



# **Strengthening the Inclusion, Protection, and Wellbeing of Human Rights Defenders with Disabilities**



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Authors

**Alice M. Nah**, Durham University

**Martin Jones**, University of York

**Marjorie Unal**, Protection International

Graphic design

**Aitor García**

Illustrations

**Nyotumba Bonaventure**

Publishing coordinators

**Lucrecia Cisneros Rincón and Megan Thomas**

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## Foreword by Mary Lawlor

It is my pleasure to introduce this much-needed Guide on Strengthening the Inclusion, Protection, and Wellbeing of Human Rights Defenders with Disabilities. In my capacity as the UN Special Rapporteur on the situation of human rights defenders, I have highlighted how defenders with disabilities around the world are making a difference in their communities and societies. In my 2022 campaign, [Breaking Barriers](#), carried out in collaboration with the UN Special Rapporteur on the rights of persons with disabilities, Gerard Quinn, I highlighted practical ways in which States and NGOs can reasonably accommodate human rights defenders with disabilities in events and consultations. These include making buildings accessible, providing sign language interpretation and close captioning, and ensuring that people with disabilities are consulted on the wide range of issues that affect them, not just about disabilities.

In the exercise of my mandate, I have engaged with human rights defenders around the world from different genders, cultures, ages, backgrounds, and identities. I see how the perspective of each human rights defender is unique and valuable. Unfortunately, I also see how human rights defenders are deliberately and systematically excluded by those in power who make decisions that affect their lives. Women human rights defenders with disabilities confront gendered risks that include gender-based violence, exclusion, and stigmatisation for challenging patriarchal and heterosexist norms.

This Guide draws on the experiences of human rights defenders with disabilities to highlight how all of us must act together to ensure that our human rights movements are inclusive and diverse. We all need to recognise how ableism shapes our interactions, expectations, and participation in society. We need to design and implement protection practices with defenders with disabilities so that they are tailored to their specific circumstances. We need to assess risks differently, recognising that defenders with disabilities face heightened risks in everyday life.

I encourage you to read this Guide, which clearly highlights ways in which human rights movements around the world can support and strengthen the voice, participation, and power of defenders with disabilities.



**Mary Lawlor**

UN Special Rapporteur on the situation of human rights defenders


## Foreword by Gertrude Oforiwa Fefoame

As the Chair of the UN Committee on the Rights of Persons with Disabilities, I have witnessed and worked with many people with disabilities involved in promoting and protecting human rights around the world. They accompany those who have experienced violence and abuse; they champion the cause of those who have been neglected and ignored. They focus on diverse issues, advocating for disability justice, gender equality, the right to health, the right to education, labour rights, LGBTQIA+ rights, the rights of people on the move, the protection of civilians in conflict, peace building, and so much more.

As this Guide highlights, people with disabilities face many challenges and risks in defending human rights. There is limited recognition of the ableism that pervades institutions in society. Their access needs – including to participation in activism – are systematically overlooked. They are more exposed to risk and harm in daily life than those who are not disabled by society.

Human rights defenders with disabilities have great potential to transform the way human rights is understood and enacted. Their unique perspectives of their contexts, their creativity, their ways of navigating challenges and solving problems, enrich the way communities respond to human rights violations and violence. By designing a world that includes and values the contributions of human rights defenders with disabilities, we enable people from all backgrounds, abilities, and identities to participate meaningfully in society.

The perspectives of human rights defenders with disabilities are crucial if we are to forge a just and equal world. May you enjoy reading this Guide and be inspired to contribute to building human rights movements that are inclusive and diverse, thus enriching everyone.



### **Gertrude Oforiwa Fefoame**

Chair, UN Committee on the Rights of Persons with Disabilities

Global Advocacy Manager – Social Inclusion, Sightsavers

President, International Council for Education of People with Visual Impairment (Africa)

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All mistakes in this text remain our own.

**Alice Nah, Martin Jones, Marjorie Unal**

## Executive Summary

Everyone has the right to promote and protect human rights. However, many people are disabled by the way society is structured and systematically excluded from participating in decisions that shape their lives. Disability rights movements have grown in strength and power over time, offering critiques of how ableism continues to shape the way people design spaces, infrastructure, and decision-making processes.

This Guide examines the definition of a human rights defender with disabilities. It highlights that defenders with disabilities advocate for a broad range of rights, not just disability rights, and may not self-identify as a 'human rights defender'. To know if someone is a human rights defender, we look at their actions to see if they involve promoting and protection human rights.

Defenders with disabilities face many challenges and risks, including:

- Heightened risks in everyday life related to their disabilities
- The constant navigation of ableist ideas about human rights activism and expectations about behaviour
- Multiple impediments to participation, including physical barriers, communication challenges, being dismissed or ignored, and the lack of resources
- Societal barriers caused by marginalisation, stigmatisation, and exclusion
- Repression and shrinking civic spaces
- The long and hard struggle for disability inclusion and rights, leading to exhaustion and disengagement

The security and protection of defenders with disabilities can be strengthened by:

- Involving defenders with disabilities and their representative organisations in the design of protection practices so that they are tailored to specific needs and circumstances
- Assessing risks differently, recognising that defenders with disabilities live with heightened risks because of their disabilities
- Advocating for laws, policies, and practices that enable persons with disabilities to exercise their right to defend human rights
- Facilitating networking and movement building amongst defenders with disabilities
- Promoting holistic 'wellbeing in action' amongst defenders with disabilities

More broadly, it is also critical for human rights movements to be more inclusive of defenders with disabilities. This can be done by:

- Centering the meaningful participation and leadership of people with disabilities
- Acknowledging and tackling ableism, and
- Resourcing defenders with disabilities and inclusion initiatives in human rights movements

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## Introduction

Around the world, people with disabilities are involved in the promotion and protection of human rights in diverse ways. They advocate for justice, equality, non-discrimination, and the enjoyment of fundamental freedoms and human rights in all spheres of life. They do so individually and in collectives, in public and private encounters, with and without the support of the others.

While disability rights and disability justice movements have grown significantly in recent years, there has been relatively little attention on the experiences of human rights defenders with disabilities and the conditions that enable them to thrive in human rights activism. Social, political, and economic structures continue to reinforce ableism, both overtly and subtly, which carry through into human rights circles. Defenders with disabilities face direct and indirect challenges and risks that inhibit their capacity and effectiveness in promoting and protecting human rights.

### Who is this Guide for?

This Guide is written for people involved in the security and protection of human rights defenders ('protection actors'). It is aimed at building common understanding and facilitating dialogue about the challenges and risks that defenders with disabilities face and the kinds of practices that strengthen their security, protection, and wellbeing. As we progressed in this project, we realised that defenders with disabilities cannot be protected effectively if they are systematically excluded and marginalised in human rights circles. As such, this Guide also focuses on measures to strengthen disability inclusion in human rights organisations and movements.

### An overview of the Guide

Section One of this Guide introduces disability and human rights movements. It highlights the importance of how we understand 'disability' and perceive people with disabilities. It recalls the significant advancements that disability movements have made globally over decades. It examines practices that strengthen the voice, perspective, and power of defenders with disabilities, as well as those that diminish them. Section Two of this Guide focuses on the key question: Who are 'human rights defenders with disabilities'? It sets out some of the key challenges and risks which defenders with disabilities experience. It highlights key priorities for strengthening their security, protection, and wellbeing. Section Three highlights broader reforms that are needed to strengthen inclusion within human rights movements.

# 1

## **Disability and human rights movements**

## Understanding 'disability': A rights-based approach

The World Health Organisation (WHO, 2022) estimates that there are approximately 1.3 billion people with significant disabilities, around 16 percent of the world's population.

### **The Convention on the Rights of Persons with Disabilities (CRPD)** states that:

"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (Article 1).

There is an important distinction between impairments and disabilities. **Impairments** refer to "problems in body function or structure such as a significant deviation or loss" (WHO 2002, p. 10). Examples of impairments include the loss of a limb, loss of hearing, nerve damage, mental health conditions, debilitating pain, difficulty speaking, hyperactivity, and problems processing sensory information. In some cases, these impairments are undiagnosed, ignored, or dismissed. Each person experiences impairment differently.

**Disabilities** are about how barriers in society prevent a person with impairments from participating fully in society. As the CRPD states, "disability 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" (Preamble, e).

Contextual factors include environmental factors such as social attitudes, the built environment, legal and policy frameworks, as well as personal factors that intersect such as a person's gender, age, experience, and coping strategies. In other words, the way our society is structured determines whether a person's impairment results in them being unable to participate in specific contexts and situations – it is barriers in society that disable people, not their impairment or difference.

This approach leads us to analyse why and how someone becomes disabled by society and enables us to identify how this can be changed. Rather than seeing the person with impairment as the 'problem' than needs to be 'fixed', we focus on how barriers in society stop them from participating fully in social and political life.

## Different approaches to disability: The medical, social, and human rights models

There are different models for understanding disability. In this section, we explore three common models, highlighting key differences between them. The first model for understanding disability is the **medical model of disability**, a dominant model that is generally rejected by disability rights movements. This model sees disability as a problem located in an individual person that needs to be fixed and cured so that they can become 'normal'.

