



CONNECTING DISABILITY AND INEQUALITY ACTIVISM: BARRIERS, CHALLENGES AND OPPORTUNITIES

NEW RESEARCH FINDINGS

Background to the research study

People with disabilities experience disadvantages in income, wealth, and how they are represented and treated by others.

Despite these experiences and the clear links between disability and inequality, inequality activism rarely seems to intentionally include the challenges people with disabilities face. This is despite the fact that the world's 1.3 billion people with disabilities make up a significant proportion of people facing inequality. In addition, disability movements often struggle to fully engage with intersectional aspects of inequality.

[Our research study](#) explored some of the reasons for the gaps in connection between disability and inequality activists. It aimed to understand how activists in Ghana and Kenya think about and understand disability and inequality. The study also looked at the things that stop disability and inequality activists from collaborating and the things that strengthen collaboration. We worked with activists to find strategies to improve collaboration between disability and inequality activists and their organisations.

In the following pages, you can read a summary of our research, including methods, findings and the tools developed as a practical outcome of the project. At the end of the summary, there is a glossary which explains the terms and keywords used in this summary.

Research study method

Many members of our research team have lived experience of disability, including mental health conditions. We worked with a wide range of research participants with relevant lived experience who are directly engaged in activism. This qualitative study used action research principles. This means it includes ideas for action based on the research findings. This will benefit all research participants. Over the course of many meetings, we brought participants together to share their ideas, reflect on findings and discuss how to act on them. The research also aimed to build collaboration between disability and inequality activists.

In this study, we interviewed 30 people. Half were based in Ghana and half were in Kenya. In each country, we interviewed eight disability activists and seven inequality activists. We aimed to get a diverse mix of participants. Participants had a range of different impairments. They were a mix of genders. Some worked in cities and others in more rural areas. Some had years of experience in activism, others were newer to it. Participants worked in a mix of local, national and regional organisations, and we also included some independent activists.

After the interviews, we analysed the findings. We then invited participants to take part in focus group discussions. There were two focus groups per country; one for disability activists and one for inequality activists. After the focus groups, we analysed the findings again. We used this to develop a draft set of strategies and tools, which are designed to overcome some of the collaboration barriers people identified. We then brought everyone together in a big workshop, one in each country. Here, people discussed and confirmed the research findings and provided feedback on the draft tools. After the workshops, all participants had the opportunity to review the draft tools again before they were finalised.

Importance of accessibility to the research study

Accessibility was an important part of our research design and data collection. We asked all participants to let us know what support they needed to be able to take part and had a budget to cover this. We checked people's access needs before the interviews, focus groups and workshops. This is because people's needs can change over time or due to the context.

Some of the actions we took to make the research accessible include translating material into Swahili and Twi languages and providing sign language translation. We also had easy-read and screen-reader-friendly material and large print for printed documents. We provided support for childcare, and we covered the costs of personal assistants, visual aides and support workers.

Ethical approval and support for the research study

The study has ethical approval from the London School of Economics in the UK, Kwame Nkrumah University of Science and Technology in Ghana and Amref in Kenya. We also have a research licence from Nacosti in Kenya.

This study was supported by an engagement group, which included representatives from the Ghana Federation of Disability Organisations, United Disabled Persons of Kenya and Kwame Nkrumah University of Science and Technology.

KEY FINDINGS



The research explored three main areas:

- **Understandings of disability and inequality**
- **Barriers to collaboration between disability and inequality movements**
- **How to strengthen collaboration between disability and inequality movements**

1. Understandings of disability and inequality

Understandings of disability are complex and evolving

Participants expressed a wide range of views on disability, inequality and the connections between them. These connections were complex and evolving. Both disability and inequality activists said that disability is shaped by social and cultural perceptions. They spoke about how stigma and misconceptions shape how disability is seen. For example, disability can be viewed as a curse. All participants presented these social attitudes as negative and rejected them. But they said they were still very common among their communities.

