

BOOK REVIEW

Disability in Local and Global Worlds

BENEDICTE INGSTAD & SUSAN REYNOLDS WHYTE (Eds)
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To say that this second anthology of disability-centred research edited by Benedicte Ingstad and Susan Reynolds Whyte, *Disability in Local and Global Worlds*, fills a gap in the literature is an understatement. Taken together with their previous anthology, *Disability and Culture* (1995), these essays currently comprise the field of comparative disability in anthropology. Consequently, this work carries enormous weight. Through their inclusion criteria, they have accomplished what the disability interest group in anthropology has been unable to do for over a decade. That is, to bring under the scholarly umbrella of disability studies eminent medical anthropologists known for their research among people with all manner of physical, mental, occupational, and age- and gender-related impairments – who do not explicitly reference their research using disability theory or literature. Their rich ethnographic examples and those of anthropologists professionally identified as disability scholars suggest the potential of the disability concept to fit into evolving canonical theories in anthropology.

The publication of this volume coincides with increasing international recognition of disability personhood as a social status facing discrimination. The treaty language of the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol adopted by the General Assembly in December 2006 (in March 2008, 125 nations are signatories to the Convention and 71 to the Optional Protocol – the US not among them) makes explicit connections between disability and gender, race, age (the very youngest and the very oldest), poverty, abandonment, and all forms of violence. Many of the essays in this anthology underscore shared, growing understandings of the fundamental disability paradox encapsulated by Douglas Baynton (2001:33): “Not only has it been considered justifiable to treat disabled people unequally, but the concept of disability has been used to justify discrimination against other groups by attributing disability to them”, as has occurred for women and people of African descent and purported cognitive and physical “defects”.

Three essays directly address the relationship between gender discrimination and disability. One in particular, Aud Talle’s comparison of feelings of “completeness” versus feelings of “impairment” among circumcised women who move from Somalia to London is a fine example of what ethnographic

research offers to anthropological understandings of “impairment” relativity and “disability” in social contexts. Marcia Inhorn and Aditya Bharadwaj provide an excellent argument for including infertility as an impairment that leads to disablement – stigma and abandonment – in Egypt and India. Less persuasive are their claims about disability rights activists’ responsibility for leaving infertility out of disability rights, as if these imagined univocal persons served hardened agendas. As with any theoretical framework under “construction”, it would be most fruitful for anthropology for its scholars to consider how ethnographic research may take emerging fields into significant directions by locating infertility, for example, within existing disability scholarship on reproductive rights and experiences (Fine & Asch 2002; Finger 1990).

Veena Das and Renu Addlakha introduce the concept of “domestic citizenship”. Using two opposing cases of rumour and innuendo in their essay, they compare acceptance and rejection of “impaired” women by their kinfolk in India. Yet here, when two are used to represent a “whole” pattern, the stretch required strains understanding. When one family refuses local mores to “disable” their visibly impaired daughter, is this idiosyncratic doting or ensuring her survival through marriage alliances? Is it her fertility that renders her opposite to the childless, androgynous, schizophrenic woman abandoned by both affinal and natal kin?

In contrast, Meira Weiss reports little variation in Israeli parents’ rejections of visibly impaired infants. Through her trope, “the chosen body”, Meira Weiss crafts a disability frame for the intersection of gender, Zionism, and bodily perfection/defects. Tracing the history of disabled people in Israeli society, Weiss finds recurring themes of segregation, even for soldiers injured in war, and widespread neonatal testing followed by “selective abortion” to prevent giving birth to disabled children. By placing the particulars that she finds in Israel within more encompassing critical inquiries into “neogenetics” by disability scholars, Weiss contributes greatly to another emerging subfield with historical and present valence for anthropology.

Margaret Lock’s essay on “laissez-faire eugenics” provides evidence for the bioethical concerns raised by Weiss, and for why disability activists find much to be concerned about in the current social practices and discourse of genetics. Lock identifies an acute need for critical scholarship on the purveyors and practices of genetic science in this “state of the scientists” report on current genetic discourse. With regard to disability conceptually, however, without reference to disability scholarship on genetics, or even to Boas – whose insights into the social consequences of eugenics ([1928] 1962) initiated anthropology’s toehold on critical eugenics – its scope entails a first step with intriguing theoretical possibilities.

Fortunately for socio-cultural anthropologists, it is not all critical medical and science studies in disability scholarship. Hilde Haualand reveals why culturally deaf signers who meet at international gatherings, such as Deaf Olympics and DEAF Way, are *not* disabled. Using Turnerian ritual theory, she describes what Patti Durr (2000) has termed “affirmation identities”: spaces and times that deaf people bridge national and signed language

differences to celebrate shared experiences of living as deaf persons. In these intentionally liminal spaces created outside of the everyday, deaf signers reinforce performances of international deaf citizenship through signing fluencies.

