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Disability Rights and Wrongs in Uganda

TYLER ZOANNI

“Uganda’s disability journey,” as scholars Julie Abimanyi-Ochom and Hasheem Mannan have described it, is justly celebrated. The country has ratified some of the most progressive disability laws and policies in the world, and it is home to a robust disability activist movement. Disability is also

**Disability
and Equality**

Ninth in a series

highly visible in mass media and public life. At the same time, however, these gains in laws, activism, and publicity have not significantly changed the lives of most disabled Ugandans. In some respects, they even further marginalize the needs and concerns of Uganda’s most marginalized disabled people.

In this way, Uganda offers a story of disability rights and wrongs, a turn of phrase I borrow from disability studies scholar Tom Shakespeare. I recount this story here because it is striking and important in its own right, and because of what it illuminates about the paradigms that dominate disability politics and activism today. Such dominant approaches thoroughly reflect the traditions of political liberalism from which they have emerged: they espouse a disability politics focused on principles like individual rights, autonomy, and self-determination, and they are grounded in laws and policies as the basis for social change. This is true in many places, but the case of Uganda brings into glaring relief what a disability rights paradigm can and cannot do.

RIGHTS

First, what is right about disability rights in Uganda? The answer is: quite a bit. The

constitution recognizes disabled people’s rights as such—that is, as the constitutional rights of disabled people to respect and dignity—and this remains unusual.

Uganda has ratified the United Nations Convention on the Rights of Persons with Disabilities, and it has enacted anti-discrimination laws guaranteeing disabled people’s access to education, community life, employment, physical space, and more. The Ugandan Parliament has five seats reserved for disabled people. Every level of government has mandated representation of disabled people, stretching down to local councils at the village level.

In addition, the central government features a number of disability-focused offices and initiatives, most notably the National Council for Disability, which monitors rights and guides policymaking. All children in Uganda have a right to primary and secondary education, and this includes disabled children. To facilitate the education of disabled children, Uganda has established a national special educator training program, as well as a mix of integrated, mixed, and segregated schools for disabled students.

Alongside state efforts, disability plays a vibrant role in social and public life in Uganda. This starts with disabled persons’ organizations, which date back to the 1970s and include groups led by people with physical impairments, Deaf and Blind people, and people with albinism. All of these groups meet under the auspices of an active umbrella organization, the National Union of Disabled Persons of Uganda, which was founded in 1987. Uganda is also home to numerous nongovernmental organizations focusing on disability services, rehabilitation, economic and social development, and the arts and cultural life, all for disabled people. Disability is a common topic across newspapers, radio, and television; media

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consumers in Uganda frequently encounter disability-focused talk shows, programs, and series.

All of this amounts to Uganda's disability "rights" in two senses—both in the sense of a progressive disability politics and in the sense of specific legal entitlements to education, political participation, and social integration. Uganda's disability rights in this double sense are remarkable in any case, but especially so in light of the considerable challenges the country has faced. Nearly 42 percent of Ugandans live below the international poverty line, the vast majority of people rely on subsistence agriculture, and the country was hit hard by the HIV/AIDS epidemic as well as decades of armed conflict and civil war. This broader context simply proves that ambitious and progressive national action with respect to disability is not merely a luxury, nor is it a prerogative of wealthy countries in the global North.

Uganda's disability rights did not come about accidentally, and this, too, bears celebrating. They were built by decades of hard work on the part of Ugandan disability activists, starting in the 1970s. The National Resistance Movement, led by Yoweri Museveni, who has been Uganda's president since 1986, played a central part as well. It made disabled people key targets of an ambitious program of postwar national "empowerment," and committed significant legal and institutional energy to the betterment of disabled Ugandans.

REALITIES

The World Health Organization has estimated that roughly 80 percent of the global population of around one billion disabled people reside in the so-called developing world. This raises the question of whether the striking prominence of disability in Uganda is partly demographic. Is disability so prominent in Uganda simply because the country has so many disabled people, compared with other countries? There is not an immediate answer, but it seems likely that the government and activist initiatives are just as important as demographics in a narrow sense, and probably more important.

It is difficult to say whether the country has higher or lower disability rates when compared with countries across the world, within sub-

Saharan Africa, or in comparable socioeconomic circumstances. This is because available statistics on disabled Ugandans vary considerably, from estimates as low as 6.5 percent of the population to as high as nearly 18 percent. These divergent estimates almost certainly stem from different survey methods and definitions of disability, ranging from narrow medical construals that focus on impairments, to global public health approaches that emphasize "functions" of daily life, to more critical activist and social scientific definitions that foreground disabling social conditions. That said, it is probably safe to assume that the absolute and relative numbers of disabled people in Uganda are not on the low end of the estimates—regardless of how exactly one defines disability—because of Uganda's history of violence as well as people's limited access to medical care in a context of widespread poverty. But it is equally safe to say that these factors do not by themselves account for the prominent place of disability in contemporary Uganda.