Some participants also framed disability as the result of structural factors, such as the lack of education and economic opportunities or inaccessible services which exclude people with disabilities. Participants' understanding of both the attitudes and the structural factors that impact disability was closely linked to their understanding of inequality more generally, which they described as more of a structural and societal issue than a purely individual one.

Alongside these understandings of disability, many participants spoke about disability in ways that expressed it as a deficit, incompleteness or something that needs fixing. Some participants viewed disability from a functional perspective. They described how disability affects a person's ability to perform tasks that are expected of them. This shows how the negative perception of disability as inability is deeply ingrained in society. This negative view can even be expressed by people who recognise how inequality affects people with disabilities.

Some participants said their understanding of disability has changed over time because of training or through engaging with people with disabilities. These participants described how they changed from seeing disability as a deficit to seeing it as something shaped by discrimination within society.

Several participants with disabilities said there are hierarchies of disability. This means different disabilities are treated differently from others.

For example, invisible or lesser-known disabilities might be ignored. Or people with psychosocial or intellectual disabilities might be more stigmatised than other people with disabilities, even within the disability movement.

Disability and inequality are seen as connected

In contrast to the different ways that people talked and thought about disability, participants showed greater agreement around the definition of inequality. Most participants defined inequality as having limited access to resources and opportunities, including a lack of political voice or access to decision making. This lack of access was seen as being linked to people's identity. For example, someone might experience limited rights and privileges due to the way society views their gender or ethnicity.

Disability activists were the participants who made the strongest connection between disability and inequality. These activists shared clear examples of how disability and inequality connect, based on their personal and professional experiences.

Some participants connected disability and inequality as a series of separate disadvantages which add up like layers. In this way, disability was seen as one of many inequalities. A few participants approached the connections between disability and inequality in an intersectional way. This means they recognised that someone may experience more complex forms of discrimination linked to different parts of their identity, such as their gender and disability.

These complex views and understandings of disability and inequality help us to understand why some barriers to collaboration exist between the disability and inequality movements. They will also help us find opportunities to build collaboration and shared understanding.

"I have attended so many forums where organisations talk about disability, yet there is no person with a disability in the room."

Inequality activist, Kenya

2. Barriers to collaboration between disability and inequality movements

The importance and meaning of collaboration

Since the challenges and issues of social justice that both sectors address are complex and connected, participants spoke of the need for the two sectors to collaborate. They felt that collaboration creates space for learning and diverse experiences to come together to build stronger movements. Collaboration can create refreshing ideas for how to tackle challenges, using the different skills and strengths that different people bring. It also helps with sharing and mobilising resources to tackle challenges. People also felt that by coming together it is possible to expand opportunities for change rather than being trapped in cycles of competition with each other. Many participants from both sectors said that collaboration needs to be done with a clear purpose. It should be seen as a process, and both sides should be receptive and inclusive to one another to create shared impact and ownership.

Among participants, disability activists understandably placed emphasis on meaningful inclusion. They stressed the need for access, avoidance of stigma and stereotypes, and a non-tokenistic approach to ensure that people with disabilities can actively participate in decision making at all stages of collaboration. Inequality activists also noted that challenges to collaboration can arise from both sides. For example, stigma and discrimination can result in certain groups being marginalised, such as people with mental health conditions, LGBTQ+ people and people with less visible or lesser-known disabilities.

Barriers to collaboration are interlinked

Participants identified several connected barriers which affects collaboration between disability and inequality activists and movements. These barriers can cause difficulties at different stages, including

when establishing, developing and sustaining collaboration. These challenges can be categorised under four main areas: stigma and stereotypes, knowledge and understanding, competition over resources, and trust issues.