In this approach, people with disabilities tend to be seen as people who need to be cared for and protected, often by separating them from people without disabilities, for example, by keeping them in special schools, hospitals, or institutions. In this approach, people with disabilities also tend to be seen as people who are not able to make important decisions for themselves and thus need others to do this for them, such as a legal guardian. A **legal guardian** is a person who has the legal authority to make decisions for someone who is deemed unable to do so, for example, decisions about their housing, medical care, and finances. This model does not strengthen the voice, participation, and power of people with disabilities.

In contrast, the **social model of disability** focuses on how society causes and reinforces the discrimination and oppression of people with impairments. As Michael Oliver, one of the founders of this model explains,

*... disability according to the social model, is all the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on. Further, the consequences of this failure do not simply and randomly fall on individuals but systematically upon disabled people as a group who experience this failure to discrimination institutionalized throughout society* (Oliver, 1996, p. 33).

The model that rights-based organisations prefer is the **human rights model of disability**, which builds upon the social model of disability and views people with disabilities as rights holders of the full spectrum of human rights. In this model, impairment is considered as part of human diversity and human dignity; it recognizes that disability has been a basis for identity, culture, and organizing (Degener, 2017). Impairment should not be used as a reason to deny or restrict a person's rights. People with disabilities should be supported to claim their rights and to make decisions

about their own lives; they should not be expected to be passive recipients of help that remain dependent on others. Indeed, the purpose of the CRPD is “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (Article 1).

An important principle in the human rights model of disability is that “impairment does not hinder human rights capacity” (Degener, 2017, p. 43). As with every other person, human rights cannot be taken away from a person with disabilities. For example, a disabled person has a right to recognition as a person before the law. The CRPD calls for States to “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity” (Article 12, paragraph 3), which might be provided through social services and other means.

The CRPD highlights the importance of **reasonable accommodation** for people with disabilities, defining this as the,

*necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms (Article 2).*

Examples of reasonable accommodation could include:

- Providing written materials in accessible formats, such as large print or electronic text
- Allowing extra time for tasks or quiet spaces for work
- Providing assistive technologies, such as screen readers, text-to-speech software, or magnification software
- Modifying workstations at offices and at home
- Installing ramps, handrails, and accessible restrooms in public buildings
- Providing sign language interpreters and live captioning in meetings
- Providing extra security during work assignments for those at risk of violence because of their identities
- Offering flexible work schedules or telecommuting options

The CRPD also highlights the importance of **universal design**, defined in Article 2 as,

*the design of products, environments, programmes, and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. “Universal design” shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.*

Universal design principles benefit not only people with disabilities but a broad spectrum of people of all ages, sizes, and abilities.

## ☰ Box 1. Eight guiding principles of the Convention on the Rights of Persons with Disabilities (UNDESA, 2023)

These are the eight guiding principles of the CRPD that are reflected in specific articles:

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
2. Non-discrimination
3. Full and effective participation and inclusion in society
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
5. Equality of opportunity
6. Accessibility
7. Equality between men and women
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

## The focus of disability movements: Awareness, inclusion, rights, justice

Disability work can be viewed as a spectrum, from building awareness about disabilities, to ensuring the inclusion of people with disabilities in society, to focusing on their rights, and ensuring they enjoy disability justice. Historically, these approaches have been championed by different movements in different political contexts with different emphases.

**Organisations of persons with disabilities** play an important role in such work, defined by the CRPD Committee in their General Comment No. 7 (2018) as organisations led, directed, and governed by persons

with disabilities that have a clear majority of membership comprising persons of disabilities and which promote and defend the rights of people with disabilities.

Disability movements challenge ableism in society. **Ableism** is discrimination in favour of people without disabilities. An ableist worldview sees people with disabilities as inferior, abnormal, deviant, or undesirable. Ableism is present in our daily activities, routines, processes, and communication, whether we are aware of it or not.

## ☰ Box 2. A definition of ableism (Lewis, 2022)

Talila A. Lewis, a social justice lawyer and educator, defines ableism as follows:

*A system of assigning value to people's bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness. These constructed ideas are deeply rooted in eugenics, anti-Blackness, misogyny, colonialism, imperialism, and capitalism.*


*This systematic oppression leads to people and society determining people's value based on their culture, age, language, appearance, religion, birth or living place, "health/wellness", and/or their ability to satisfactorily re/produce, "excel" and "behave".*

*You do not have to be disabled to experience ableism.*

Advocates for **disability justice** emphasise that people with disabilities have different experiences of oppression, domination and exploitation depending on aspects of their identities. As one of the founders of this approach, Patty Berne, explains:

*A Disability Justice framework understands that all bodies are unique and essential, that all bodies have strengths and needs that must be met. We know that we are powerful not despite the complexities of our bodies, but because of them. We understand that all bodies are caught in these bindings of ability, race, gender, sexuality, class, nation state and imperialism, and that we cannot separate them. These are the positions from where we struggle (Berne, 2015).*

Sins Invalid (undated), a disability justice organisation, put forward their **10 Principles of Disability Justice** which are:

- 
1. Intersectionality
  2. Leadership of those most impacted
  3. Anti-capitalist politics
  4. Cross-movement solidarity
  5. Recognising wholeness
  6. Sustainability
  7. Commitment to cross-disability solidarity
  8. Interdependence
  9. Collective access
  10. Collective liberation

Sins Invalid emphasises the importance of **intersectionality**, recognising how different aspects of identity such as race, class, sexuality, age, religion, immigration status and geographical location matter in our experiences of privilege and oppression. They call for the **leadership of those most impacted**, that is, for disability justice movements to be led not by 'experts' but by people most affected by systems of oppression so that the



work is grounded in real world problems and in creative ways of resisting. They emphasize the importance of **cross-movement solidarity**, that is for disability justice movements to align with other movements that work for justice and liberation, as well as a **commitment to cross-disability solidarity** to break down isolation between people with different

types of disabilities. They also advocate for **collective liberation**, stating:

*"We move together as people with mixed abilities, multiracial, multi-gendered, mixed class, across the sexual spectrum, with a vision that leaves no body/mind behind."*  
(Sins Invalid, undated).



## Diversity in the experience of disabilities

How each person experiences their disability is unique and depends on factors such as the extent of their impairment, how their impairment interacts with other aspects of their bodies and identities, and the ways in which their impairment is understood, accepted, and accommodated in their social contexts. As a woman defender with hearing loss described to us:

*Disability is confusing, messy, and nuanced – my hearing loss is not the same as anyone else’s hearing loss – there is so much variation in the way each person interacts with similar and different disabilities.*

As such, we cannot presume that people with a particular kind of disability (e.g. chronic illness) experiences it in the same way, and we cannot presume that the accommodation they need is the same.

Many people do not think of themselves as a person with disabilities even though they may fit the definition. In this project, several defenders with disabilities shared with us that they develop an awareness of themselves as a ‘person with disabilities’ as they learned more about the concept of disability. As a woman defender with disabilities highlighted in an interview,

*... my recognition of my disability and being able to name it... had to do with the feminist circles I was in, and meeting other women with disabilities who helped me navigate their articulation.*

*And also, not feeling shamed when you’re asking for accommodation; to politicise it,*

*understanding where your labour needs to stop, and how to protect yourself around that ongoing labour of asking for accommodation.*

*So, I think the political aspect started when I entered feminist circles properly...*

Some described this development of self-awareness as a journey of discovery as they learned more about themselves, their functioning, needs, and how to advocate for themselves and for others about disabilities. They highlighted how it was easy to **internalise ableism** themselves, as they were constantly exposed to societal expectations of beauty and the ‘perfect body’. Internalised ableism can cause people with disabilities to feel ashamed of themselves; it can lower self-esteem and result in people with disabilities not asking for accommodation.

Many disabilities are **non-apparent** (or **non-visible**). That is, someone may have a disability that is not immediately obvious from their appearance. Some have a **dynamic disability**, that is, their needs or abilities change over time, as does their need for support and accommodation. For example, someone who suffers from frequent migraines may have days where they are relatively pain-free and days where the pain is debilitating.

Many people have **multiple disabilities**. For example, a person might have a medical condition (such as diabetes, asthma, epilepsy, chronic fatigue syndrome), a psychosocial disability

(such as depression, schizophrenia, post-traumatic stress disorder, or anxiety), and an intellectual, cognitive, or developmental disability (such as autism spectrum disorder, dyslexia, and sensory processing difficulties).

Intersecting systems of oppression shape how defenders with disabilities are treated because of aspects of their identity, such as their gender, sexual orientation, ethnicity, education, and class. For example, an indigenous girl with intellectual disabilities in a rural community experiences disability differently from a man with visible disabilities from an economically privileged background. The former may not have her disabilities recognised and may not be able to secure the assistance she needs at school. The latter may be able to afford the equipment he needs to help him function in society. As described above, an intersectional approach can reveal how each person experiences disability differently depending on their identities, situation, and context.

## Disability etiquette

Non-disabled people can feel awkward and unsure about how to behave with people with disabilities. They may not know what is right or appropriate to say or do. Because ableism is deeply embedded in society and shapes the way people communicate, some of the words that non-disabled people use in everyday speech can be insulting or hurtful to people with disabilities, for example, phrases such as ‘fall on deaf ears’, ‘turn a blind eye to’, and ‘needing a sanity check’.

