

Decolonial Disability Studies

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It is important to ask, when considering a new community research project, “What can research really do to improve this situation?” The answers might reveal that . . . it is not the research that will make the difference but, rather, who participates in the research, who poses the questions, how data are gathered, and who conducts the analysis.

—Tuck 2009, 423

Introduction

This chapter begins by critically revisiting what Indigenous scholar Eve Tuck calls “damage-centered research”—a type of research focusing on exploring Indigenous communities’ “damages” without necessarily empowering them. Tuck calls for an epistemological shift from how research with Indigenous communities has been historically conducted to a framework of desire that recognizes complex aspects of personhood and struggles in shaping the lived experiences of Indigenous youths and communities.

Tuck’s argument is useful for us to interrogate the ways damaged-centered research has been widely applied in Western research that reinforces social othering (see also Smith 1999). Social science research has utilized damaged-centered research to evaluate the degree to which communities have been affected by humanitarian crises. Consequently, disabled people in the South are usually known to the West through numbers or statistics (which focus primarily on their health condition, poverty, and impairments) and through representations of their victimhood (as illustrated in human and disability rights monitoring reports). As Leslie Swartz (2018, 281) observes, “Most of academic writing about disabled people in the global south is written by people from the global north, some of them disabled and some not. Disabled people in the global south, whether written about, or filmed or photographed, commonly enter the world of the ‘global’ through the intervention of people in the north.” And yet, why research disability, what is researched and by whom, and who is excluded from research are political questions. They remind us how research has materialized the “coloniality of power” (Quijano 2000) through the universalization of Western theories and methodologies in the global context.

Questions regarding who “we” are, what epistemological framings we use, and where we stand in order to do research make the politics of disability theorizing challenging. As a discursive and material practice that produces social relations, disability studies has been dominantly conducted by researchers in the Global North. This question of authorship unveils epistemological challenges to research conducted in the Global South (Santos 2018). Disability studies, written by scholars situated in the Global North, has been powerful in disrupting the modernist thinking about disability as an individual problem, and it has created sociopolitical foundations for reframing disability and difference as historically produced by colonial, imperialist, and capitalist social forces (Erevelles 2011). Critical disability studies sees disability and ability as discursively coconstituted by the intersections of racism, colonialism, ableism, and other forms of oppression. Its struggles for disability justice have created more radical spaces for resisting these intersectional forms of oppressions and, in so doing, reframing the question of access for all bodies and minds (Sins Invalid, 2019). As Dan Goodley (2013) puts it, disability is *the* space from which we think about political, theoretical, and practical issues that are relevant to all of us.

At the same time, Western disability studies writings assume the spaces located in North American and Western European nation-states as universal; thus, disability discourse from the Global North tends to be universalized in disability studies writings. There is an implicit assumption that disabled people share similar experiences with oppression across nation-states and transnational spaces. At the same time, there is a hierarchy of knowledge that frames understandings of disability across these geopolitical spaces in that disability discourses in the Global North are centered on questions of access, representation, citizenship, and identity, and as such are perceived to be more valuable in the pursuit of disability justice. In contrast, the Global North’s framing of disability discourses in the South is usually constructed through the discourses of poverty, development, and inclusive practices in ways that marginalize the geopolitical production of disablement in Southern spaces (see, for instance, Barnes and Sheldon 2010; Shakespeare 2012; Wissenbach 2014). Such discursive practices have reinforced unequal relations of power between disability scholars in the Global North and South. By applying the epistemic and political implications of Western disability studies to the Global South without considering the South’s distinctive epistemological and social positions, Western disability studies has reproduced epistemic injustice.

Crip is a keyword that attends to the radical act of resistance and reimagination in ways that create spaces for radical love and transnational solidarity. At the heart of crip theorizing is the political question associated with unsettling the structures of power and oppressions produced within a global neoliberal capitalist order. *To crip*, like *to queer*, means to get into the process of unsettling, to make something twisted and strange (McRuer 2018). *Crippling* denaturalizes

the normative culture of compulsory able-bodiedness and able-mindedness and invents new ways to counter intersecting forms of oppression. As such, crip theorizing could offer an alternative way of addressing marginalized spaces in Western disability studies by decolonizing Western structures of power/knowledge (Foucault 1980) and creating other spaces for resistance, radical love, and transnational solidarity.