Stigma and stereotypes: Negative ideas around disability create barriers to collaboration. For example, participants said that some people may assume that activists with disabilities have less expertise than other activists. Participants also commented that some disabilities are more heavily stigmatised than others. This means that people may be less likely to want to collaborate with certain groups of people with disabilities compared with others. This is particularly the case when people with certain disabilities are seen as needing greater changes to a working process in order to fully participate. Activists said this was an issue both within the disability sector and in cross-sectoral collaborations between the disability and inequality movements. Minoritised groups within the disability movement, for example LGBTQ+ people or people with intellectual disabilities, also experienced greater stigmatisation than other disability activists.

Knowledge and understanding: Participants said that many inequality activists have limited understanding of disability. As a result, disability activists experience constant pressure to educate others about disability. This extra burden is an emotional and practical drain on their resources and capacity.

There is limited understanding of intersectionality among some disability activists. These activists may not consider, for example, the specific experiences of women with disabilities compared with men with disabilities. Collaboration can be difficult when disability activists and inequality activists do not fully understand each other's perspectives.

Disability activists felt that inequality activists are uncomfortable working with people with disabilities and their movements. Some inequality activists also mentioned this discomfort. Disability activists saw inequality activists' discomfort as being due to a lack of experience and expertise. However, inequality activists saw this discomfort as being due to challenges in organising access. Some inequality activists also found it difficult to identify which disability groups to work with.

Alongside other forms of discrimination, activists with disabilities discussed the additional daily barriers they face when collaborating with inequality activists, which are rarely considered. This includes inaccessible information, activities, travel and meetings. These things make it difficult

for activists with disabilities to collaborate with other activists if their access needs are not properly addressed.

Competition for resources: Activists said they were often competing for the same limited resources. They described funding structures as encouraging competition, rather than collaboration. This results in a situation where activist spaces remain divided, and knowledge is not shared.

Unrealistic funding criteria, like short timeframes or restrictive financial requirements, create significant barriers for smaller organisations. Funding calls do not often require applicants to consider disability inclusion or access requirements. This means that inequality organisations do not often think about disability inclusion when designing bids, which makes it harder to collaborate later. Funders may see organisations that do include disability as presenting funding bids that are more expensive and lower value for money.

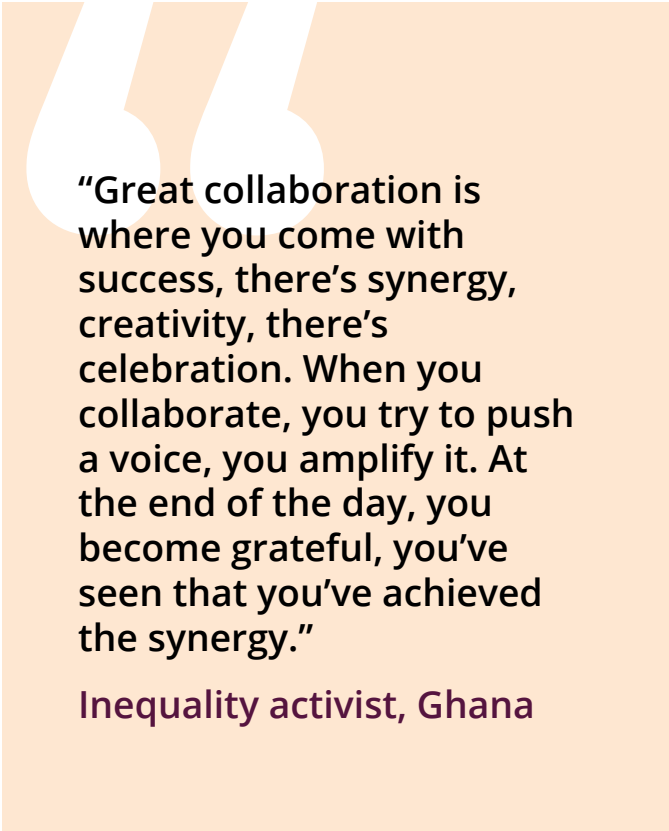
Trust issues: When there is competition over limited resources, some activists were concerned that other groups would take their ideas without crediting or involving them. They were concerned that others would use these same ideas to access funding or other opportunities. For example, disability organisations might be included to win a funding bid but then not properly included in delivering work.