The appropriateness of language is also contextual and subjective – what is acceptable to one person with disabilities can be inappropriate to another.

There are several useful resources available on **disability etiquette**, that is, how to treat people with disabilities with respect and care. Judy Cohen (undated) suggests the following key principles:

- Don't assume a person with disabilities needs help – only offer help when the person seems to need it, and ask how you can help before you act
- Be sensitive about physical contact, recognising that they may not want their bodies or their equipment to be touched
- Speak directly to the person with a disability, not their companion, aide, or interpreter, respecting their privacy about their disability
- Respond graciously to their requests for accommodation, rather than interpreting these as complaints

- Don't make assumptions about what they can or cannot do, and don't make decisions for them about whether they can or cannot participate in a particular activity

She also provides the following tips on language:

- Put the person first before the disability, for example, saying "person with a disability" instead of "disabled person", asking individuals about their preferences
- Avoid outdated terms such as "handicapped" or "crippled" as well as euphemistic terms such as "physically challenged" and "differently abled"
- Say "wheelchair user" rather than "confined to a wheelchair"; recognising the wheelchair liberates rather than confines the person
- Using idioms such as "it was good to see you" or "see you later" to a blind person is acceptable

- People who are Deaf and communicate in sign language may be offended if you refer to them as "hearing impaired" because they consider themselves a cultural and linguistic minority

- Avoid negative, disempowering words like "victim" or "sufferer"

In her guide, *Disability Etiquette*, she provides further guidance on respectful communication with people with specific disabilities, including people who use wheelchairs or have mobility impairments, people who have psychiatric disabilities, and people who have cognitive disabilities. These tips need to be assessed in relation to the expectations of people with disabilities, to see their relevance and significance.



# 2

## **Human rights defenders with disabilities**

## The right to defend human rights

Everyone has the right to promote and protect human rights. The 1998 United Nations Declaration on Human Rights Defenders (formally known as the Declaration on the Right and Responsibility of Individuals, Groups and Organs of Society to Promote and Protect Universally Recognized Human Rights and Fundamental Freedoms) affirms this right, stating:

*Everyone has the right, individually and in association with others, to promote and to strive for the protection and realization of human rights and fundamental freedoms at the national and international levels.*

People promote and protect human rights in diverse ways. For example, they do so by: speaking up about social and political issues; highlighting experiences of discrimination and inequality; drawing attention to incidents of violence and abuse; providing services to marginalized communities, such as legal aid, education, and health care; rescuing people from dangerous situations; monitoring places where people are detained (such as prisons and detention centres) to make sure that they are treated humanely; campaigning for laws, policies, and government practices to safeguard rights, and so on.

While everyone should be able to promote and protect human rights safely, these actions can be risky. Some defenders are directly threatened and attacked for their work. For example, they may be shamed publicly online or offline, threatened with violence, or put under surveillance.

Some have been beaten, criminalized, imprisoned, and even killed or disappeared. The threats and attacks they face depend on factors such as the issues they fight for, their identity and social connections, the motives and actions of perpetrators, and the political, social, and economic contexts in which they act (Nah, 2021).

Over time, both state and non-state actors have developed an **international protection regime for human rights defenders at risk**, aimed at enabling them to promote and protect rights in safety and dignity (Bennett et al, 2015). These protection actors engage in a wide spectrum of activities aimed at building a safe and enabling environment for the defence of rights, as well responding to the situation of human rights defenders during emergencies. Their activities include advocating for laws, policies, and practices that recognize and protect the right of everyone to defend human rights; denouncing impunity for crimes against human rights defenders; and providing human rights defenders with security training, accompaniment, emergency grants, temporary relocation, and other forms of support, so that they can stay safe as they promote and protect rights.

## Who are human rights defenders with disabilities?

A human rights defender with disabilities is any person with disabilities who promotes and protects human rights.

Defenders with disabilities do not just focus on disability rights, they focus on all types of freedoms and rights, such as environmental rights, land rights, labour rights, women's rights, LGBTIQ+ rights, climate change, transitional justice, economic justice, and so on.

The experience of disabilities can lead to activism, and disabilities can be acquired through activism. That is, people with disabilities may advocate for change so that they and others like them can enjoy rights that they have been denied. Some people also acquire impairments because of their activism, for example, they may suffer physical, psychosocial, or cognitive harm from experiences of harassment, violence, stigmatisation, and criminalisation, which lead to them being disabled.

Many people, including those with disabilities, do not think of themselves as a 'human rights defender'. They may describe themselves in other ways, for example, as an activist, advocate, community worker, student, teacher, journalist, carer, a concerned friend, or a family member. In some communities, the term 'human rights defender' has been used very narrowly and exclusively, for example, to refer to high-profile, well-known activists, and not to the full range of people who might fit the term.

In many contexts, people are unfamiliar with the term 'human rights defender'.

Many people who promote and protect human rights do not use human rights vocabulary to describe their work. They may refer to their work in different ways, such as work for social justice, equality, fairness, inclusivity, diversity, peacebuilding, humanitarianism, or community development. To know if someone is a human rights defender, we look at their actions to see if they involve promoting and protecting human rights, rather than what they call themselves or what others call them.

## Challenges and risks: The experiences of defenders with disabilities

Human rights defenders with disabilities face challenges and risks in promoting and protecting rights that can be different to those experienced by defenders without disabilities. What is not considered risky to a person without disabilities can be risky to a person with disabilities. Some of these challenges and risks are **direct** – that is, they specifically target defenders with disabilities. Some are **indirect** – that is, they occur when the same laws, policies, and practices are applied to everyone but have a worse impact on defenders with disabilities.

## Heightened risks in everyday life

Defenders with disabilities navigate risks in daily activities that are not experienced by those without disabilities. Depending on the type and severity of their disabilities, they face challenges and risks that arise from poorly designed spaces, exposure to communicable diseases that further compromise their health (including Covid-19), exclusionary communication, social isolation, and political marginalisation. For example, walking on poorly constructed streets with high traffic is much riskier for a person who is visually impaired. Social interaction during the pandemic is much riskier for a person who is immunocompromised. Defenders with albinism must work with caution in places where they are at risk of being maimed, abducted, or killed, because of witchcraft and traditional rituals. In some places, women defenders with disabilities are confined at home by their families, restricting their ability to participate in activism.

Because they navigate heightened challenges and risks in daily life, the defenders with disabilities that we interviewed tended to stay away from high-risk forms of activism – activities that had a higher chance of exposing them to danger and harm. The impact of high-risk activities can be greater for people with disabilities; they can have fewer resources to mitigate these risks. As an example, several defenders observed how they avoided Pride events, marches, and public protests, worried about how they would escape if the police shut these

down aggressively. As a defender with disabilities explained, “There is a level of self-preservation and seeking other ways to resist.”

Defenders with disabilities in this study also spoke about the **emotional risks** they face for defending their rights. They risk being excluded from social circles, losing friends, being criticized on social media, being seen as a “difficult person”, and so on. As a woman defender with disabilities observed with regret, “people say that I am complaining too much, that I’m too angry”. Such losses can have a deeper impact on those already struggling with isolation and alienation because of their disabilities.

The risks that defenders with disabilities face also depend on how they are impacted by other systems of oppression. **Women human rights defenders** experience additional and different risks because of their gender (Forst, 2019). For the same actions that men are praised, women can be stigmatised. Women are often perceived as ‘vulnerable’ and ‘victims’ in need of protection, rather than champions of change. The intersection of gender, race, class, education, age, sexual orientation, gender identity and expression, and other characteristics matters in experiences of risk. In this study, a queer defender with disabilities shared how they faced risks related to their sexual orientation and gender identity as well as those related to their disabilities, all of which impacted on their mental health and wellbeing.



## Navigating ableism

Defenders with disabilities must navigate ableism where they promote and protect human rights. As the UN Special Rapporteur on the situation of human rights defenders and the UN Special Rapporteur on people with disabilities observed, defenders with disabilities “often have to advocate for rights in spaces and processes that are ableist, with stakeholders who do not understand, or are not willing, to provide resources for reasonable accommodation” (Lawlor and Quinn, 2022).

As explained above, the way we define ‘human rights activism’ can reflect an ableist bias. It is a common belief that all actions to promote and protect human rights must be public, confrontational, contentious, and involve taking high risks. In this study, some defenders with disabilities choose to engage in **soft activism**, what artist Samet Durgun (2023) defines as: “A subtle form of advocacy that gradually influences hearts and minds without causing shock,

emergency, or disturbance.” As he observes, “This approach may be less ‘visible’, yet its deep roots can bring about lasting transformation over time”. As a defender with disabilities said in an interview,

*“just by people seeing how you do your things, or how you carry yourself, how you respond to issues, that is still activism... it is ‘activism by example’ – by how you go about your things.”*

A person can promote and protect human rights through their words and their lifestyles; through their decision to resist discrimination in the face of opposition; through daily efforts to shift the attitudes of those around them. It is important to recognize the full range of ways in which people defend human rights, as a narrow definition can lead to the exclusion of defenders with disabilities who take action to transform society in gentler, quieter, less visible ways.



