# **Book Review:**

Authentic Voices in the Discussion of Disability in Kenya:

A Review of Disability and Social Justice in Kenya:

Scholars, Policymakers, and Activists in Conversation

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## Abstract

This is a review of *Disability and Social Justice in Kenya: Scholars, Policymakers, and Activists in Conversation* (Berman & Monteleone, 2022). The anthology includes 14 chapters by scholars, policymakers, and activists working in disability. It invites readers to develop a nuanced understanding of disability in Kenya, past to present, and provides recommendations to push current developments and progress forward. The anthology caters to readers with diverse interests, whether disability representation in media, infrastructural initiatives, parental engagement, early screening, legislation, advocacy, or education.

Keywords: Kenya, global disability studies, social justice, human rights, disability rights, special needs education, social movements, culture, media, law

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Disability and Social Justice in Kenya: Scholars, Policymakers, and Activists in Conversation, edited by Nina Berman and Rebecca Monteleone (2022), offers a comprehensive consideration of disabilities in Kenya through a social justice lens. The title is apt for an anthology that includes 25 authors with varied experiences with disability, including scholars, policymakers, and activists. Notably, it includes first-hand accounts and lived experiences of at least five authors living with disabilities and, impressively, 80% of the authors are Kenyans. These key stakeholders add crucial voices and perspectives by virtue of their roles, positions, and influence.

The introduction is prefaced by a poem, "How to Negotiate a Disability Convention in New York," by Lawrence Murugu Mute, a Kenyan disability activist and lawyer. Mute paints a picture of the complexities and differences involved in understanding disability globally, including the role played by language. The introduction also provides readers with robust information on the history and activism of the disability movement in Kenya, including legislative mandates and the key roles played by faith-based institutions. The introduction contextualizes disability, acknowledging the ways in which indigenous practices may problematize disability constructs. Furthermore, the introduction highlights the contradictions rife in policy and implementation. More broadly, the editors use the introduction to carefully frame a work in which the distinctive voices of the authors shine. Situating disability rights in

the context of human rights is important in understanding the urgency and critical nature of the struggle. In light of this, in Part I (From Human Rights to Disability Rights), Patrick Onyango, Fredrick Omondi, Arlene Kanter and Everlyn Koiyiet, and Monteleone share stories of their experiences as activists, legal scholars, and researchers. They elaborate on legal and constitutional developments in disability. Their stories provide authentic interactions with the daunting efforts toward the struggle for human rights in Kenya (e.g., toward workers' rights and against political exclusion and suppression of academic freedom). They illustrate resilience to fight despite the odds.

To begin, Chapter 1 notes the initial oversight for the establishment of disability rights in Kenya and includes an overview of some engagement strategies deployed to facilitate a progressive and informed constitution. It highlights author involvement in advocating for the participation of persons with disabilities in the Constitution of Kenya (2010) reform process. Similarly, Chapter 2 discusses the intricacies of justice and social inclusion specifically for persons with disabilities. Access to justice empowers persons with disabilities, unlocks provisions of the constitution, and facilitates inclusion. The chapter emphasizes the key role played by legislative mandates and includes examples of ways that persons with disabilities benefit from accessing justice. For instance, people may benefit from exemption of court fees when defending their rights in court. Additionally, the chapter provides examples of existing gaps between legislative measures and access to justice for persons with disabilities, all of which can lead to exclusion and denial of basic rights. The chapter calls for strengthening the link between advocates, lawyers, and judges to further actualize the provisions of law for persons with disabilities. Similarly, Chapter 3 discusses the international and domestic legal protections for girls and women with disabilities and highlights strides Kenya has made on this front. Also, the chapter calls for Kenya to address the root causes of violence against

women with disabilities, among them societal attitudes. Some of the proposed recommendations include investment in programs and initiatives that increase awareness and support victims of violence. Also cited are ensuring domestic laws meet international mandates as well as implementing existing laws. Connected with a need to value local context and actors, Chapter 4 emphasizes the necessity for a critical African perspective on disability. The chapter calls for scholars, policymakers, and activists to be vigilant against privileging Western understandings of disability, particularly the medical model, over local knowledge development and mobilization specific to Africa. This vigilance includes paying attention to current developments using genetic technologies in prenatal screening as well as pushing back against media narratives that are harmful to and likely ignore the hard-fought gains of activists and the disability community.