“If we want to have an equal society, a society that is fair, there should be reasonable accommodation for persons with disability to accommodate our individual differences based on our different impairment and disabilities.”

Disability activist, Ghana

Some disability activists also reported issues with tokenism or superficial participation. This is when a group, or a representative of a group, is present but does not have any real influence. For example, they may be invited to a meeting and then not given enough support to speak up. This breaks down trust and make collaboration more difficult.



“Great collaboration is where you come with success, there’s synergy, creativity, there’s celebration. When you collaborate, you try to push a voice, you amplify it. At the end of the day, you become grateful, you’ve seen that you’ve achieved the synergy.”

Inequality activist, Ghana

3. How to strengthen collaboration between disability and inequality movements

By analysing the barriers and gathering suggestions from participants, we found three main areas where changes could strengthen and promote collaboration.

Fairer resourcing

Barriers arising from people’s attitudes, plus structural and social barriers, create inequality in terms of resources, trust and knowledge. Funding plays an important role in creating a level playing

field. However, resourcing is broader than just financial support. It also relates to attitudes, skills and knowledge. For example, initiatives for stigmatised groups may be considered less worthy of funding. Inequality movements may lack knowledge and lived experience of disability. While disability movements may sometimes lack certain technical expertise because of the limited opportunities available to them.

Participants noted that inequalities in resourcing, and related difficulties in collaboration, could be addressed by interventions such as:

- Joint training sessions, which support shared learning and dialogue between the disability and wider inequality sectors.
- Targeted funding to deliberately support collaboration and inclusion for people with disabilities and their representative organisations. This could be done in a similar way to initiatives in which funders have required organisations to achieve outcomes for women and girls within their overall plans.
- Joint budgeting and financial transparency to reduce mistrust and create shared ownership.
- Financial, educational and other resources being made accessible to people with disabilities and organisations of people with disabilities through disability-sensitive design and implementation.

Intentional collaboration

Currently, collaboration between the disability and inequality sectors only happens to a limited extent and is often unplanned. Collaboration can also occur in a tokenistic way to meet funding requirements or perform inclusion without truly including and benefiting disability movements.

Collaboration will face challenges and obstacles when activists with disabilities are only invited to participate after plans have been finalised. Collaboration needs to be intentional, meaning that it needs to evolve from co-creation and be deliberate and planned. Collaboration should be seen as a process and an ongoing relationship, rather than a single event or project. Collaboration should be seen as an opportunity to learn from each other, as peers.

To improve collaboration, participants recommended:

- Planning for disability access and inclusion from the start, including within the budget,

- activities, communication and outreach.
- Building trust and transparency between and across movements, including by reflecting on positionality, transparent budgeting and shared ownership.
- Co-creating joint and collective advocacy goals and projects.
- Fostering the exchange of ideas through dialogue and learning exchanges.

- Activists should address power structures within movements by reflecting on the impact of their relative power, resources and advantages and taking steps to share them more fairly.
- Movements should ensure that people with lived experience of oppression and discrimination can have a meaningful impact through their participation in decision making.

Understanding disability and intersectionality

Disability affects people of all races, ethnicities, genders, sexual orientations and socioeconomic backgrounds. And people with disabilities are much more likely than others to live in poverty, with restricted opportunities in life. However, people often understand disability in an individualised way, meaning they focus on someone's medical diagnosis, rather than thinking about their disability in relation to the many other social identities someone has and the circumstances of their life.

This can result in different groups being missed out or their issues not being addressed. Within disability movements, we might see that disability is seen as one single thing, which results in some forms of disability and some marginalised identities being excluded. Within inequality movements, we might see that disability is left out entirely because the connection between disability and inequality is not recognised.