Another way in which ableism shows up in human rights communities are **expectations about behaviour**. Priority for participation is often given to those who move easily, communicate well, think fast, and can connect emotionally with audiences. Such expectations make it difficult for defenders with disabilities to participate effectively. Describing her experiences of facilitating meetings, a woman defender with hearing impairment said in an interview:

*People who are at the centre of movements, they generally – at least from the cognitive and verbal perspective – seem to appear to have less struggle. For people who are not able to hear or see... it is very limiting in terms of how we facilitate and what facilitation means. How do we take up the stage when we may not be understood?*

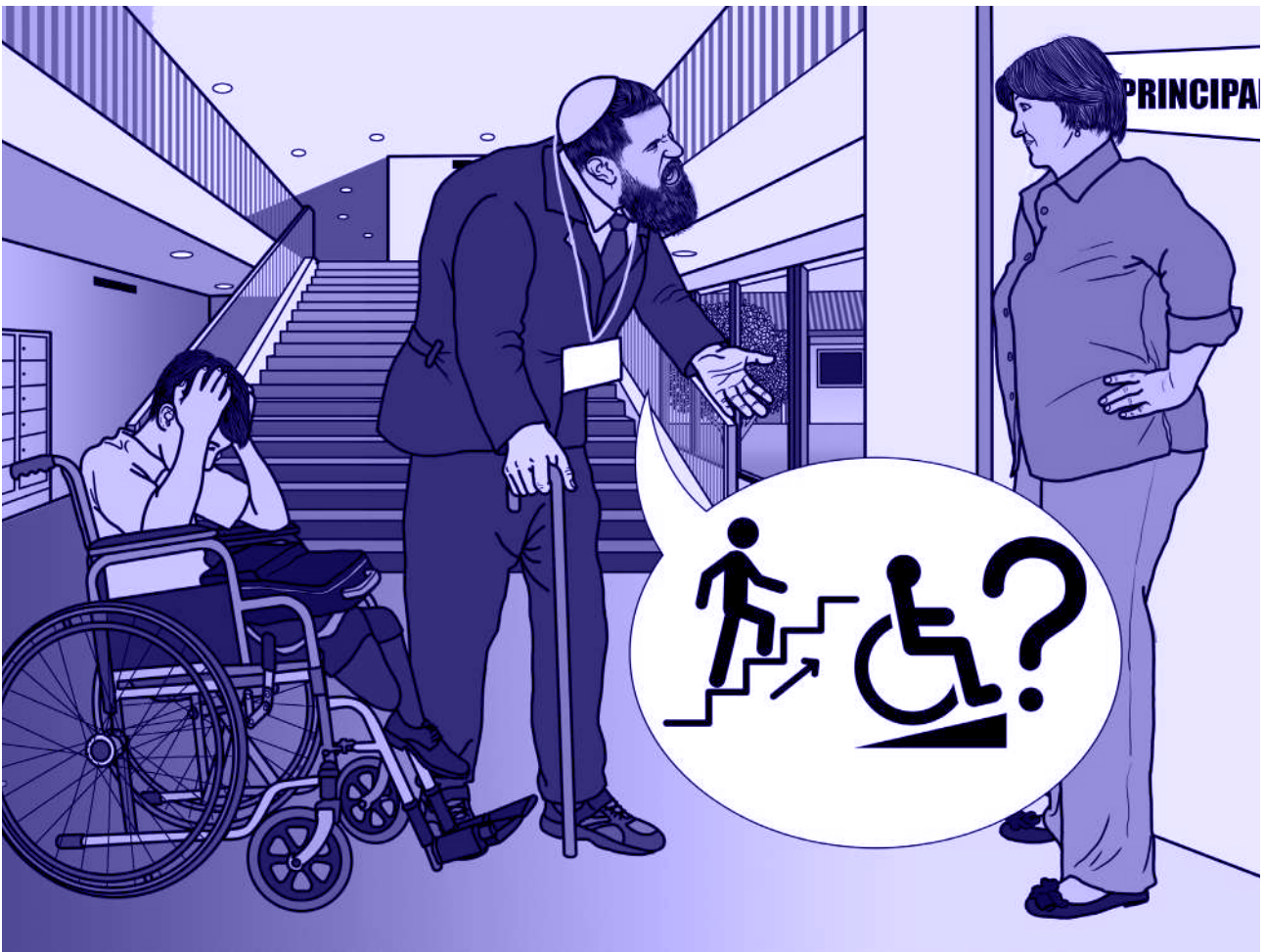
*I have struggles where I am trying to facilitate. But if my needs are not met with a microphone or other things, then I'm not engaging with the participants in the same way, and I just disconnect... these kinds of things are always limiting for me. So, sometimes I stop and say, "How do I want to go into that particular space?" Because I know I will find myself limited...*

## Accessibility to participation in activism

Defenders with disabilities often face challenges in accessing the places, people, and conversations where they can present their issues. In some cases, they – along with people without disabilities – are systematically blocked from participation. For example, they may not be informed that an important meeting is happening, or if they are told about it, they are not given permission to participate. There are also dimensions of accessibility that relate specifically to disabilities.

The first is **physical accessibility**. This means being able to access the physical space where they want to participate. This has to do with the design of the space and infrastructure that affects the way they travel to a meeting, attend it, and return home. For example, a defender who uses a wheelchair will find a place that requires the use of stairs inaccessible. Wheelchair accessible vehicles, ramps with the right gradient, and clear and wide walkways from the start to the end of their journeys would increase accessibility. Defenders who are located far away or in remote, rural areas, will also find it more difficult to access decision-making spaces.

The second is **communicative accessibility**. This means being able to receive, understand, and communicate information in a timely way so that they can participate effectively. A defender with hearing loss in a noisy room will find conversation difficult. A place equipped with hearing induction loop systems would increase accessibility. A defender



who has intellectual disabilities would find documents that are complicated, full of jargon, poorly formatted, and given to them immediately before a meeting inaccessible. Easy-read documents that are jargon-free, formatted appropriately and provided in advance would help them to prepare for a meeting properly. Some defenders might need material to be provided in large font, Braille, colour contrasted documents, or accessible documents that can be read with screen readers.

The third is **representative accessibility**. This means being recognized and seen as a person that is relevant to participate – that is, not being dismissed, overlooked, or side-lined. The International Disability Alliance (2020) observe that some people with disabilities are left out more than

others in consultations and decision-making processes, particularly those with psychosocial disabilities, intellectual disabilities and deafblindness, as well deaf people, women with disabilities and indigenous people with disabilities. If people with disabilities are seen as being unable to speak for themselves and others, they will be excluded from meetings. Invitations to participate in meetings also tend to happen through social networks. If defenders with disabilities are systematically excluded from social networks, they are less likely to be invited to participate in meetings.

The fourth is **resource accessibility**. This means having the resources needed to participate effectively. This includes knowing how to obtain resources and

manage them, such as knowing how to apply for funds, navigate the bureaucratic requirements of funders, set up and maintaining organisational infrastructure, meet legal requirements for organisations, develop policies and processes for managing people and funds, and so on. This has become even more challenging with the introduction of laws, policies and administrative practices aimed at regulating civil society organisations tightly (elaborated below).

### **Societal barriers: Marginalisation, stigma, and exclusion**

Ignorance and prejudice about disability in society can result in people with disabilities being shamed, ignored, excluded, or mistreated. In some cases, cultural and religious beliefs can increase the danger faced by defenders with disabilities significantly.

In many contexts, defenders with disabilities face economic precarity, as they are systematically excluded from educational institutions and workplaces. The United Nations Children’s Fund observes that “in general, persons with disabilities are more likely to live in poverty and less likely to have access to clean water, sanitation and hygiene” (UNICEF, 2022, p. 16). People with disabilities are at higher risk of being locked up at home, at hospitals, psychiatric institutions, and detention centres. The World Health Organisation (2023) estimates that people with disabilities die up to twenty years earlier than those without disabilities.

Defenders with disabilities may also face higher risks because of their political contexts. In conflict situations, for example, those with physical impairments may find it harder to flee from attacks (DefendDefenders, 2022), while those with sensory, developmental, or intellectual impairments may not have the information they need to understand what is happening (Human Rights Watch, 2022).

Public perceptions and popular portrayals of people with disabilities matter. As a defender with disabilities highlighted, “Negative media coverage of disability advocates affects their effectiveness”. Media portrayals that cast defenders with disabilities as needy, weak, or a ‘charity case’ are unhelpful. Disability can be deemed unappealing or uninteresting to the public and thus not be given media focus.

### **Repression and shrinking civic spaces**

Around the world, States have been using laws, policies, and administrative practices to restrict people in their defence of human rights. For example, some States have made it difficult for people to register civil society organisations, imposed extraordinarily high reporting requirements, restricted the receipt and transfer of funds, and so on. States use different explanations to justify these, for example, saying that these actions are aimed at countering terrorism, improving public health, or reducing corruption and crime. However, these restrictions have been used against human rights defenders to stop their work.

CIVICUS (2023) observes that almost one-third of people in the world live in countries with **closed civic space**, that is, where:

*There is complete closure – in law and in practice – of civic space. An atmosphere of fear and violence prevails, where state and powerful non-state actors are routinely allowed to imprison, seriously injure and kill people with impunity for attempting to exercise their rights to associate, peacefully assemble and express themselves. Any criticism of the ruling authorities is severely punished and there is virtually no media freedom. The internet is heavily censored, many websites are blocked and online criticism of power holders is subject to severe penalties.*

CIVICUS highlights that only two percent of people live in countries where they can organise, participate, and communicate freely and openly with each other without hindrance from their governments. In many countries around the world, CIVICUS observes that people exercising their rights have been harassed, detained, intimidated, subject to restrictive laws, attacked, had their protests disrupted, and have been censored, prosecuted, and detained.