When it comes to Euro-American nation-states, historians have shown that the twentieth century's two world wars produced impairments on a massive scale. The expansion of the welfare state and new categories of entitlement and rehabilitation subsequently made disability

a category and concern of public as well as personal life. Put crudely, war and welfare made it possible to be a disabled person, in the sense of making disability a meaningful category of identification and social organization. In turn, disability became politicized alongside other projects of social change starting in the 1960s, providing the basis for new forms of disability activism and civil and human rights movements.

Uganda's disability history has taken a track that converges with this Euro-American history in some respects, but in many others diverges from it. It is true that disability as a category first emerged from welfare initiatives for disabled veterans within colonial Uganda in the wake of World War II. Yet my own reading of the archival files of postwar disability pension claims in Uganda suggests that African claimants rarely succeeded, whereas European colonizers living in East Africa often did.

The late-colonial programs for Deaf and Blind Ugandans run by missionaries and the colonial

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government likely came closest to anticipating the later, more broadly based disability consciousness. British missionaries and colonial officials viewed Deaf and Blind Ugandans as capable of being productive disabled people, and thus useful parishioners and colonial subjects, if only they were given the proper training and education. These programs, however, did not disseminate a widespread sense of the category of disability as a meaningful term of identity, belonging, or claims-making. This came only later, likely in the 1970s, as disabled Ugandans began to follow and participate in the emergence of a form of global rights activism.

After independence from the British Empire in 1962, the shaky patchwork of incredible ethnolinguistic diversity that the British had stuck together to create Uganda began to fall apart, leading to decades of armed struggle and war in the successive regimes of Milton Obote, Idi Amin, and the Okello brothers. These decades of violent conflict certainly produced many impaired bodies and minds. But this was outside the context of the emergence of formal disability activism in Uganda, which historically was led by people with physical impairments, blindness, and deafness who were not often immediately connected to war or political violence, even though they had lived through such experiences as bystanders and civilians.

Northern Uganda, however, is one part of the country where violent conflict does directly connect to disability in a quite particular way—namely, as a category of humanitarian and NGO intervention. In the 1990s and into the 2000s, this region was the epicenter of fighting between the Ugandan military and the rebel movement known as the Lord's Resistance Army. During the course of this fighting, nearly 2 million people were displaced, and many thousands were kidnapped, injured, tortured, or killed. Alongside high levels of physical and psychological impairment, this violence generated a small industry of state, transnational, and NGO postconflict rehabilitation efforts, many of which focused specifically on disability and disabled people.

Anthropologist Herbert Muyinda studied these efforts, which often supported what he calls “skilling,” or training in income-generating skills like tailoring, carpentry, shoemaking, craft-making, leatherworking, pottery, and metalwork, all intended to enable poor disabled people to make their own lives and livelihoods. This focus on skilling in the context of postconflict northern Uganda did not simply follow the model of early colonial

training for Deaf and Blind people. Rather, it reflected a more recent neoliberal turn within humanitarian and developmental efforts—a turn away from providing people in need with direct material assistance, and toward disseminating skills, awareness, and empowerment.

As Muyinda and others have shown, skilling initiatives for disabled Ugandans have had mixed results. They certainly can support basic survival, in the sense of helping the disabled find ways to make enough money to get by. They also provide the basis for entrepreneurial achievements that have the potential to dramatically change a person's circumstances. Even if making and selling clothing, pots, or crafts provides a relatively minimal income, this is not insignificant within the context of individual lives in Uganda. One of the most important factors in the life chances of many disabled Ugandans is not whether they have impairments, but whether they can be economically and socially productive. Nayinda Sentumbwe, a rehabilitation studies scholar, found that Blind people in central Uganda who were able to work could also find partners, raise children, and ultimately lead relatively typical family lives, though this proved easier for men than for women.

In my own work, I have found cases of people who would be diagnosed as having intellectual impairments in many other countries, and likely would be steered into some kind of state-supported living arrangement. But some of these individuals simply went about ordinary menial jobs: driving motorcycle taxis, selling fruits and vegetables, and the like. This does not free such individuals of stigma and discrimination on the part of colleagues, neighbors, and families, as Sentumbwe, anthropologist Susan Reynolds Whyte, and my own work have shown. But being socially and economically self-sufficient does mean that people with impairments can live relatively ordinary lives, in ways that are not significantly diminished or perceived as such.