In line with the continuing global conversations around equity and inclusion, in Part II (Access and Inclusion), authors Theodoto Ressa, Samuel Odawo, and Christopher Odinga make connections between access and inclusion for persons with disabilities. They argue that inclusion and active engagement of persons with disabilities are directly related to civic engagement, nation-building, and achievement of Kenya Vision 2030. Kenya Vision 2030 outlines the plans to foster growth and development focused on three areas: social, political, and economic. Notably, the plans emphasize the provision of a high quality of life for all citizens.

With this vision, Ressa references personal experiences in Kenya and provides vivid examples of infrastructural oversights evident in a society that reduces persons with disabilities to second-class citizens. The chapter discusses the slow progress of planning and constructing modes of transportation as well as the limitations of such projects to consider the needs of persons with disabilities, making their travel difficult. These realities leave them

vulnerable and excluded from active engagement. The author challenges persons with disabilities to assert their agency and disrupt these exclusive spaces.

Furthermore, the work considers ways poverty and disability are often intertwined. Chapter 6 underscores the link between disability and poverty brought about by barriers and disempowerment of persons with disabilities. This disempowerment leads to diminished dignity and well-being. The chapter highlights the role of culture in constructing disability and marginalizing persons with disabilities. It also considers the role education may play in increasing access and inclusion though demystifying disabilities and tackling negative stereotypes. Importantly, the chapter includes legal frameworks at the national and international level geared towards increasing access to the labor market. Moreover, it highlights the various constitutional mandates that call for participation of persons with disabilities in governance such as representation in Parliament. The chapter also highlights the glaring lack of enactment of laws by the National Assembly as well as the lack of transparency in the process. Even existing social protections (e.g., the cash transfer system) are flawed and not properly implemented. With the rising cost of living, current social protections are inadequate to meet the needs of the persons with disabilities.

To bring to life the impacts of poverty, in Chapter 7, a Kenyan sculptor, having contracted polio at age two, describes his life experiences. He provides an account of living with disabilities, defying the odds, and working to build an art center. Although the sculptor developed his talent, providing an example of success, low-resourced environments are stifling talent development, placing responsibility on stakeholders to address the challenges many people with disabilities encounter. The chapter further describes the vulnerability of people living with disabilities as they navigate daily activities complicated by physical barriers, poverty, and exploitation.

Attention is also paid to the role media plays in shaping beliefs and attitudes about

such topics as beauty and ability. Crucially, in Part III (Education and the Media), Sheilah Lutta, Nathaniel Murungi and Collins Ombajo with Mercy Musomi and Dennis Mutiso, John Ndavula and Jackline Lidubwi, and Lubna Mazrui and Margaret Murugami discuss developments in education and media related to persons with disabilities. For information on the current landscape, Chapter 8 provides an overview of post-independence national policies for special needs education and highlights developments in technology and the administration of assessments. Financial investments such as a provision of capitation grants for students with disabilities have increased enrollments for students with special needs. The chapter also notes that the Kenyan government's collaboration with development partners facilitated the creation of key initiatives such as eKitabu that develops accessible digital content and includes Kenyan Sign Language. The chapter calls for collaboration among the various education stakeholders to ensure coherent development and implementation of initiatives. It also calls for continued strengthening of current initiatives and increased investment for technical and vocational institutions (TVETs) and educational assessment and resource centers.

In line with these recent developments, Chapter 9 lays out best practices to increase access to education for learners with disabilities. Through the girl child network, for example, one organization connects over 300 groups working to empower girls across Kenya and, more broadly, protects and promotes the rights of boys and girls in Africa. The chapter also highlights activities and interventions that increase participation in education for children with disabilities. These interventions include child-led clubs, parent support groups, outreach activities, capacity building, advocacy, and partnership. Outreach and capacity building activities focus on equipping educational assessment research center officers, teachers, and school leaders with the skills needed to identify students with disabilities and providing them with basic equipment for training students. The chapter also elaborates on the lack of specific

provisions for implementing the speical needs education policy.

