



OPINION PIECE

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When research speaks, do differently-abled persons hear their stories?



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This paper is based entirely on desk research. No original fieldwork or interviews were conducted. All information are attributed to their sources, and any errors remain responsibility of the authors.

Cover photo: Inable Powering Potential, https://inable.org/

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Introduction

In recent years, Africa's research landscape has been expanding, sparking diverse debates and growing scholarly engagement. Between 2001–2018, African researchers produced over 508,102 scientific publications underscoring the continent's rising contributions to global knowledge¹. Yet, within this progress lies a critical blind spot which is disability. Far from being an abstract concept, disability shapes the daily realities of millions across the continent. Still in many research projects, disability remains invisible, skewing findings and eroding the credibility of outcomes. A particularly overlooked dimension is the representation of persons with disabilities throughout the research process. This exclusion means that many studies fail to reflect the lived experiences of one of society's most vulnerable groups, resulting in knowledge that only partially mirrors African realities. Globally, an estimated 1.3 billion people or about 16% of the population, live with significant disabilities² of these 80% reside in developing countries many of them in Africa³, sidelining their perspective is not merely an oversight but fundamentally undermines the inclusivity, integrity and transformative potential of African research outputs.

Recognizing this gap, Research Enterprise Systems (RES) convened a webinar to spotlight and analyze disability inclusion in policy-oriented research across Africa⁴ and also trained young researchers on policy-oriented research⁵. Despite global and regional commitments such as the UN Convention on the Rights of Persons with Disabilities (CRPD), the African Union's Agenda 2063 and the African Disability Protocol, there remains a disconnect between rhetoric and reality. In light of this, it might be necessary to ask why has it been difficult for researchers in Africa to adequately mainstream disability voices in the research process?

Thorny Issues in Disability-inclusive Research

Although Africa continues to expand its footprint in global scholarship, research on the continent still grapples with entrenched barriers to disability inclusion. These issues which cut across design, implementation and dissemination include:

- a) <u>Lack of consultation with PWDs</u>: too often research agendas are designed without the voices of persons with disabilities. When they are mentioned, it is usually as case studies, data points or statistical categories rather than as co-researchers or decision-makers. This absence is compounded by researchers' limited training on how to mainstream disability perspective during project design and implementation. When persons with disabilities are absent from research, the result is not only ineffective policies but the reinforcement of deep-seated structural inequalities.
- b) Methodological gaps and barriers to participation: a major challenge lies in limited capacity of many researchers to adopt disability-inclusive methodologies. Approaches such as participatory design, adaptive data collection are rarely employed making it difficult for persons with disabilities to contribute meaningfully. This methodological gap not only narrows the scope of research but also reinforces stereotypes by failing to capture authentic experiences.
- c) Weak policy outcomes and institutional commitment: disability is still widely framed through a lens of charity or pity rather than social justice and equal opportunity. While policies exist, their enforcement is weak and institutions treat disability inclusion as "good to have" rather than a non-negotiable requirement. This breeds superficial gestures, symbolic representation without systemic change leaving disability voices marginalized.
- d) <u>Poor data systems and limited awareness</u>: reliable disability data remains scarce and fragmented. National surveys frequently omit disability metrics and when they are included, they rarely disaggregate by type of disability. The needs of a deaf person are not identical to those of someone with a visual or physically impairment yet research often collapses the distinctions.

e) Environmental and attitudinal barriers: deep-seated prejudices, inaccessible environments, limited psychosocial support from families and inadequate access to assistive technologies collectively perpetuate the marginalization of persons with disabilities. These barriers restrict their participation thereby reinforcing exclusion.

Towards Disability-inclusive Research in Africa

Ending the persistent exclusion of persons with disabilities in African research requires more than rhetoric ideas; the principle of 'nothing about us without us' is not just a slogan but a call for deliberate and concrete actions. To make research truly disability-inclusive, the following recommendations are essential:

Policymakers and development partners:

- a) Institutionalize inclusion standards by mandating disability inclusion benchmarks for all publicly funded research
- b) Invest in assistive technologies through expansion of access to devices, infrastructure and services that enable persons with disabilities to participate in research and policy process
- c) Strengthen social protection and support systems in providing psychosocial services for families and caregivers to reduce barriers to engagement
- d) Ensure that research frameworks integrate disability considerations from the outset, invest in disability-focused research training and make inclusion a non-negotiable funding criterion.
- e) Policies must be comprehensive and encompass all form of disabilities given their wide spread and variety.

Researchers:

- a) Adopt participatory methods and involve PwDs as co-researchers in study design, data collection and dissemination.
- b) Produce research materials in formats accessible to diverse disability spectrum metrics example, braille, sign language among others.
- c) Challenge biases by undertaking continuous training to recognize and eliminate ableist assumptions that distort findings.
- d) There is a need for deliberate efforts to build the capacity of PwDs, enabling them to actively participate in research. Empowering PwDs ensures their voices are heard and their perspectives are integrated into solutions.

General public:

- a) Disability is not solely a government concern; it is everyone's business. Individuals, communities, organizations, and private sectors all have a role to play in promoting inclusion and addressing the needs of persons with disabilities (PwDs)
- b) Early detection of disabilities is vital for timely interventions. It is crucial for professionals in health and social protection sectors to think beyond basic survival needs.
- c) There needs to be a shift in mindset and challenging stigma by fostering inclusive attitudes within communities and workplaces

- d) Voices needs to be amplified through support advocacy initiatives led by PwDs and hold leaders accountable for disability commitments
- e) Promote solidarity by encouraging support groups, mentorship and community-led initiatives that normalize disability inclusion as shared responsibility.

Conclusion

Disability inclusion in African research cannot remain an afterthought. It is a moral, intellectual, and practical imperative. If our research fails to include one of our continent's largest minorities even as we celebrate rising output then our knowledge remains fundamentally flawed.

True transformation requires that researchers design with, not for; that funders embed inclusion in their terms; that policy frameworks demand, not just encourage; and that society respect, not pity. Above all, persons with disabilities must be recognized not as passive subjects but as full co-creators of knowledge. In doing so, African research will move closer to excellence not just measured in publication counts, but in justice, credibility and real-world impact.

Endnote

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