WRONGS

There are clear limits to “skilling” initiatives, however. They tend to train disabled people for low-paying jobs in markets already oversaturated with similar goods and services. And such a trajectory of skilling, as noted by development studies scholar Christina Nett, reflects the agency and plans of bureaucracies, rather than the wishes, choices, and goals of disabled people themselves. What is more, these interventions frame the

project of improving disabled people's lives at the level of individual betterment, rather than in terms of wider social conditions.

In a way, then, these skilling initiatives encapsulate some of the larger problems facing disabled Ugandans—disability wrongs that shadow the success story of disability rights. The problems with such initiatives—the very limited kinds of possibilities these governmental and nongovernmental efforts provide—also suggest a counternarrative to commonplace explanations of the difficulties that disabled people face in Uganda. A great deal of policy, activist, and academic work points to stigma, “cultural” beliefs, ignorance, and attitudes as the causes of unfavorable living conditions, social marginalization, and oppression faced by disabled people in Uganda. Without denying the existence of anti-disability assumptions and biases in Uganda (similar to everywhere else, it bears emphasizing), other attitudes are equally at work.

For example, one encounters frequent human-interest newspaper stories about disabled Ugandans. Some of these are celebratory; others are stories of pity and personal misfortune that end in calls for assistance. In my research in central Uganda, I found that a number of proverbs and traditional sayings emphasize the formidable skills and capacities of disabled people, rather than their limitations. I note this simply to underscore the fact that problems facing disabled Ugandans are not merely attitudinal or cultural, but also political, social, and economic.

Skilling efforts may (and the “may” bears emphasizing here) help particular disabled individuals make ends meet, and this is surely important. But such projects do not challenge the fact that an estimated 80 percent of disabled Ugandans (or nearly double the overall percentage among Ugandans in general) live below the poverty line.

Uganda's disability wrongs are further evident when it comes to the country's progressive disability laws, policies, and activism. As disability activist James Anyimuzala notes, much of Uganda's disability legislation exists largely on paper, while many disability programs and policies go underfunded, unfunded, or unimplemented. Activists I met during my research often offered some version of this mordant quip: “Oh yes, we have the best laws in the world. Too bad we don't follow them.” Progressive laws and policies readily circulate

within a highly rarefied atmosphere of official documents and reports, offices, and initiatives, which may have little to do with the lived realities of disabled people.

Indeed, despite the promise and notable gains of disability law, policy, and activism, the material circumstances of the vast majority of disabled Ugandans have not significantly changed in the past few decades. One can even discern the emergence and entrenchment of substantial socioeconomic inequalities between the vast majority of poor disabled Ugandans and a kind of disability elite, made up of highly educated politicians, activists, lawyers, academics, and other professionals holding well-paying jobs in government, NGOs, and transnational organizations.

Such a stratification is evident in the contrast between the few who are elected to the reserved seats for people with disabilities in Parliament and the many more who are offered the menial prospects of skilling initiatives. One can also detect this stratification in statistics for school attendance. Despite the existence of universal education pro-

grams, a 2014 UNICEF study found that only 9 percent of disabled children in Uganda were in any form of school, whether pre-primary, primary, or secondary. This is likely due to the lack of accessible and supportive

learning environments, the high cost of fees for private schools to which many people wish to send their children, and the burdensome costs of supplies, uniforms, and transportation, even for government schools that do not require tuition.

In many ways, then, disability policies and interventions are often far removed from conditions on the ground, particularly in rural areas, where the majority of people in Uganda live. In northern Uganda, Muyinda found a critique of what his interlocutors called “groupism,” a dismissive gloss on NGO efforts that talked a lot but actually brought few tangible benefits to struggling disabled people. Moreover, the distance between Uganda's progressive disability policies and interventions and ordinary disabled people's lives is evident even outside the successes and failures of various state and NGO efforts.

Thinking of themselves in terms of disability or engaging in disability initiatives is not always a primary concern of many disabled Ugandans. Food, employment, money, and families are often more

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pressing. Disability, as Susan Reynolds Whyte has shown in a study of elderly disabled people in rural eastern Uganda, both is and is not a priority for individuals at different junctures and moments, a balance that varies considerably over the life course. Such a perspective may well be common among disabled Ugandans outside activist circles, who do not necessarily identify with a paradigm of disability rights and identity. Saying this is not meant in any way to diminish the historical achievements or contemporary importance of disability rights and activism in Uganda; it is simply to note their limits.

RIGHTS, WRONGS, AND BEYOND

Despite many reasons for celebration, one can detect a certain thinness within the project and paradigm of liberal disability politics as it unfolds in Uganda, manifested in its distance from the lives and problems of many ordinary disabled people, who continue to face poverty and significant barriers to access to physical space, social life, education, work, medical care, and political participation. An overly celebratory account of disability rights in Uganda can obscure such problems.

