



Hidden Leaders

Briefing for external audience

Background

In January 2020 ACEVO undertook an open commissioning process in order to recruit consultants to carry out a piece of work that would help ACEVO to understand the steps it needs to take to realise its ambition of becoming accessible and inclusive of disabled people.

The consultants working on this project, Zara Todd and Ellie Munro, produced two reports as part of the project. The first report provides an overview of disability in the voluntary sector, and an introduction to disability legislation and an overview of what is already known about disabled representation and disability inclusivity in the voluntary sector. The second report is based on interviews with ACEVO staff, trustees, members and non-members and concludes with a set of actions ACEVO should consider in order to become more inclusive.

We have published both reports because we think it is important for ACEVO to be acting transparently and because we hope it will be helpful to other charities that may also be looking to improve equity, diversity and inclusion. However, much of the content in the report is specific to ACEVO and we have therefore produced this briefing to highlight the key learning points that are also relevant to other civil society organisations.

What do we mean by the terms ‘disabled’ and ‘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.

For the most part we will use **identity-first language** in this report (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.

The disabled workforce

There are no reliable statistics about the voluntary sector disabled workforce. Nationally and across all sectors we know that 4.4 million disabled people were in employment in the last quarter of 2019 – this represents 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.

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.

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 (see box on page 15 for an explanation of the charity model of disability). 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.

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.

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 fewer 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.

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.

Taking action: how can organisations support disabled people in the workforce

We recognise 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 organisations being able to make the best use of talented disabled leaders.

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 people is a long-term project, 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 reflects 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 any real change.

| 1. Inclusive Foundations | | Is this in place yet? | What more do we need to do? |
|--------------------------|--|-----------------------|-----------------------------|
| Knowledge and data | <ul style="list-style-type: none"> • Have clear information available for staff around reasonable adjustments and the Access to Work programme, including at recruitment, induction and appraisal stages. | | |
| | <ul style="list-style-type: none"> • 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 | <ul style="list-style-type: none"> • Adopt the social model of disability/ human rights model of disability into organisational practice and make this clear in relevant internal and external communications. | | |
| | <ul style="list-style-type: none"> • Create an organisational disability inclusion and accessibility manifesto or statement of commitments and promote to all staff. | | |
| Access | <ul style="list-style-type: none"> • When running events for civil society provide all attendees with access information about the event and an opportunity to share their access needs. | | |
| | <ul style="list-style-type: none"> • 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 | <ul style="list-style-type: none"> • 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: <ol style="list-style-type: none"> Reasonable adjustment policy Disability leave policy An induction policy and process that provides explicit space for employees and board members to share access needs and reasonable adjustment requests | | |

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|------------------------------------|--|--|--|
| Policy and procedure (cont) | <ul style="list-style-type: none"> • Target and design recruitment materials to disabled candidates, with explicit mention of reasonable adjustments, flexible working and wanting a representative workforce. | | |
| | <ul style="list-style-type: none"> • Consider the adoption of workplace wellness action plans ⁸ | | |
| Training, learning and development | <ul style="list-style-type: none"> • Provide disability equality training for all staff and board members and ensure that it is part of any new staff member's induction. | | |
| Representation | <ul style="list-style-type: none"> • Ensure that all materials, including the website, reflect the diversity of the organisation's membership or service users, including disability. | | |
| | <ul style="list-style-type: none"> • Ensure materials produced have basic accessibility features such as alt text, plaintext, transcription and closed captioning. | | |
| | <ul style="list-style-type: none"> • Produce materials and stories which show civil society as a viable place to succeed as a disabled person. | | |
| Working at the intersections | <ul style="list-style-type: none"> • 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 | <ul style="list-style-type: none"> • Develop a standard expectation that disability data will be shared in annual reports by all large civil society organisations. | | |
| | <ul style="list-style-type: none"> • Actively engage the workforce and beneficiaries in discussions around reasonable adjustments and adaptations, especially in induction processes. | | |
| Approach and ethos | <ul style="list-style-type: none"> • Review what it would take to move your organisational practice from a social model approach to a disability justice approach (see glossary on p11). | | |
| | <ul style="list-style-type: none"> • Have measurable targets as part of an organisational inclusion and accessibility manifesto or strategy, and carry out annual reviews around implementation. | | |
| Access | <ul style="list-style-type: none"> • 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 | <ul style="list-style-type: none"> • Annually review all policies and procedures to ensure that they align with current best practice around access and inclusion. | | |
| | <ul style="list-style-type: none"> • Operate a guaranteed interview scheme for candidates who meet the essential criteria of jobs who identify as disabled. | | |
| | <ul style="list-style-type: none"> • Have established policies and procedures in place for reasonable adjustments, which support requests and include deadlines for implementation. | | |
| Training, learning and development | <ul style="list-style-type: none"> • Annually set aside staff development time to explore issues around disability inclusion. | | |
| Representation | <ul style="list-style-type: none"> • Ensure there is disability representation in all events, and that representation is not tokenistic and representative of the diversity of the disabled community. | | |
| | <ul style="list-style-type: none"> • 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 | <ul style="list-style-type: none"> • 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 | <ul style="list-style-type: none"> • 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. | | |
| | <ul style="list-style-type: none"> • 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 | <ul style="list-style-type: none"> • Develop and monitor an organisation-wide strategy for embedding Disability Justice as an intersectional approach. | | |
| Access | <ul style="list-style-type: none"> • Choose venues and activities based on accessibility as a key criteria. | | |
| | <ul style="list-style-type: none"> • 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 | <ul style="list-style-type: none"> • Commission independent reviews of policies and procedures to ensure they are promoting disability equity. | | |
| | <ul style="list-style-type: none"> • 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 | <ul style="list-style-type: none"> • 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. | | |

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| Training, learning and development (cont) | <ul style="list-style-type: none"> 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 | <ul style="list-style-type: none"> Ensure that disabled leaders are visible in activities and events - particularly on issues not related to disability. | | |
| | <ul style="list-style-type: none"> Employ and retain disabled leaders at the forefront of the organisation both in staff and board. | | |
| Working at the intersections | <ul style="list-style-type: none"> Embed an intersectional approach to organisational working through policy and procedure, and measure and report on intersectional grounds. | | |

Conclusions and next steps

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 providing 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.

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. Civil society organisations have an opportunity to be at the forefront of this effort.

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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