). 20% of those executives did not feel comfortable telling their colleagues about their disability. Visibility of disabled senior leaders increased the likelihood of conversations about disability inclusion at a senior level; 63% of executives who were aware that a board-level colleague had a disability reported having these discussions, compared to 37% of those not aware of any senior disabled colleagues.⁽³⁴⁾

One study in Canada looked at support for disabled workers in the context of the aging workforce and prevalence of age-related chronic illness. This is likely to become an increasing issue for all employers. The research found that, while older employees with arthritis and/or diabetes did report poorer health and employment outcomes than those with no chronic conditions, they were also aware of available policies and practices for making accommodations, and the majority of respondents reported their accommodation needs had been met. The authors suggest that this may relate to the fluctuating nature of their conditions, and employees' own coping strategies for managing their health and work within existing policies and practices. Part-time workers were less likely to have their needs met, although part time work may also help employees to balance their career and health needs.⁽³⁵⁾

Another study highlights the problem of 'sickness presenteeism' – or going to work while still ill. It specifically looks at people with rheumatoid arthritis, and distinguishes between two types of presenteeism: voluntary (wanting to work despite ill health) and involuntary (feeling pressured to work when ill). Participants' motivation to work remained high after their diagnosis and onset of symptoms. Workplace adjustments, including specialist equipment funded through the government's Access to Work scheme, flexible working and changing duties, helped them to stay working and to work well. This was part of maintaining a sense of 'normality', for some. A further study on the experience of people living with Hepatitis C also argues that supportive workplaces with reasonable adjustments allow disabled people and those with chronic conditions to work in sustainable ways.⁽³⁶⁾ However, access to and approval for reasonable adjustments was variable. In the previous study, two participants with rheumatoid arthritis actually saw their adjustments withdrawn after time, due to 'coworker's jealousy', and a perception that employers in fact wanted these disabled staff members to resign. Some may feel pressured to work where other colleagues hold negative perceptions about levels of sickness, where there was a fear of being disciplined by punitive sick leave policies, or where an organisation's policies are too inflexible, or not responsive to fluctuating conditions. While voluntary presenteeism, if managed sensitively and appropriately, can be helpful for both employee and employer, involuntary presenteeism can result in extended absence due to exacerbated ill health and a loss of productivity.⁽³⁷⁾ These are all issues that are likely to be common to charities and voluntary organisations, and highlight the need for flexible policies, a responsive attitude to changing staff needs, and a supportive workplace culture where prejudice is robustly challenged.

'High-performance work practices', such as competency testing, performance appraisal, individual performance-related pay, teamworking and functional flexibility (moving employees to other parts of the organisation), have been found in some cases to improve ability, motivation and offer more opportunities to contribute to the business, in turn improving worker wellbeing. Other studies have found that they increase stress and anxiety through an intensification of work. A 2017 paper looks specifically at their impact on disabled people. It found that workplaces that used these practices in combination had fewer disabled employees, apart from where the workplace had a wide range of

disability equality practices.⁽³⁸⁾ A second article looks at levels of pay and at performance-related pay. It similarly finds that disabled employees report lower levels of pay satisfaction than nondisabled employees, and individual performance-related pay exacerbates this. The authors argue that trust both in management and in organisation-wide policies and practices make a difference to levels of satisfaction; when trust in management is high, pay satisfaction rises, and becomes even higher when this is combined with firm-wide disability policies. Where there is a policy but no supportive management or human relations practices, the gap in satisfaction is worsened.⁽³⁹⁾ This is potentially a useful demonstration of how some policies designed to improve practice, reward performance and support people to build their careers do not work for disabled people (and likely other marginalised groups). While equality practices and policies are an important mitigation here, it is important to design policies for maximising the skills and talent in an organisation that do work across these groups, rather than further marginalising them.

Three studies were identified that look at the intersectional nature of workplace discrimination; all looked at gender and disability. One statistical study used the 2009-14 Life Opportunities Survey to look at the intersection between disability and gender in terms of employment. It found that disabled women were significantly less likely to be employed and more likely to be economically inactive than disabled men, nondisabled women and nondisabled men, and were least likely to work full-time than these groups. They were also less likely to be supervisors than disabled men.⁽⁴⁰⁾ A second paper by the same authors, using the same method, added that disabled women's economic wellbeing improved significantly between 2009 and 2014, but that these improvements did not narrow the gap between disabled women and disabled men, non-disabled men and non-disabled women.⁽⁴¹⁾ One further related study using the same data set looked at the economic wellbeing of people with a hearing impairment or D/deaf people, finding that they had a lower household income, found it harder to make ends meet, would be unable to pay an unexpected but necessary expense of £500, and were less likely to work in paid jobs than non-hearing impaired people, even after taking into account other demographic characteristics.⁽⁴²⁾