And yet, how can crip theorizing engage with and unsettle transnational colonial and imperialist practices without reinforcing damaged-centered approaches in Southern contexts? How can research make visible the colonial, imperialist, and epistemic violence that underpins power dynamics without prioritizing damage? How can we create decolonial spaces for inventing new forms of existence for disabled and marginalized bodies? What impacts do we want our research to have for communities experiencing sustained consequences of colonialism, imperialism, and transnational capitalism? In other words, how can disability studies and crip theory be *decolonial*?

Drawing on the lived experiences of women and girls with disabilities from Vietnam as a part of the Transforming Disability Knowledge, Research, and Activism (TDKRA) project, I raise epistemological and political questions regarding the ways research can unsettle the hegemonic structures of knowledge embedded within Western disability studies. I refer to this work as decolonial disability studies—a collective body of theories, knowledges, and praxis that engages with the lived experiences and struggles of disabled communities in distinctive contexts in the Global South to resist the colonial imposition of Western disability studies and create alternative spaces for knowledge production *with, from, and across* Southern spaces (see the Decolonial Disability Studies Collective, n.d.). I argue that decolonial disability studies can tackle gaps of knowledge in disability studies in the Global South by creating more inclusive and accessible spaces for disabled, minority, queer and transgender, and young people who have been excluded from the Western framing of disability studies. This approach resists damage-centered research in ways that invent new possibilities for reexistence and resurgence.

Decolonial Disability Studies

The uncritical transfer of Western disability studies from the North to the South has been problematic because it privileges theories and discourses from the Global North (Meekosha 2011; Mehrotra 2020; Grech 2015; Swartz 2018). Referring to the unquestioning application of Western disability models to Indian contexts, Nilika Mehrotra (2020, 2) argues that “Global North theories appear largely incompatible with ground realities of people with disability living on this continent.” According to her, disability is deeply bound by cultural, historical, religious, and sociopolitical conditions; how disability is understood in these contexts is historical, cultural, and political.

Decolonial disability studies could be seen as a collective body of knowledge that resists the tendency to universalize the hegemony of Western theories and epistemologies in disability studies. A decolonial approach to disability studies offers resources for understanding the ways Western regimes of knowledge exercise power relations through, for instance, the production of “normate standards” that constitute difference, and it illuminates how such normative standards exercise violence on the Other’s bodies and minds (Dirth and Adams 2019; see also Meekosha 2011; Nguyen 2021). A decolonial disability studies approach recognizes the geopolitics of power that shapes specific lived experiences of disabled people in the South. Edelweiss Murillo Lafuente and Mark Sherry (2021, 136) define a decolonial approach as “one that recognizes and challenges the geopolitics of power, including the continuing effects of racism and colonialism on knowledge production, and is committed to challenge such power through a focus on the unique experiences, knowledges, identities, and wisdom of the Global South, particularly Indigenous people.” Emerging in the Global South from centuries of Indigenous struggles, decoloniality is an epistemic and political struggle to create an alternative paradigm for knowledge creation in ways that connect theory and praxis. Decolonial thought arises from non-Western ways of knowing and being in relation to the struggles of communities in the South to formulate their own knowledge and counter colonial violence. However, one cannot decolonize knowledge without engaging and questioning the very foundations of Western epistemology (Mignolo 2018). In fact, a fundamental task of decolonial theory and concepts is to recognize the complex structures of colonial management and control, or “the colonial matrix of power” (Mignolo 2018, 142), in constituting the very epistemic assumptions and principles that regulate our discourses, narratives, and conversations. In so doing, it seeks to reclaim non-Western forms of existence and reexistence, recognize difference, and foster transformation. The goal of decolonial theory, then, is to restructure social relations as a result of epistemic and political struggles with the global project of Western modernity (Santos 2018).

Western approaches in disability studies reinforce the coloniality of power through their uncritical application of the same concepts and theories to historically colonized spaces. Much of what we know about disability in the Global South is through Global North representation. Voices from the Global South are most often silenced; their actions and agency are usually stripped away from research design and implementation. Their stories are only mentioned when they represent what Western intellectuals value, such as human rights and democracy. Furthermore, applying Western disability studies to the Global South is epistemologically and methodologically challenging. Shilpaa Anand (2010, 157) explains, “Western modes of theorizing force us to evaluate such an absence [of disability] as evidence of Asian antiquity not being sophisticated enough to have treated and cared for its disabled people.”