Another area needing further development is media representation of people living with disabilities. To demonstrate this, Chapter 10 provides some background on representation of disability in media and shares findings from the *Abled Differently* program on Kenyan television. The authors examine the development of the first television program accentuating the voices of persons with disabilities. Their findings from a mixed-methods research study show that different languages were used in the 27-minute program; there was 70% use of subtitles and 25% use of both subtitles and sign language. The largest population of participants were 18 to 30 years old, with the majority being female. Children in the show were featured in mainly private spaces beyond the school environment. The authors' call for increased diversity of content and representation as the media is a powerful tool for social construction.

Similarly, Chapter 11 focuses on advocacy for improving service delivery for persons with disabilities and provides a model from Australia that could offer a guide for advocacy work to improve implementation of the special needs education policy and promote access and inclusion in education. Moreover, access and inclusion include attention to the stigma associated with people living with disabilities and ways to eradicate it. In Part IV (Stigma and Culture), Prisca Kiptoo-Tarus, William Kurumei, and Stephen Ngososei, Nina Berman, and Cynthia Bauer and Leonard Mbonani with Jessica Charles focus on the broader ecosystem that includes caregivers. Chapter 12 discusses the psychosocial and economic challenges of parents of children with disabilities in one county in Kenya. The authors share findings of a mixed-research survey of parents and local leaders. The study revealed that parents of children with disabilities have limited psychosocial support, health care, and education and face psychological problems with isolation, stress, and frustration. The authors discuss some of the stigma facing them and their children in different settings such as school and

community. To make matters worse, stigma denies them access to social services and educational opportunities. Additionally, the authors note that parents are often overlooked as valuable stakeholders in the education process.

Compellingly, the anthology expands readers' understanding by examining disabilities that arise from addictions while advocating for consideration and protection of individuals experiencing challenging life circumstances. As an example, in Chapter 13, Berman argues for considering those experiencing heroin addiction as people with disabilities, and advocates for their protection. The author posits that people are pushed into heroin addiction as a result of their sociocultural environment, including limited job opportunities and exposure to substances without adequate protection. The author shares the example of Ukunda, a coastal town in Kenya, and calls for multi-layered interventions to address the addiction crisis. The chapter provides a vivid personal account that moves the discussion about addiction from an abstraction to one humanizing the situation. Changing the negative attitudes around disability is an important factor in driving success for people living with disabilitities. For this reason, Chapter 14 focuses on altering cultural perceptions of disability. It provides an interesting case study about confronting myths and cultural stereotypes through education, empowering the community. Follow-up work and engagement with traditional healers and church leaders offer a blueprint to connect with more people across the country in stamping out cultural perceptions that exclude people with disabilities from living dignified lives.

Overall, the anthology provides rich and compelling information on disability in Kenya. There are, however, several limitations. One echoed throughout the volume is the inconsistent data available on people with disabilities in Kenya, including numbers on student populations identified with disabilities. As stakeholders implement the SNE policy framework, a shared language is important to accurately identify students with disabilities

across the different categories. Secondly, several authors attempt to extrapolate that 13% of the population in Kenya likely have disabilities based on statistics used by WHO or statistics used in the United States. The authors do not address the risk that such estimations may overlook the impact of differing definitions of disability; nor do they address the possibility that such definitions may perpetuate biases and misconceptions.

Another limitation of the book is the editors' reaction to the missing emphasis on ethnic and religious groups from the contributors. This is likely due to the editors' bias from experiences in their own countries that do not translate in the same way in Kenya. In Kenya, there is less of a focus on ethnic or religious influences as a lens for understanding various topics. Unlike certain countries, for instance the United States, which emphasize sorting of people based on a socially constructed notion of race, and by extension use a race-based lens in various explanations, Kenya does not organize people using race or ethnic tribes; therefore, people do not automatically use race when describing social phenomena.

Lastly, the editors challenge stakeholders, including activists, scholars, policymakers, and researchers, to explore the role of both pre- and post-colonial practices on the development and understanding of disability in Kenya. This exploration helps the educational community fill gaps and informs future directions for policy development. The anthology acknowledges the existing repositories of work on disabilities in Kenya that are unexplored and may provide valuable information. Importantly, the book mentions current databases and search engines that exclude voices from the African continent and challenges scholars and stakeholders to find avenues to bring voices of African authors to the fore. Assembling a diverse group of voices, this anthology strikes a balance between, on one hand, amplifying the progress Kenya has made with respect to disability and, on the other, raising areas needing further development and focus.

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