A final study looked at employees with hidden neurological impairments including dyslexia, dyscalculia, dyspraxia, ADD/ADHD and Asperger syndrome working in the male-dominated transport industry. It suggests that some features of the workplace, such as task restriction, which have often been seen as gendered practices, can also be seen as ableist. Task restriction can be self-imposed, based on lack of confidence engendered by an unsupportive culture, or imposed by managers who lack faith in a disabled employee's abilities. The study provides examples of where this has affected career development prospects and social isolation for both disabled women and men. Workplace culture and 'humour' posed an additional challenge; some men reported they were reluctant to disclose their disability out of fear of being laughed at, while other neurodivergent colleagues struggled to participate in social conversations, and were mocked because of this. Regular reorganising of teams, which had become a common feature of the industry, meant that disabled staff had to repeatedly rebuild supportive relationships, and repeatedly disclose their disability to new managers.⁽⁴³⁾ These issues affected both men and women, and were rooted in the interaction between disability and gender, especially constructions of masculinity in this male-dominated industry. Different assumptions are made about disabled women and disabled men, and both can have a significant negative impact on access to opportunities and career development. It is important, again, that employers – including in the voluntary sector – recognise when these stereotypes are coming into play, and robustly tackle resulting discrimination.

While the COVID-19 crisis has put severe pressure on disabled people and the services that support them, it has also demonstrated that alternative ways of working are possible, and also desirable. Alternatives such as working from home and digital meeting places do need to be done in a way that works for disabled people, rather than only their non-disabled colleagues. This means thinking about meeting timings and length, having regular breaks and maintaining supportive line management relationships. Some of the lessons and findings from the previous research across different sectors begin to point the way to some issues faced by disabled employees, and potential solutions available. As the next section will discuss, there are already a number of schemes and programmes available for supporting disabled leaders and future leaders. However, more work will need to be done to better understand experiences and needs in charities and voluntary organisations. This project will begin to fill some of that gap.

4. What support is out there already for employers and employees?

There are already a number of schemes run by charities, businesses and government to help disabled people develop their careers, and employers to create the spaces in which people are able to do so. This section briefly outlines some of these. Some of the examples below include public evaluations, and where possible learning from these has been included. Others detail the key elements of the programme or resource. These are not programmes endorsed by this report, but rather examples to learn more about.

Voluntary sector-run programmes for leadership and employment

Leadership Academy Programme: Disability Rights UK

The **Leadership Academy Programme** provides leadership training for an annual cohort of employees with lived experience of disability. It works with employees in large private, public and voluntary sector organisations, looking to develop their skills or identified as potential leaders, through workshops, a cohort and alumni network, and mentoring. Disability Rights UK reports that 80% of participants have gone on to achieve new promotions, joined committees and networks, and increased their self-confidence and motivation.

Developing Deaf and Disabled Leaders for the Future: Inclusion London

Inclusion London's 18 month **Leadership Training and Development Programme** began in August 2019, funded by the National Lottery Community Fund. It is being trialled with ten Deaf/Disabled people who 'have shown an interest or potential for leadership' within the DDPO movement. Unexpectedly, this has included developing leadership skills and responses to new challenges as a result of the COVID-19 crisis.

Change100: Leonard Cheshire

Change100 is a programme in its seventh year, providing paid internships for disabled students and graduates in businesses and other workplaces. It helps people at the start of their careers to learn about the workplace, build their networks and begin to develop the skills they will need to continue their careers.

Leonard Cheshire reported in 2018 that 70% of participants were in or had secured employment after taking part in the scheme, and 84% of employers reported that it had prompted them to consider how inclusive their recruitment is.⁽⁷⁾

Learning for Leadership: Foundation for People with Learning Disabilities

Learning for Leadership offers adults with a learning disability access to a personal development programme to help them develop the skills and knowledge to thrive in leadership roles. It works through coaching, mentoring and skills workshops, as well as shadowing an existing leader in the field. They are also expected to complete a demonstration project to complete the course.

Business support

Purple Space

Purple Space describes itself as 'the world's only professional development hub for disability network leaders'. It provides training, consultancy and networking for disabled employees and their employers from all sectors, and supports leaders to build disability networks within organisations, of the kind identified in a number of charity annual reports in section 2. A guide to **disabled employee networks** produced by partner organisation Kate Nash Associates identifies three types of networks: peer group or alumni networks (often set up by disabled employees themselves), consultation forums and leadership or champion groups (often set up by the organisation).⁽⁴⁴⁾ Purple Space's vision is to build disability confidence among employers 'from the inside out' through these networks.

Purple

Purple is an organisation seeking to 'change the conversation' between businesses and disabled people. In part this means helping businesses to develop inclusive products and services in order to tap into the 'purple pound' – the spending power of disabled people, estimated at £249 billion per year. It also supports organisations to achieve different levels of the UK government's Disability Confident employer accreditation scheme, offers training and consultancy on disability in the workplace, and provides a jobs board for organisations looking to advertise their roles to a wider talent pool.