Participants recommended that collaboration should be grounded in understandings of disability and inequality that focus on the structural links between the two. They recommended that activists should be aware of the diversity of disability and how it intersects with other social identities and circumstances. They advised that activists should gain the knowledge to recognise and challenge stigmatising approaches to disability. Finally, they underlined that collaboration must reflect the complicated reality of lived experience and reflect multiple, overlapping and complex inequalities.

To improve understanding of disability and intersectionality, participants recommended the following:

- Movements should support activists to reflect on different lived experiences of injustice, both within disability and inequality-focused organisations and across them.



PRACTICAL TOOLS TO SUPPORT COLLABORATION

Based on our analysis and participants' suggestions, we identified three key strategies to address the barriers to collaboration between the disability and inequality movements.

These strategies address:

- the need for fairer resourcing
- more intentional collaboration
- enhancing understanding of disability and intersectionality.

To promote these strategies, we drafted six tools and shared them and the research findings with participants in two, one-day workshops to get their feedback.

These tools will not fix all the barriers identified. But they will support activists to reflect on and explore collaboration and provide practical ideas

for closer working. We encourage activists to think about other actions they can take in addition to using these tools. We also provide a range of reflections through stories, blogs and short videos to be used alongside the tools.

Six tools to support collaboration



1. Inclusive budgeting checklist: This tool is designed for organisations developing their project budgets. It suggests key things which should be part of a budget from the very start to include people with disabilities and strengthen their meaningful inclusion.

2. Inclusive and accessible activity checklist: This is a starting point to think through how to make events, meetings and other activities more inclusive. It is important to consider inclusion at every point of planning, implementation and evaluation. Any organisation can use this checklist to be more intentional about inclusion. It will be useful for any activity, event or meeting where you want a mix of different types of people to participate.

3. Inclusive and accessible communications guide: Our research found that people with disabilities are not always meaningfully considered in organisations' internal and external communications. This lack of consideration becomes a social justice issue because it means that people with disabilities may not be able to access the information you share. This guide will show you how to make the design and layout of print and digital communications more accessible. It also explores how to consider aspects of representation, consent, and decisions around whose story is being told and how to tell these stories.

4. Reasonable accommodations guide: Our research shows that while many organisations and activists want to include people with disabilities, they are sometimes unsure how to provide the right support. Often, when reasonable adjustments are made they tend to focus on physical access, leaving out other important types of accommodation, such as support for people with intellectual, psychosocial and other disabilities. This guide outlines why reasonable

accommodations are necessary and gives examples of what they might look like.

5. Disability inclusion self-assessment tool: This is designed to help organisations explore their current level of inclusion for people with disabilities and plan for ways to become more inclusive. It can be used at any stage of your organisation's inclusion journey, whether you are just starting to think about these issues, or you are from an organisation of people with disabilities that wants to include more marginalised groups.

6. Positionality mapping facilitation guide: Our participants shared many experiences around unequal power dynamics, tokenistic forms of inclusion and exploitative collaboration practices. This facilitation guide will help you to identify these power imbalances before any collaboration starts, giving everyone a chance to recognise and address them. Whether you are starting a new partnership or trying to strengthen an existing one, this guide offers a shared space to reflect on expectations, responsibilities and potential areas of tension within a context. Although power dynamics are not always obvious, you may be able to identify them by considering who sets agendas and controls access to funding and information. Power dynamics are affected by the wider context in which resources and opportunities are distributed. For example, the lack of access to education that certain groups experience can go on to affect their access to power.



“For you to know a person with disability well, or to understand someone well, you need to stay with the person and understand the person. So, I would say that excluding disability from inequality conversations will perpetuate marginalisation.”

Disability activist, Kenya



Ableism: This is an ideology that favours bodies and minds without disabilities and assumes that they are typical or normal. We can experience ableism in the design of our systems, cultures, mentalities and buildings. Ableism causes discrimination and prevents participation. It is linked to other forms of oppression in complex ways. For example, society might also determine people's value based on their culture, age or appearance.