In addition to these, defenders with disabilities may also have their freedoms and rights restricted by laws, policies, and practices that discriminate against them directly and indirectly. In some countries, for example, they are seen as being without legal capacity to make decisions of their own. Some countries may not have laws, policies, and practices that protect them sufficiently from



discrimination and exclusion. As such, defenders with disabilities face multiple layers of discrimination – in their social life, in human rights spaces, in workplaces, and because of the lack of legal protection of their rights.

### **The protracted struggle for disability inclusion and rights**

Across our interviews, a strong theme that emerged was how long and hard the struggle was for disability inclusion and rights. As a defender with disabilities observed in an interview,

*After some years and decades, it is frustrating because the other stakeholders do not understand what disability and disability rights are all about. We have been raising awareness, organising lots of events and training, but one way or another it doesn't lead to changes that would be essential or compulsory. It is a frustration that we are talking about the same matter, the same issues, after ten years. It's a stressful feeling, feeling frustrated.*

Another participant in this study observed,

*Activists [with disabilities] are quickly able to learn from others and become activists, but you see them walking away from activism, because they don't see the positive outcomes from their activism. Why do we not manage to retain those activists for a long time? That might be connected to the lack of support for activists.*

Despite these struggles, people with disabilities have emphasised the importance of maintaining connection, hope, and joy as they act for change.

## **Strengthening the security and protection of defenders with disabilities**

Efforts to strengthen the security and protection of defenders with disabilities must address the challenges and risks that they face in their specific contexts. Over the past few decades, many States, civil society organisations, and human rights defenders have come together to strengthen the security and protection of human rights defenders at risk through a range of protection initiatives. In this section, we highlight key recommendations from defenders with disabilities about how protection actors can support them in their security and protection as they promote and protect human rights. These recommendations sit within a broader framework of recommendations on how human rights movements can better enable people with disabilities to defend their rights through inclusion (Section Three of this Guide).

### **Involving defenders with disabilities and their representative organisations in the design and implementation of protection practices**

To increase the inclusivity and effectiveness of protection practices, it is essential to involve defenders with disabilities and their organisations in the design and implementation of protection practices at all stages. As a defender with disabilities observed in an interview,

*In anything that you're trying to come up with to assist persons with disability... you need to ensure that they themselves are involved in what you want to do for them... it would be ill-advised to come up with a solution where they have not been involved, because most of the time, you may find some subtle details that were left out.*

*And remember, by the time you're coming up with that solution, you have already used your resources. So, the resources become useless when the right approach is not taken. If you want to come up with anything... have the persons with disability themselves in that from the outset – from objective-setting to monitoring and evaluation... That way, I believe it will work, at least, maybe 80%. And it would gain acceptance from a wide range of persons with disabilities.*

Focusing on training specifically, another defender with disabilities suggested,

*... involve defenders with disabilities and their assistants or caregivers in planning for best methods of guaranteeing their participation and learning in training sessions. For example, in digital security training, some technical terms might not be easily comprehended by sign language interpreters, or some practical demonstrations may exclude blind participants. This needs to be looked upon before implementing such activities.*

To support a defender with disabilities in their activism, it is important to listen to them, ask them what they want to do, what they want to achieve, and the barriers that impede them. Each defender has a unique experience of disabilities, and they should lead the solutions and responses for their own situations.

Examples of good practice include:

- In **conferences, meetings, and workshops**, setting agendas that are led by defenders with disabilities. Train facilitators and meeting convenors about disability awareness and access issues. Plan in sensory breaks and avoid rushed agendas packed with information. Design activities that are inclusive of people with different types of bodies – don't assume that they should move or behave in particular ways. Offer alternatives, for example, facilitating bodywork exercises that have different options. Provide funding so that the defender can have an assistant with them who understands their needs, thus reduces their dependency on those around them. Provide funding for their participation in events, for example, when they participate as speakers, rather than expecting them to do it as an unpaid volunteer, recognising that people with disabilities often suffer from unemployment or underemployment. Pre-identify accessibility needs for each participant and arrange for reasonable accommodation. Plan such events properly, with sufficient resources, communicating logistical information in advance.

- When **re-granting** or providing **emergency grants**, ensure that disability inclusion is a criterion in grant-making guidelines and calls for proposals. Explicitly include defenders with disabilities as a priority group of the grant. Consider how decision-making about the urgency and validity of grants may be ableist, for example, by privileging defenders advocating for civil and political rights through visible, high-risk actions. Ensure that grant-making processes are accessible, easy to understand, and easy to complete, including the application form for the grant and the websites where information is publicized. Include a section in the application form where defenders with disabilities can explain how their specific needs can be addressed and include a budget line for reasonable accommodation.
- Creating and providing **learning grants** that explore how defenders with disabilities understand and navigate safety, protection, risk, and wellbeing, as well as **joy grants** for people with disabilities to pursue activities that bring joy, celebrate resilience, and support wellness (such as those provided by the [Borealis Philanthropy Disability Inclusion Fund](#)).
- In **temporary relocation initiatives**, consider the specific needs of people with disabilities, such as accessible housing and offices, the provision of medical treatment, accessible transportation, and personal care assistance.
- Providing **capacity building** for defenders with disabilities on topics such as: unpacking biases and assumptions (for example, around gender, sexual orientation, religious freedom); conducting risk assessment and mitigation, developing self-protection plans; accessing resources for activism, including funding, volunteers, and social networks; accessing protection resources and initiatives specifically designed for human rights defenders at risk; organisational development; and looking after individual and collective wellbeing.



### ☰ Box 3. Seven principles underpinning good protection practices (Forst, 2016)

(Then) UN Special Rapporteur on the situation of human rights defenders, Michel Forst, in his report to the Human Rights Council in 2016, put forward the following seven principles that underpin good protection practices.

**Principle 1:** They should adopt a rights-based approach to protection, empowering defenders to know and claim their rights and increasing the ability and accountability of those responsible for respecting, protecting, and fulfilling rights.

**Principle 2:** They should recognize that defenders are diverse; they come from different backgrounds, cultures, and belief systems. From the outset, they may not self-identify or be identified by others as defenders.

**Principle 3:** They should recognize the significance of gender in the protection of defenders and apply an intersectionality approach to the assessment of risks and to the design of protection initiatives. They should also recognize that some defenders are at greater risk than others because of who they are and what they do.

**Principle 4:** They should focus on the “holistic security” of defenders, in particular their physical safety, digital security and psychosocial well-being.

**Principle 5:** They should acknowledge that defenders are interconnected. They should not focus on the rights and security of individual defenders alone, but also include the groups, organizations, communities, and family members who share their risks.

**Principle 6:** They should involve defenders in the development, choice, implementation and evaluation of strategies and tactics for their protection. The participation of defenders is a key factor in their security.

**Principle 7:** They should be flexible, adaptable, and tailored to the specific needs and circumstances of defenders.

## Assessing risks differently

People with disabilities are diverse, and their personal experiences of disability and risk can be very different. As mentioned above, defenders with disabilities face risks that defenders without disabilities do not. What might be a relative safe context for a person without disabilities can be risky to a person with disabilities. It is important for risk assessments and protection interventions to recognise that a person's experience of risk can be heightened considerably by their disabilities.

For example, a woman human rights defender with a physical disability might ask for support to travel by taxis, because this is the only way for her to move around safely in her area. Another might ask for financial support to cover the costs of an assistant to help her to attend an advocacy workshop. Those who assess such requests may question why such support is necessary and how it links to 'activism', not recognising the significance of access issues and the importance of soft forms of activism.

An intersectional approach to risk assessment and management is helpful for revealing root causes of risk and mitigation capacities. Protection actors can work with defenders with disabilities and their organisations to review the protocols they use to assess risks and make decisions about the protection support offered to defenders with disabilities.

## Advocating for laws, policies and practices that enable people with disabilities to exercise their right to defend human rights

Because defenders with disabilities are impacted by laws, policies, and practices aimed at repressing human rights work and shrinking civic space, both directly and indirectly, protection actors need to focus on documenting, analysing, and countering these impacts. In some cases, reforms are required; in other cases, new legislation and policies are needed to protect the rights of people with disabilities. It is critical to hold States accountable for their obligations under international human rights law, including the CRPD.



### Facilitating networking and movement building amongst defenders with disabilities

Participants in this study highlighted the importance of building solidarity with people across issues and movements. As highlighted in Section 2.2, many people with disabilities who promote and protect rights do not consider themselves as a human rights defender. Many are also unaware of the international protection regime for human rights defenders at risk. Connecting them with protection actors and resources in their contexts can strengthen their work and help them to withstand opposition.

Similarly, another key step is to ensure that disability rights groups are connected to local, regional, and international human

rights networks and coalitions. This can help to raise awareness about disability rights issues and ensure that the unique perspectives and experiences of people with disabilities are represented within human rights spaces.