It is important to emphasize that the limits of a liberal disability politics are not unique to Uganda. Within North America, for example, radical disability activists, many of whom are queer and people of color, have developed a paradigm called “disability justice” as an alternative to that of disability rights. Disability justice approaches question the assumption that individualized disability rights and self-determination—touchstones of mainstream disability activism everywhere—are truly emancipatory. In contrast, disability justice advocates call for intersectional coalition-building across diverse social identities and positions, mutual aid, and experiments in interdependent collective living. All of this is intended to support a broader struggle to inaugurate a more just social and political order—a better world for disabled and nondisabled people alike.

Although the vocabulary of disability justice is without question distinctly American, thinkers and activists like Oche Onazi have begun to explore what this perspective might mean and do in African settings. Onazi draws links between disability justice and the importance within African philosophy of the notion of *ubuntu*, which can be translated as “humanity” or “personhood,” but in a way that begins from the fundamental

interdependence of all human existence. *Ubuntu* is regularly invoked within disability activism in Uganda as well as throughout sub-Saharan Africa, and it is used to claim membership in the wider human community.

There is great potential here for an approach to disability politics that is more vigorous and radical than a liberal disability politics, not to mention potentially more meaningful or intuitive in a place like Uganda. But there is a long way to go within mainstream disability activism in Uganda (and anywhere else, for that matter). Counterintuitively, in my own research, I found that the communities that most realized this potential in Uganda, even if incompletely, were far removed from those espousing from either *ubuntu* or disability justice perspectives—namely, Christian schools and homes for people with cognitive and developmental impairments. These disabled people are precisely those most overlooked by Uganda’s progressive disability laws and robust activist movement. They are nominally recognized in legal and activist conversations, but in practice are largely excluded from both.

One reason Ugandans with cognitive and developmental impairments are excluded from mainstream disability politics in Uganda (and most of the world, in fact) is an ironic or even tragic corollary of a fundamental principle of disability activism: self-representation, summarized pithily by the activist slogan “Nothing about us without us.” This is an important principle, but it has the dangerous capacity to reinforce rather than challenge dominant expectations about what it means to represent oneself, and to be a self in the first place. The notion of self-representation can function as a demand for voice that ends up backgrounding or even excluding people who do not use language or communication in conventional ways. The demand for self-representation thus always risks falling into an ableist trap—an expectation that people be articulate language-users first and foremost.

For this and other reasons, many Ugandans with intellectual and developmental impairments fall outside of mainstream disability activism and politics in Uganda. What little care and advocacy exists is provided by a thin web of Christian organizations, largely Pentecostal and Catholic (on which my research has focused). On the face of it, these organizations are anathema to both liberal disability politics and disability justice critiques. They provide institutional settings where disabled

people often live or are schooled at a considerable remove from so-called mainstream settings. They maintain clear distinctions between the disabled students and residents and the nondisabled staff members. Daily life often unfolds according to fairly paternalistic or even infantilizing logic; disabled people are treated as children regardless of their biological age. In such ways, these Christian institutions almost seem like a caricature of all that secular disability activism opposes.

And yet, such Christian efforts enable lives and worlds of disabled people that might be foreclosed otherwise. Such people not only fall outside national disability services and conversations; they are also often excluded from or outright abandoned by their families. Against this background of neglect, even the use of the category of “child,” so heavily attacked in Euro-American critiques of the infantilization of disabled people, extends a meaningful category of personhood, which in turn implies that people are deserving of recognition, care, and support.

What is more, these Christian institutions bring disabled and nondisabled people together in relations of care and support over the long term. For example, at a Catholic home where I worked, many people, whether disabled or nondisabled, spent a great deal of time gathered in the

living room or on the benches that line the porches of the main compound’s house. There they listen to the radio, gossip, joke, or just sit quietly. Days begin, end, and are punctuated by joining together for meals, prayers, and leisure. Efforts like this Catholic home embody a kind of disability politics that is radical in its own right, based not in rights or self-representation, but in presence, interdependence, and life together. This is rare in a place like Uganda; it also runs against the grain of the wider project of “independent” living within liberal disability politics in Euro-American contexts.

One must not romanticize such Christian efforts, but neither should one dismiss them. The thinness of disability rights in a place like Uganda, and arguably everywhere, needs to be thickened with social and material support. Rights and liberal politics alone are not enough, and their rhetorical invocation can actually foreclose the needs and concerns of the most marginalized of disabled people, as certainly happens in Uganda. This is perhaps the key lesson of the story of disability rights and wrongs in Uganda, a country that has achieved remarkable successes in its “disability rights journey.” Uganda’s experience also underlines the ways that such a journey can and should continue. ■