Accessibility: This refers to removing barriers that prevent people with disabilities from equal and meaningful participation in a process, service or opportunity. Types of barriers include physical, social, cultural, attitudinal, financial and digital. Examples of tools or actions to overcome barriers include easy-read text, screen-reader compatible materials, sign language translation, level-access and payment of transportation. See **Reasonable accommodation**

Activist: An individual who, by themselves or with others, contributes to shaping a collective identity and mobilises for a particular aim. Anyone actively working for social or disability justice can be an activist. Activism also includes self-advocacy. This is when a person advocates for their own rights and needs and influences things in a way that benefits and meets the rights and needs of others. For example, a person with a sensory impairment who encourages their university to make resources available in a more accessible format benefits themselves and other people with similar sensory impairments.

Collaboration: The means working with someone. In this study, participants understood collaboration to be about working together across diverse movements, sectors and identities to breakdown different forms of oppression, discrimination, marginalisation and exclusion. Collaboration is an ongoing process. It means working together at all stages, from identifying the problem to evaluating the proposed solution or intervention. Fair collaboration is sensitive to existing discrimination and power inequalities. It works to overcome these issues and build trust between collaborators.

Disability: This term has a wide variety of definitions and encompasses a huge range of people. The UN Convention on the Rights of Persons with Disabilities (UNCRPD) emphasises that disability is an evolving concept. The UNCRPD

states that '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'.

We recognise the diversity of disability, and that individuals decide how they define and describe their own disability. We use **people with disabilities** because it is the most commonly used description in our study. It is the description commonly used in Africa, Asia and the US. Sometimes in our examples we talk about different types of disabilities, using the terms preferred by our participants. The term **psychosocial disabilities** was used by participants as an overall term for any mental health condition.

The international disability movement uses the term **persons with disabilities**. This is the terminology used in the UNCRPD.

The UK disability movement prefers the term **disabled people** to emphasise that barriers in society are 'disabling' for people with impairments. This comes from the social model of disability. This model views disability and impairment as two different things. Here, impairment refers to physical and mental conditions, while disability refers to the discriminatory way society responds to those conditions. The social model emphasises that the issue to be addressed and resolved lies in changing a discriminatory society, rather than with people with disabilities themselves.

Exploitation: In the disability context, exploitation refers to situations where the stories, labour and presence of people with disabilities are used for the benefit of others. For example, an organisation uses the experiences of people with disabilities to secure funding, but people with disabilities get no benefit or very limited benefit from this work. Or a disability organisation may be a partner on a project but not hold any leadership positions. The misuse of people with disabilities' labour and expertise can happen in any kind of project, including advocacy, policy and research projects.

Inclusion: This refers to the environments in which people with disabilities, or other marginalised groups, are present and actively and meaningfully participate, including by taking leadership roles and influencing decisions. Inclusion goes beyond just being present. It requires us to breakdown

physical, attitudinal (relating to attitudes), social, economic, political and other barriers that marginalise people and limit their participation in political, social and economic life. Inclusive environments are responsive and change to reflect people's changing needs and priorities.

Inequality: Structural, economic, political, cultural and social differences and unfair treatment which negatively influence the availability, accessibility and quality of opportunities, resources and inclusion that people have. As well as resource distribution, people may experience inequality as a lack of respect or because they are stigmatised. They may also experience unequal access to representation and influence on decision-making processes.

Intentionality: In this study we understand intentionality as a deliberate and conscious attempt to ensure that people are fully included. Intentional actions and practices go beyond tokenism and symbolic gestures. They seek impactful participation and co-learning. They are sensitive to taken-for-granted assumptions and address issues that prevent participation and collaboration.