While not within the purview of Haualand's essay, a sidebar to this narrative illustrates yet another disability paradox, one that inflects desires for an international deaf citizenship. In the US, ASL (American Sign Language) is increasingly inaccessible to deaf babies as a first language – through cochlear implant providers' claims about its "crippling" effects on the ability to speak. At the same time, its accessibility increases as a first language for hearing babies – through the popularisation of Baby Sign among hearing parents seeking its superior early communication "abilities".

Nancy Sheper-Hughes and Mariana Leal Ferreir relate a complex symbolic narrative of kidney disease and transplant among Suyá Indians in Brazil, in which the key figure is also not disabled in the discriminatory sense. Although the authors do not frame their work within disability scholarship, their data encourage thinking about what counts as an impairment that leads to disability and what does not in its context. The explanatory narratives of Dombá and his kin suggest he became ill "with a white man's sickness" because of his refusal to "pierce his lip and wear a lip disk" (162). His "impairment", then, lies in an improper lifestyle (to deliberately compare with biomedical notions of causality) – which may be socially rehabilitated – and not in a bodily "defect", his renal disease. The fracture in the social body healed when Dombá embraced Suyá shamanic healing and understandings that stitched together the soul of a "white man's kidney" with his Suyá body, re-incorporating him and ensuring his survival.

Engaging and diverse respondents come to life in the nuanced essay by Susan Reynolds Whyte and Herbert Muyinda on "mobilisation" in Uganda. Deftly interweaving the multiple meanings of mobility – from rural to urban settings; from few technologies to "wheels"; from impoverishment to the means to marry and support families; from discrimination as individuals to representative politics and fellowship with like persons – the authors give voice to the complicated interplay of local and global issues within current disability scholarship.

John Traphagan presents a cogent, also stand-alone essay about the moral imperatives for aged people in Japan to prevent becoming a burden to Japanese society and kinfolk by preventing age-onset impairments. He locates such super-individualised responsibility for health outcomes most particularly in tensions between gendered expectations for women to provide kinship support through care-giving and to provide economic support through work. While Traphagan finds comparative similarities with Lawrence Cohen's on aging in India, his analysis differs greatly through his references to disability scholarship. Thus, he contributes toward much-needed understandings of how age-onset impairments fit within disability conceptual frameworks.

Benedicte Ingstad and Matthew Kohrman both engage in critical "politics of culture" approaches (Handler 1988) to the problems with exporting and importing de-contextualised "disability rights" discourse. After revisiting

fieldwork sites and previous respondents in Botswana, Ingstad proposes that “human rights discourse” fails to capture their lived experiences or to be relevant to their daily lives. Pointing to a WHO manual on how to use white canes in a local setting where their use instead signifies a “blind woman’s family is not taking care of her”, she critiques “the agendas of activists from the developed world” (pp. 250–251). Yet, in her preoccupation with apt concerns about universalised discourse, she inadvertently reproduces an imagined univocal activist armed with an enforceable mandate, and refutes her stated intentions by de-contextualising disability experiences. These concerns aside, Ingstad contributes a most necessary corrective to what might be deemed “first-wave” disability discourse in human rights arenas.

Matthew Kohrman’s exceptional work on disability in China takes a Handlerian turn toward critiques of the politics of culture and nationalism in this essay on China’s commodification of “disability rights” to undergird performances of national modernity. Recounting the absurdities of counting disabled people to fit invented international statistics and using one woman’s experience of not being disabled enough to qualify for disability employment quotas to illustrate how truly enforceable are these mandates, his arguments are persuasive and well documented. However, through focusing only on unmasking China’s co-optation of disability rights, Kohrman’s body of work on disability in China and disabled people’s lived experiences somehow disappear.

On the whole, this remarkable anthology exemplifies comparative medical anthropology at its best. The additional freight it must carry, then, lies in the tensions produced when medical anthropology subsumes disability in a democratisation that includes any illness, loss of function or sense (“we are all temporarily able-bodied”), without regard to issues of discrimination. Clearly, much is gained that remains under-theorised. Davis (2002) proposes with “dismodernism” that disability could become the “encompassing whole” (Dumont 1980) within which all possible forms of human variation become equally “part”. Does disability democratisation become a curb cut that levels imagined boundaries between “able-bodied” and “disabled” people, providing inclusionary access for all? Or, does it smooth over the extremely rough edges lived by the majority of people in the world with severe mental, cognitive, sensory, and physical disabilities?

Further, while the disability concept may be found underlying social justifications for gender, race, and economic inequalities, anthropologists writing on disability topics often do not undertake reviews of the literature and theory of disability scholarship as would be expected for analyses of gender, race, kinship, and even biotechnology. As a consequence, the hermeneutic circle ensues in which “the horizon of our expectations” (Ricoeur 1988) about disability scholarship’s role in anthropology and anthropology’s investment in disability scholarship have, in my opinion, remained almost unchanged in the twelve years since these editors compiled their first anthology, *Disability and Culture* in 1995.

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