On disability rights specifically, participants in this study advocated for a **pan-disability approach** that includes people with any form of disability, whether physical, behavioural, or emotional, sensory, or developmental. As a disability rights defender argued,

***Solidarity can be interpreted as including different types of people. We encourage different organisations with disabilities to work together... a united voice is always stronger than one individual voice. Solidarity in those contexts mean we are not leaving***

*any disability group behind... we are not just focusing on our own special needs, but we understand that there are different needs... That kind of 'working together' can support the disability rights movement and make the disability sector more visible. Then promoting their rights can be easier – it is a joint action, and we can expect more tangible results.*

However, they also recognized that some defenders only wanted to focus on their own specific disability instead of engaging in pan-disability activism.

In some cases, people with some types of disabilities might not be familiar with other types of disabilities. Asked to compare his experiencing advocating for people with intellectual and development disabilities compared to other disabilities, a disability rights defender said in an interview,

*It's so different. It's so different. It's so different.*

*I think that even in disability, there are those who are much more marginalized... [they think] "well, with those with intellectual disability, we cannot really involve them". Even within [the disability movement] there is some tokenism for other types of disabilities.*

Participants in this study also cautioned about inequalities in power and representation in disability movements. As a disability rights defender observed in an interview,

*I've seen people who have obviously come from a place where they've felt oppressed, and they've come into power, and they've*

*forgotten their roots. And that can happen in any movement... power is such a big issue because of ableism... definitely, there are activists where their disability can fuel their insecurity... and [they want] to maintain that power-hold once they've got it.*

Patriarchal norms are also present in human rights movements, and this can result in patronizing behaviour, tokenism, and sexual harassment. It is important to recognise heterogeneity within disability movements and to examine power-relations with an intersectional lens. This can help to reveal inequalities in positionality, voice, and representation amongst groups and communities, helping to identify whose voices are ignored or silenced.

### **Promoting holistic 'wellbeing in action' amongst defenders with disabilities**

There has been growing attention amongst human rights defenders about the significant of wellbeing in human rights movements but also of the challenges in addressing this topic. Cultures of human rights practice value bravery, commitment, sacrifice, and selflessness, prompting feelings of guilt amongst human rights defenders about self-care (Barry and Đorđević, 2007; Barry and Nainar, 2008; Nah, 2021). Discussions about mental and emotional wellbeing are culturally informed, politically laden, and socially sensitive; human rights defenders are concerned about being deemed unwell or unable to cope. A participant in this study noted, "we wrongly assume that mental health is the price we have to pay for [our activism]".

In this study, defenders with disabilities shared with us that their wellbeing was linked to financial insecurity; the feeling of 'living below your potential'; being perceived as lacking value in society; and fear of being rejected, stigmatized, and side-lined. As a defender with disabilities observed in an interview, "being accepted, being seen, is essential to wellbeing". They also emphasized the struggles they had with maintaining physical wellbeing. A defender with disabilities said, "we are a bit more restricted when it comes to opportunities and services to do [physical] exercises". Just navigating daily life can be a struggle. Describing her daily relationship with wellbeing, a defender with disabilities said in an interview,

***It's really a collection of very little things... that accumulate over time throughout your day... eventually, you just come to the end of the day, and you're... just exhausted and completely drained. Because of minor things that – if they just got fixed – you would feel so much better... each one of them on their own seems trivial, but when you put them all together... it's too much. It's overwhelming. It's draining.***

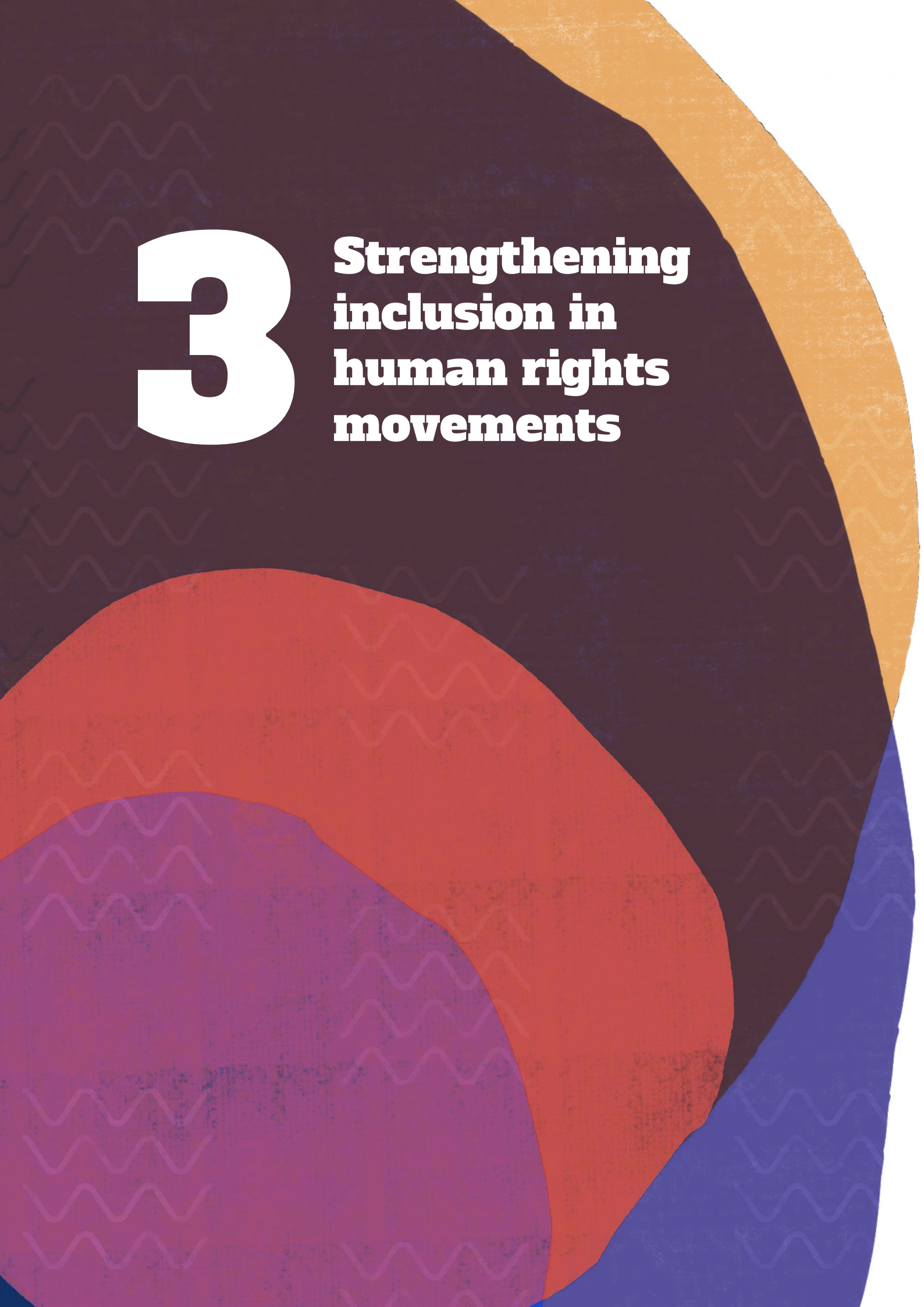
***So... for me to have good mental health, I need to get rid of all these little things that are a constant nuisance in my life... they are a constant nuisance, not because that's just the way they are, it's because people don't think about people like me when they're designing things... [and when] you go and tell them about it, they can't change it anymore because it is either 'too expensive' or it is 'too much trouble'.***

And yet, as another defender with disabilities noted, "people with some form of disabilities cannot survive without thinking about their relationship with wellbeing". We found in this study that defenders with disabilities were constantly navigating their limits. They welcomed conversations about their wellbeing, which was often overlooked. They emphasised the importance of positive framings for conversations on wellbeing – such as focusing on resilience, joy, empowerment, and strength.

They shared that being in peer-support groups, connecting with like-minded people in safe spaces, personal hobbies (such as gardening and creating art), spiritual practices, wellbeing retreats, and therapy sessions, strengthened their wellbeing. Those who worked on difficult human rights cases also found it helpful to have opportunities to share about their work, and to ask for advice about how to handle cases and complicated situations. There was overwhelming support for more research and reflection on the wellbeing of defenders with disabilities in human rights movements.

# 3

## **Strengthening inclusion in human rights movements**



Inclusion means respecting the full human rights of all persons, acknowledging diversity, and ensuring that everyone can actively participate in human rights processes and activities, regardless of age, gender, disability, state of health, ethnicity, or any other characteristic. Inclusion is not just about involving or integrating people with disabilities in activities, it is also about upholding rights by recognising barriers to inclusion and taking active measures to address these. In this section, we highlight recommendations from participants about how human rights movements can better enable people with disabilities to defend their rights more effectively.

## Centering the meaningful participation and leadership of people with disabilities

**‘Nothing about us without us’** has been the slogan and integral message from disability rights movements for decades. This means that people with disabilities must participate in decisions that relate to them; nothing that concerns them should be planned or implemented without their input. Involving people with disabilities in decision-making processes contributes to a more comprehensive consideration of their needs. Non-disabled people may not capture nuances around inclusion when designing activities. As a defender with disabilities observed,

*Persons with disabilities often have unique insights about their disability and their situation. They have the potential to contribute actively and meaningfully to develop inclusive workplaces as well as programmes at all stages. Therefore, organisations of persons with disabilities should be consulted as experts in identifying and responding to access barriers.*

Another defender with disabilities emphasised, “It is equally important to have a good sample of persons with disability representing different disabilities and different contexts”. The participation of defenders with disabilities must be planned from the beginning of an event, because it takes time to find participants, create engagement formats that are meaningful, and plan for reasonable accommodation. It is important to invite and include defenders with disabilities on all human rights issues, not just when disability is on the agenda.