Intersectionality: The word intersect is used to describe the point at which two things meet. Intersectionality is the idea that a person can experience multiple oppressions like racism, sexism and ableism due to their identity. Intersectionality recognises that different forms of oppression interact with one another. When a person experiences multiple types of oppression, it produces a specific experience for them. Intersectionality is not about listing different forms of oppression. Rather, it is about understanding how different forms of oppression operate, what their connections are, and how they intersect to produce different experiences. Importantly, it asks us to be aware of these complexities when trying to find solutions to further equality because people can be excluded from movements that tackle just one form of oppression without considering the others.

Movement: Movements are organisations and individuals that come together around shared goals to tackle the roots of injustice. In this toolkit, we use the term 'movement' to refer to collective struggles which mobilise resources to work towards justice. Movements often need and build collaborative networks. They build alliances and mobilise resources to reach their aims.

Organisation of people with disabilities: This is a collective run by people with disabilities. An organisation of people with disabilities usually advocates for social justice for people with

disabilities. Sometimes organisations are also described as **user-led**. This means that the people in the organisation's leadership positions are from the same group as the people using the organisation's services. For example, women leading a women's rights organisation.

Participation: Participation is when an individual, group or collective takes part in some sort of social process, such as civil society organising. Meaningful participation is when this participation is genuine, not tokenistic. **Meaningful participation** requires addressing access needs, power inequalities and contextual barriers that limit engagement and enforce inequality. Participation is a universal right and a requirement for social justice.

Positionality: This is about reflecting on your own social identity to understand how it influences and shapes your perspective, knowledge, advantages or disadvantages and access to power. Positionality asks individuals and organisations to consider who they are and how this influences their work and the knowledge they create. Positionality suggests that certain social identities, such as woman, man, person with a disability, might carry more or less power or respect. These differences make it easier for certain groups of people to be heard and have impact than others. Addressing this form of inequality is an important part of working collaboratively.

Power dynamics: The way that authority, voice, resources and opportunities are distributed within a context. Although power dynamics are not always obvious, you may be able to identify them by considering who sets agendas and controls access to funding and information. Power dynamics are affected by the wider context in which resources and opportunities are distributed. For example, the lack of access to education that certain groups experience can go on to affect their access to power.

Reasonable accommodation: This refers to removing barriers to make full participation and engagement possible for people with disabilities in line with the UNCRPD. To be effective, reasonable accommodations should go beyond technical fixes to challenge and address the social constructions and attitudes that disable people. People with disabilities' preferences and right to chose should always be respected. For example, an individual's preferred sign language interpreter should be used wherever possible.

Stigma: This refers to negative social attitudes and prejudices which attach to certain identities. For example, a person with a disability may experience stigma because of their disability.

Structural: Refers to systems that shape people's lives and their access to resources, opportunities or services outside of their own decisions or actions. Examples may include laws, regulations and institutional practices.

Systemic: Refers to patterns that result from how various parts of a system interact. When laws, policies and institutions work in ways that lead to the same results on a regular basis, those results are then considered systemic. For example, if an institution often leaves out people with disabilities because of how it operates, that exclusion becomes systemic.

Tokenism: This is when certain groups of people are only slightly included or represented to give the impression of inclusion but without actually redistributing power. Tokenism refers to situations where people are present but have no meaningful influence on decision making. It is not always done on purpose. Rather, tokenism can happen due to simplistic understandings of issues, such as disability or power dynamics. To address tokenism, it is important to be aware that someone's presence in a space is not enough to ensure their meaningful participation in it.

Unconscious bias: These are assumptions or learned ideas that influence how we think, behave or make decisions without us realising it. They may come from our personal experiences, cultures, upbringing and the information we are exposed to over time. Because we are unaware of them, we may not notice when and how they affect our decisions and choices. Unconscious bias can lead to unfairness because it can mean we behave in negative ways towards certain groups or act more favourably to others.

"That is what we mean by nothing for us without us. If you want to do something for us, consult us to find out how best you can do it to help us, instead of thinking or assuming the way that you do it for us is the best way you can help us."

Disability activist, Ghana

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