

BOOK & FILM REVIEWS

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Disabilities, Human Rights and International Cooperation: Human Rights-Based Approach and Lived Experiences of Ugandan Women with Disabilities. Author: Hisayo Katsui. The Center for Human Rights of Persons with Disabilities (VIKE) Publication Series No. 8. Arkmedia Oy Vaasa. 2012. Print and pdf versions available free of charge. 219 pages. ISBN978N952N5977N04N2 (printed version) ISBN 978N952N5977N05N09 (pdf)

In the fifth chapter of her impressively researched book on disability and the human rights-based approach in Uganda, Hisayo Katsui includes the following quotation from her interview with a staff member from a DPO (Organisation of Persons with Disabilities) from the Global North:

You could say that in the whole of Uganda, this disability movement is a big experiment. It's conflicting with the basic ways of organising things in Uganda because we are organising across family, tribal and class issues, everything. And normally we are trying to organise Ugandans in a horizontal way, where the Ugandan system is organised in vertical lines. So it's a very crazy experiment. And it only goes because we have this solidarity of disability among us, due to something which is more than a tribe, more than anything. Yeah. Solidarity. Because otherwise you don't meet the word solidarity in the Ugandan context, it is patronising. If you have something, then of course it's charity. You'll give something to those in your family who are under you vertically. (133)

Though expressed from the perspective of a foreigner to the Ugandan context, in a book that also gives ample space and time to the voices of Ugandans with disabilities, this passage effectively encapsulates some of the book's central issues. Specifically, and as the author herself notes, the interviewee highlights the conflicts, as well as the ambiguous continuity between charity-based and human rights-based approaches to disability, even when the goal for many organisations may be full adoption of a human rights-based approach. As Katsui states, the vertical and the horizontal 'are very close to each other, divided only by 'something' (134).

As the reader learns here and elsewhere in the book, insistence on a strictly human rights-based approach to disability, even at a time when the UN Convention on the Rights of Persons with Disabilities enters into force, encounters contextual limitations, as in the case of many deaf Ugandan women at the grassroots level, who lack access to the most basic education and other resources, and therefore may not be equipped to assume their rights. Attention to this dilemma makes the research relevant to those working in other areas of the

Global South, since as the author notes in her introduction, the disproportionate levels of poverty and illiteracy amongst disabled people is not a situation unique to Uganda. Such devastating conditions add impetus to the UN Convention's emphasis on human rights (Katsui 1) yet as the author also demonstrates throughout her study, it is precisely these conditions that complicate the practical application of a human rights approach.

One of the key strengths, and also a useful paradox of this book occurs precisely in its simultaneous focus both on the lived experiences of Ugandans with disabilities, particularly deaf women, and on the mid and high-level operations of local and international DPOs, Ugandan electoral politics, the United Nations, the African Union and related disability organisations, as well as on the global context of neoliberalism. In the above-cited passage too, the juxtaposition of the Northern "we" and the "Ugandans" underscores the inevitable complexity of structural inequality both within and beyond Uganda, and of a broader North-South relationship, in which many committed stakeholders seek to overcome such inequality, even as their own positions and opportunities are defined by its parameters.

The book's introductory sections include a foreword by Shuaib Chalklen, United Nations Special Rapporteur on Disability, with whom the author travelled to policy meetings pertaining to the formation of the African Union Disability Architecture and related projects, and with whom she collaborated on research, as discussed later in the book. Following this, the author's introductory comments discuss the particular characteristics of Ugandan disability politics that led to her interest in the research. She notes Uganda's progressive Constitution, and its affirmative action quota system for the election of members of Parliament with disabilities. The author also outlines the significance of the UN Convention in relation to the human rights-based approach. Of particular importance here, and throughout the book, is attention to the Convention's stipulation of 'extraterritorial obligations', meaning in practice that individual countries of the North are duty-bearers to citizens of Southern countries, as well as responsible for the rights of their own citizens. This point has major implications for contemporary disability politics at the global level, and also works to underscore the distinction between the human rights-based approach (which must look beyond a given national context) and the social model of disability studies (which often does not).

Chapter two, the lengthiest portion of the book, offers theoretical models and concepts relevant to the study as a whole, including emphasis on the challenges of defining disability from one location to the next. Some attention is paid to the notion of intersectionality, through reference to Robert McRuer's work; this concept is undoubtedly crucial to the present study, and a more detailed theoretical backdrop would have been helpful here. The

chapter gains strength with a shift towards the lived realities of deaf women in Uganda, and in analysis of disability in the Global South (versus the North) and in the more specific Ugandan context. One of the key issues here is the “twin-track” approach to human rights for people with disabilities, consisting of a combination of mainstreaming and empowerment, and to which the Finnish ministry for foreign affairs added a third track, in 2009, focused on policy dialogue and multilateral negotiation. This point becomes relevant in the structure of the present book, in its movement between political processes and material conditions.

A detailed chapter on methodology outlines the main questions of the study, and pays particular attention to the benefits and shortcomings of the participatory research model. The author notes that the project aimed towards an empirical, rather than a normative theory of human rights, that is, focusing on actual practice, rather than on how things ought to be (54). It is worth noting that she returns to the same point in her conclusion, and that this is a central challenge that the book as a whole navigates effectively. The methodology chapter also provides detail on the author’s background and relationship to disability and disability studies, and on the dissemination of the project, including the use of captioned photographs to make the work more accessible to diverse populations in Uganda.

The author presents many of her research findings in a fourth chapter, consisting of case studies, preceded by brief life stories of two Ugandan women with disabilities. One case study looks at the activities of various Ugandan DPOs in cooperation with mainstream HIV/AIDS prevention, care and treatment projects. This sub-chapter is a particularly powerful example of the synthesis of research on the work of stakeholder organisations with first-hand interview-based research on Ugandans with disabilities, in this case primarily deaf Ugandan women living with HIV/AIDS. A second case study considers the general assemblies of two major Ugandan DPOs, focusing on the strengths and limitations of the human rights-based approach in this context. The final case study addresses international policy and processes in the creation of the African Union Disability Architecture, thus drawing the study beyond the Ugandan context.

In chapter five the author deepens her analysis of the human rights-based approach to disability, complicating the separation between human rights and charity-based approaches, and integrating evidence gleaned from the case studies into her theorization. The sixth chapter places Ugandan disability politics and experience in global context, paying particular attention to the roles of globalization and neoliberalism and their impacts on the lived realities of people with disabilities in Uganda. Here the author employs the notion of “ontoformativity” as central to her discussion, reading bodies and their social dynamics as enmeshed and inscribed with global social processes.

Throughout the book, the author poses questions on methodology, and engages in self-reflection regarding the terms of her study. This is the central focus of chapter seven, in which she considers whether the participatory research approach may be a burden for Southern researched people. Such reflection on the complex inequalities that emerge in the research process does not lead to clear solutions, but enriches the project by critically engaging with the practical limits of given models for both research and disability rights.

This book's accessibility is certainly enhanced by the fact that it is freely available on line, and by the incorporation of captioned photographs. Some additional editing for clarity and readability, along with further foregrounding of the book's importance in the contemporary global context might also improve its circulation and impact. These points notwithstanding, Katsui's book represents an outstanding work of research, and an engaging negotiation of grassroots disability experience, research methodology, and disability politics at global and local levels.

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