### Employing people with disabilities and providing reasonable accommodation

**Employing people with disabilities** is a crucial step in ensuring the meaningful participation of people with disabilities human rights movements. Studies show that organisations that take accessibility seriously benefit from stronger organizational performance – it boosts their workplace reputation, and they are better able to attract talent (Accenture, 2018). Human rights organisations should lead such initiatives and serving as role models for others.

A common response by organisations is that people with disabilities don't apply for jobs that are advertised. To address this, they could collaborate with organisations of people with disabilities to jointly identify qualified candidates with disabilities for job openings and provide disability awareness training to staff involved in recruitment. Organisations could set recruitment and retention goals for people with disabilities and track their own progress in achieving these goals. For example, there are organisations that proactively encourage people with disabilities to apply for jobs and that guarantee an interview for applicants with disabilities who meet the minimum criteria for a vacancy.

Another key priority is for human rights organisations to provide reasonable accommodation for people with disabilities to enable them to perform their jobs effectively. Some managers fear that employing people with disabilities will pose an economic burden that their organisations cannot bear. However, as a defender with disabilities explained,

***When organisations think “if we bring people with disabilities on board it will mess up our budget”, this is how exclusion happens... Most of the time, this is not related to the lack of budget but rather the will to think about what can be reasonably accommodated. It can be simple and not expensive.***

A woman defender with disabilities emphasized the importance of flexibility as a form of reasonable accommodation, stating,

***flexibility on working arrangements, like the possibility to work from home, is important for persons with disabilities. If I must work from the office, then having the possibility to leave work earlier, before peak hours, can improve my wellbeing as I have challenges related to mobility. For instance, in [my city], public buses are always in a hurry so, if they see me in a wheelchair during peak hours, they speed up and do not take me, as they think I am going to slow them down.***

The provision of reasonable accommodation is essential for people with disabilities – this should not be seen as a favour or as special treatment, but as a means of enabling them to secure their rights. Planning for reasonable accommodation is essential and should be reflected in annual budgets.





### Partnering with defenders with disabilities and their representative organisations

Partnerships are a way of engaging defenders with disabilities in meaningful participation. This can be a journey of learning for both partners. As a participant in this study urged,

*... partner, cooperate, and collaborate, since this is how you get diverse knowledge. This is how you will be sensitive and inclusive. This is how you know the correct language to use. This will help the organisation grow and know more in depth every human right they need to take care of.*

Partnerships can open opportunities for small organisations, helping them to develop their systems, structures, networks, and public profile. As a participant highlighted, “The objective for organisations of persons with disabilities is to be visible, to be known, to be out there on topics concerning us. In this way, you can also go from being a sub-grantee to a direct grantee”.

### Supporting the leadership of defenders with disabilities

There have been strong calls with disability movements for people with disabilities to lead their own causes. Sharing his ideas about the roles and relationships between people with disabilities and allies who act in solidarity with them, a defender with disabilities articulated in an interview,

*The disability movement has historically experienced the lack of autonomy when it comes to anything, particularly about activism. We still need to fight to be recognised to be the person with the right to speak. It is key that you [supporters without disabilities] know what your role is – to support and not to lead. If you are not clear on that, you contribute to the problem.*

*Second, the advocacy agenda has to be defined by people with disabilities. You [allies without disabilities] do not have the right to decide the agenda. Support but recognise that you are not part of the disability movement.*

*Lastly, the most positive input, there are certain spaces where people with disabilities cannot access because we don't have the capacity, skills, and we are not recognised as possible partners. The role of allies is to open those doors, their universities, research centres, because they are better positioned than we are. We expect that.*

It is important to consider the balance of power in partnership arrangements, and to ensure that partnerships are respectful of and empowering for people with disabilities.

## Acknowledging and tackling ableism

It is essential to recognise and tackle ableism within human rights movements. This requires all of us to observe our own attitudes, biases, and assumptions concerning disabilities. It also requires us to identify and address sexism, misogyny, racism, xenophobia, and any other form of discrimination that rob people of their rights and dignity. A significant barrier to the introduction of inclusive practices is the **silence** around this topic amongst non-disabled people.

While many human rights organisations agree in principle with the importance of making their workplaces and activities inclusive, that is still not the case in practice. In this study, defenders with disabilities highlighted the prevalence of **tokenistic** and **paternalistic** actions around disability. A defender with disabilities trying to get their own human rights organization to commit to disability inclusion described their work as “a lonely journey”.

## Learning continuously about disabilities, rights, and justice

Barriers in society that cause disabilities are often unrecognised and unseen. Understandings about disability rights and justice can evolve quickly. As a participant in this study observed, “awareness of disability and its implications is the crucial first step for organisations to become more inclusive”. Another highlighted the need to “grasp the diversity of disability and the diverse needs of different groups”. The journey to inclusivity involves acknowledging personal biases, being willing to make mistakes and to apologise, and maintaining an attitude of learning.

Organisations can facilitate this learning in different ways, for example by ensuring that employee induction programmes cover topics related to disability and inclusion; inviting defenders with disabilities to share their knowledge and experiences on a regular basis; and facilitating joint learning sessions with partners, donors, and other stakeholders.

Many people do not interact much with people with disabilities, and thus can be surprised or confused when people with disabilities display behaviours that are unfamiliar or unexpected. In one of our interviews, an advocate for people with intellectual and developmental disabilities described how he brought a child with autism into a room during a training programme on disability inclusion for health professionals. He observed them as being “in a state of shock” when they saw the child whining, expressing hurt, and walking around in circles, as they were

not accustomed to these behaviours. He observed, “What you have not seen, you cannot associate with”. Part of learning includes interacting with people with different types of disabilities and reflecting on our taken-for-granted expectations about behaviour, communication, and social interaction.

Part of learning also means respecting the right of people with disabilities not to engage in conversations about disabilities. As a woman defender with disabilities observed,

*“Many people with disabilities have faced intrusive and dehumanising questions, so although the goal of these conversations is to demystify disability, different individuals will have different boundaries for what they will be willing to talk about”.*

## Mainstreaming disability

A way to tackle ableism is **mainstreaming disability**, that is, the process of incorporating disability perspectives and the needs of people with disabilities into all policies, programmes, and activities of an organisation. This could involve:

- Developing a **strategy for mainstreaming disability** that has the buy-in and commitment of leadership, ensuring it is prioritised and implemented across all areas of the organization
- Conducting a **disability needs assessment** with defenders with disabilities and their organisations to identify barriers to inclusion and accessibility within the organisation and its programmes

- Establishing a **disability inclusion working group** or task force that includes representatives from different departments and disability stakeholders to guide the development and implementation of disability-inclusive policies and practices
- Designing and implementing **disability-inclusive policies and practices**, such as those that promote comprehensive accessibility, universal design, and reasonable accommodation
- Providing **disability-awareness trainings** to all staff members, including disability awareness, accessibility, and inclusion, with regular updates
- Establishing a **monitoring and evaluation framework** with clear indicators, as well as tools, to assess progress towards disability mainstreaming goals and identify areas for improvement
- Appointing a **disability equity inclusion (DEI) focal person** to support and guide all the processes listed above

## The twin-track approach

The **twin-track approach** is a strategy towards disability inclusion that involves implementing **disability-specific programmes** to address the specific needs and challenges faced by people with disabilities while promoting disability mainstreaming. By using both approaches, organisations can address the unique needs of people with disabilities while also ensuring that disability is integrated into all aspects of their work. Disability-specific programmes could include providing specialised services, advocacy, and awareness-raising activities.

In the field of the protection of human rights defenders, the twin-track approach can be used for instance, by including people with disabilities within already existing training programmes on security and protection, while designing specific training sessions targeted only at organisations of persons with disabilities to address their specific protection needs. In this way, organisations can promote both mainstream inclusion and disability-specific inclusion.

## Disability inclusive programmes, projects, and budgets

Human rights organisations should mainstream disability in their strategic framework and reflect disability inclusion in their programmes, projects, and budgets. Every key step of the **project development cycle** (including design, implementation, data collection, and monitoring and evaluation) should involve people with disabilities, not just as a 'target group' but as a key actor in decision-making.

It is equally important to focus on **disability-inclusive budgeting**, a process that considers both the needs and priorities of people with disabilities, ensuring that budget allocations are made to support their inclusion and full participation in society. Unfortunately, it is often the case that disability budgeting is wrongly perceived as expensive. However, if projects aim at disability inclusion from the start, the process is easier and more cost-effective. Here we suggest some guiding points towards more disability-inclusive budgets:

- Budget based on **disability-inclusive needs assessments** that identify the specific needs of people with disabilities in projects.
- Have a **budget line** specifically for disability inclusion. Between 10 to 15 percent of costs should be added to key activities (such as training sessions, advocacy actions, publications) to ensure full accessibility and reasonable accommodation. These expenses are more than justifiable and can rarely be questioned/ reduced by donors.
- Involve **people with disabilities in the budgeting process** in every phase, including budget consultations, decision-making, and monitoring.
- Ensure **budget transparency**, making sure that people with disabilities have access to information about the budget and can participate in the process.