Recruitment Industry Disability Initiative (RIDI)

RIDI works with recruiters and employers to give them the tools to become 'disability confident', and create a level playing field for disabled candidates. It also hosts an annual awards scheme, promoting and celebrating best practice across sectors in disability confident recruitment and employment. It has a number of guides and resources on recruitment and other human resources practices freely available.

Government support for legal requirements and reasonable adjustments

What equality law means for your voluntary and community sector organisation: Equality and Human Rights Commission

A **detailed guide** bringing together and explaining different parts of equality legislation, including organisations' responsibilities under the law. This is a guide for charities and groups providing services. There is also a separate **set of guides for employers**.

Access to Work

Access to Work is a government benefit scheme to support disabled employees, in partnership with their employers, to pay for adjustments, aids and equipment to help them do their job. This means that

employers do not have to fund expensive support themselves (including support workers, specialist equipment and help getting to and from work), but employees can still get the help they need.

There are some considerable problems with the Access to Work scheme. The programme did not grow significantly in either number of grants or value overall between 2010/11 and 2017/18, despite rising costs. Not all employers know about Access to Work, and people will get less support if they apply after having worked for their organisation for some time. 69% of disabled people who had received Access to Work reported having to wait for more than three months for their application to be approved.⁽⁷⁾ Research in 2017 found that half of survey respondents had seen changes, normally cuts, to their Access to Work package, as well as more frequent reassessments and tighter eligibility criteria. One in four respondents reported severe difficulty in using the scheme. Respondents also reported a negative impact on their productivity and standard of work, and on their levels of stress, health and confidence.⁽⁴⁵⁾ It can be an onerous application process, which has to be completed on paper, and requires substantial evidence of need. It also does not cover all costs; for instance, while it will pay for travel to and from work, it will not necessarily pay for travel to meetings during the working day. There are challenges when moving from a previous employer to a new one, which requires a fresh application each time. A cap on awards also limits support for the small number of disabled people with high cost and complex equipment and support needs.

With these challenges in mind, employers in the voluntary sector need to make sure they are aware of how Access to Work functions, how to streamline their own involvement in the process, and how to best support employees who may be struggling, either professionally or personally, as a result of delays, cuts or uncertainty. The rules are extremely complex, and it is difficult to find clear guidance on them. This may be an area where voluntary sector infrastructure organisations, working with disability specialists, can offer organisations support.

Disability Confident employment accreditation scheme

Disability Confident is a government-run scheme that invites organisations to sign up to three levels of membership – committed, employer and leader – to demonstrate their willingness and ability to employ and support disabled workers. Currently over 18,000 organisations have signed up, including 3,583 voluntary organisations, charities and social enterprises (20% of total signatories, but only 2% of the total voluntary sector).

However, as Independent Living points out, the scheme involves a lot of self-assessment, only requiring external validation at the final 'Leader' tier. This makes it difficult to tell how much the scheme has translated into real change for disabled employees. An evaluation was promised by the Department of Work and Pensions (DWP) by 2020, but this does not yet appear to have been published.⁽⁴⁶⁾

5. What more do we need to know and do?

It is clear from this review that we need better data on disabled people who work across the whole voluntary sector. There is limited data from national data sets, and charities are not routinely reporting on their own practice.

We also need to know more about disabled people's experience of working in the voluntary sector. As discussed, there are a number of studies that look at the experience in the private sector, but far less in charities and other voluntary organisations. We need to understand not just how disabled people find jobs and enter work, but whether they are supported properly, whether they are able to stay in their jobs and their organisations for as long as they would like, and whether they are able to access opportunities to develop their skills and progress in their careers. We need to know what works and what doesn't in charities and voluntary organisations of all types, and we need champions to take good practice forward.

We also need to understand the diversity of experience within the disabled voluntary sector workforce. Different people with different conditions or disabilities will find different types of support useful. Those who become disabled later in life are likely to have a different experience to those who were born with their condition. The experience of disabled women may be different to that of disabled men, and from disabled trans or nonbinary people. Other intersections between disability and race, sexuality and class need to be understood, and support needs to be tailored and effective for people across these groups.

Finally, we need to know more about, and hear from, current disabled leaders across the voluntary sector. We need to understand what has helped and hindered them in developing their leadership careers, what lessons they would pass on to future and potential leaders, and what needs to change in the sector.

Next steps for this project

This review is only one part of our project looking at disabled leaders and future leaders in the voluntary sector. Working with ACEVO, which initiated and funded the project, we are hoping to better understand the shape and nature of the disabled voluntary sector workforce, and to start to understand some of the challenges and success factors disabled people encounter when developing their careers in this sector. The next stage is about listening to disabled leaders and future leaders. We have already begun interviewing current leaders and learning from their career journeys.

The project itself is only one early step in a longer journey to making the voluntary sector more accessible to disabled people and more supportive of their needs. In return, of course, the sector will get to benefit from the talent, skills and experience of people who are passionate about their work.

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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 discrimination 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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