## Collecting and disaggregating data on disabilities

**Collecting and disaggregating data on disabilities** in programmes and projects can help organisations in:

- **Identifying the needs of people with disabilities** in an organisation or a community, such as the types of disabilities, the level of access to services and infrastructure, and the extent of discrimination or stigma they face
- **Monitoring progress towards disability inclusion** including whether budget allocations are being used to support the inclusion of people with disabilities in society
- **Ensuring accountability** – holding governments, organisations, and other relevant stakeholders accountable for their commitments to disability inclusion
- **Informing policy and programmatic decisions** to ensure that the needs of people with disabilities are identified and barriers addressed.

As an example of how to collect data on disabilities, The Washington Group on Disability Statistics (2019) developed a set of six questions known as the **Washington Group Short Set on Functioning (WG-SS)**. These questions constitute a standardized, internationally recognised tool to measure disability prevalence in a population.

The questions are important for disability inclusion and programming because they provide a consistent and comparable way to measure disability across different contexts, which can inform the design and

implementation of policies, programmes, and services that are inclusive for people with disabilities. The questions are also useful for identifying and addressing barriers to the full participation and inclusion of people with disabilities in society.

## Inclusive communication

This section focuses on accessible communication methods and styles, including online facilitation and the use of digital platforms.

Unfortunately, not all online/ digital platforms are accessible for persons with disabilities. A defender with disabilities highlighted, “accessibility tools and gadgets constitute a barrier to inclusion in the digital space. If you cannot have that phone or computer that can accommodate the software, then you cannot even access the digital space”. A participant observed,

*when communicating online, we need to make sure that everyone who is involved can get the information. For this purpose, maybe we need to collect information about the people first. Before you communicate to others, you might find out that there are different types of disabilities to take into consideration. If there is a deaf person who needs to receive the information, we must make sure that there is a sign language interpreter available. If someone has a visual impairment, you find out whether the screen reader that this person will be using is fitted with the necessary software to enable effective communication.*

Another participant mentioned that “it is key to predetermine accessibility needs because, most of the times, organisations just deal with issues when we are already in the session and people miss out. It is recommended to send a form and ask people “do you have any disability need?” instead of assuming this.

These are some tips for online communication to ensure accessibility for defenders with disabilities:

- **Use accessible platforms:** there are several accessible communication platforms that can be used to facilitate online communication for persons with disabilities, including screen-reader-compatibility, sign language video support, and captioning software.
- **Website accessibility:** websites should be designed with accessibility in mind, including providing alternative text for images, ensuring that content is easily navigable with a keyboard, and avoiding flashing or moving content that can trigger seizures.
- **Document accessibility:** any documents shared online, such as reports or meeting minutes, should be made accessible, such as providing alternative text for images, using accessible fonts and formatting, and ensuring that documents can be navigated using a keyboard. **PDFs and other formats may not be accessible to screen readers.** Try using HTML or other formats that are accessible.

- **Use alt text for images:** alt text is a brief description of an image that screen readers can read out loud. This allows persons with visual impairments to understand the content of the image.
- **Use accessible fonts and colours:** use fonts and colours that are easy to read and distinguish and avoid using text that is too small or too light. High-contrast colours make it easier for people with visual impairments to read text on a screen.
- **Provide captions, transcripts, and audio descriptions:** these allow people with hearing impairments to follow conversations, videos, and webinars. They also benefit individuals who may not be able to turn on the sound or who speak a different language.
- **Use plain language:** use simple and concise language to ensure that the content is easily understood by all readers.
- **Avoid ableist language:** use person-first language, avoid derogatory terms, and avoid using disability as a metaphor.

However, it is important to note that not all tools and features in software are accessible to all people with disabilities, and additional adjustments may need to be made to ensure full accessibility.

## Committing to comprehensive accessibility and universal design

**Comprehensive accessibility** focuses on removing disabling barriers in society and widening access for people with disabilities. It means identifying and addressing barriers in society that impede access to participation in activism for people with disabilities, such as the ones described in Section 2.3.3.

A step towards comprehensive accessibility is conducting **accessibility audits** in partnership with defenders with disabilities and their representative organisations to identify ableist practices and barriers that may exclude people with disabilities. Such audits can explore the built environment, identifying barriers such as narrow doorways, stairs without ramps or handrails, and inaccessible restrooms. They could also include the evaluation of digital content for accessibility, such as websites or electronic documents, or the presence or absence of screen readers and keyboard-only navigation. Organisations can also adopt universal design principles when creating programmes, projects, and infrastructure, to ensure that these are accessible to the greatest extent possible by all people regardless of their age, size, and abilities.

A useful concept for assessing progress towards comprehensive accessibility is **access intimacy** put forward by Mia Mingus (2011). She describes this as:

*that elusive, hard to describe feeling when someone else “gets” your access needs. The kind of eerie comfort that your disabled self feels with someone on a purely access level. Sometimes it can happen with complete strangers, disabled or not, or sometimes it can be built over years. It could also be the way your body relaxes and opens up with someone when all your access needs are being met. It is not dependent on someone having a political understanding of disability, ableism or access. Some of the people I have experienced the deepest access intimacy with (especially able bodied people) have had no education or exposure to a political understanding of disability.*

As such, an indicator that comprehensive accessibility has been achieved is when defenders with disabilities feel welcomed, comfortable, relaxed, open, connected, and engaged in the spaces where they participate.

## Resourcing defenders with disabilities and inclusion in human rights movements

Donors play a critical role in supporting defenders with disabilities in their work, and in advocating and supporting human rights organisations and movements in the implementation of disability-inclusive practices. Participants in this study shared with us their struggles in accessing funding. One observed, “Out of the million dollars that are devoted to human rights defenders, how much is allocated to those with disabilities? I have never heard about any funding available for defenders with disabilities”. A strong theme that emerged was that people with disabilities should be involved in decision-making processes within disability-related projects. As a participant said,

*whoever sits in funding committees... decide(s) where the funds go and where the funds are channelled. [A person with disabilities] can tell if there is a specific need for a specific thing, and what specifically needs to be funded for that purpose. This is way better than having an outsider deciding where the funds are being channelled... So, involve human rights defenders in decision-making processes.*

Defenders with disabilities also spoke about the importance of accessible, flexible funding from pragmatic donors. They also wished they had opportunities to influence donor funding practices, and to ensure that funds were dedicated specifically for defenders with disabilities.

The Disability & Philanthropy Forum supports funders in dismantling ableism through increasing funding for disability inclusion, rights, and justice. They encourage foundations and philanthropy-serving organizations to participate in their **Disability Inclusion Pledge**, which commits them to eight areas of work: disability community engagement; disability-inclusive language; accessible events; inclusion audits and plans; staff training and participation; board training and participation; disability grant-making; and measuring and reporting. They suggest the following tips to funders (Disability & Philanthropy Forum, 2023):

- Launch a community of practice, made up of staff who are interested in and knowledgeable about disabilities, to foster peer-learning and inform institutional practice
- Map disability inclusion initiatives at the intersection of one or more grant-making areas, to identify ways to support both current and new grantees working to address disability inequality
- Connect with and learn from research focused on disability rights and justice
- Join a collaborative disability justice fund to advance the rights of disabled people
- Develop a long-term strategic plan to guide disability inclusion efforts including targets, timelines, and a team to lead the work
- Identify a funding target for disability inclusion to measurably strengthen this work (e.g. 5 percent of funding, or a specific amount of money)



- To learn more and to understand the field better, make one grant to an organisation of persons with disabilities working on an issue of focus
- Involve people with disabilities in convenings or other strategic discussions where programmatic agenda-setting occurs
- Incorporate disability inclusion in strategy development so that people with disabilities are included in grant-making approaches from the start
- Organise and fund convenings, networking, and learning opportunities between organisations of persons with disabilities and other human rights groups for grantees
- Launch a learning series for staff on disability and inclusion, looking at a mix of programmatic and operational issues
- Review grant-making processes for accessibility and disability inclusion. Is the application accessible? Are there funding criteria related to disability? Does the coding scheme categorise disability beyond health and medical approaches?
- Ensure that disability inclusion is a criterion in any calls for proposals and grant-making guidelines
- Review all communication to ensure inclusivity of people with disabilities

In their brief for donors, *Supporting Inclusive Movements: Funding the Rights of Women with Disabilities* (Dobson, undated), The Disability Rights Fund and Channel Foundation provide specific guidance on how to fund organisations of women with disabilities.

## » **Ways Forward**

Human rights defenders with disabilities have always been a critical and integral part of human rights struggles around the world. However, ableism shapes the way they, and other people with disabilities, are perceived and treated in society. Ableist understandings of human rights activism have influenced the way their contribution to human rights struggles and their experiences of challenges and risks have been understood. This Guide highlights concrete ways in which the security and protection of defenders with disabilities can be strengthened, which requires the deepening of inclusion in human rights movements. This is an inter-dependent journey that requires collective commitment, learning, and struggle from all sectors in human rights movements; it is a necessary journey towards achieving a just and equal society with rights and dignity for all.

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