The decolonial disability studies approach offers an alternative to the colonial structure of knowledge. First, it shifts the power dynamic between researchers and researched by making the knowledge, experiences, and perspectives of disabled people in Southern contexts central to research direction and development. Second, its methodology can offer a decolonial space for reclaiming and reimagining disability as a form of existence and coexistence (Nguyen et al., forthcoming). Grounded in the interconnection between theory and praxis, a decolonial approach to critical disability studies is vital for resisting the hegemonic structures of Western modernity by engaging with the everyday struggles of disabled people in the Global South. As illustrated in the case study that follows, the use of creative methods such as participatory visual research within decolonial disability studies offers an opportunity to imagine alternatives to what currently exists, and in so doing creates a decolonial space for shaping the content, form, and method of artworks produced in collective and imaginary ways (Nguyen et al., forthcoming).

In short, while Western disability studies has been slow in tackling epistemic injustice between itself and Southern epistemologies, a decolonial turn in disability studies can interrogate the coloniality of power that is embedded within the universalization of Western disability studies. This approach engages in decolonial praxis by illuminating more complex, nuanced, and sometimes difficult experiences of disabled people and their communities in the Global South. In so doing, decolonial disability studies puts disability theory and praxis from the Global South into conversations with the Global North while refusing to accept the master's narratives about disability from the perspectives of scholars and activists in the North.

Research as a Decolonial Praxis

The Transforming Disability Knowledge, Research, and Activism (TDKRA) project has emerged as a step toward “unsettling” the boundaries between research and activism to build a more transformative approach to inclusion and social justice in the Global South. The project's main objective is to tackle the gaps in knowledge in relation to girls with disabilities in the Global South. Throughout the research process, we engaged disabled girls and women in three disadvantaged communities in Vietnam in knowledge creation and mobilization as a form of activism for inclusion. The researchers, disabled people's organizations (DPOs) in different regions in Vietnam, and participants worked together over four years, from 2016 to 2020.

Central to TDKRA is the politics of engagement (Nguyen 2016; Stienstra and Nguyen 2020)—the ways in which girls and women with disabilities in the Global South engage in research as a way of claiming their existence, building their social relationships and networks, and developing the potential for



Figure 10.1. Art produced by Meo, A Luoi, 2017.

Image description: A woman standing by a house with two chickens. At the front of the picture, a man is harvesting what appears to be paddy rice in the field. There are banana plants, mountain ranges, and a glimpse of sunshine in the background.

activism. TDKRA materializes forms of decolonial struggle by centering the voices and perspectives of disabled girls and women within the research and activist process. For example, in our conversations, disabled women and girls shared their collective struggles for livelihoods and survival as their embodied experiences within the social dynamics of the Global South (Connell 2011). Their stories and participatory approaches created a basis for framing the research direction.

The participants' experiences with different forms of marginalization were unique and contextually based. Disabled girls and women who lived in more urban areas shared challenging experiences with job opportunities after having left school or an institution. In contrast, ethnic women with disabilities in the mountainous region experienced shortages of food and resources within their homes and communities. Some were able to borrow money from the government with low interest rates and repay their debts after harvesting. However, with unpredictable weather and the regular flux of natural disasters, many shared that they were not able to repay their debts.

In a drawing produced in a community workshop (figure 10.1), a fourteen-year-old girl whose nickname is Meo drew a rural space with a banana plant,

mountain ranges, and a glimpse of sunshine in the background. At the center is a woman standing by a house with two chickens on her right. At the front of the picture, a man is harvesting what appears to be paddy rice in the field. In her story, Meo revealed the invisible side of disablement when she talked about the meaning of her drawing: “My drawing is about my parents. My father works, and my mother stays at home. My mother is not able to work because of the pain on her hand.”

Meo’s reflection on her visual production illuminates her experiences with oppressions in a specific space in the Global South. Located in one of the three “dioxin hotspots” heavily destroyed by the herbicide Agent Orange during the US-Vietnam War, A Luoi Valley is a geopolitical space with constant struggles among different social forces. Intensive sociopolitical conflicts during the war caused widespread destruction to the local communities. Between 1965 and 1970, more than four hundred thousand liters of Agent Orange were sprayed in A Luoi, causing massive forms of debilitation and disability in the region (Tran et al. 2021). The herbicide targeted cultivated land, destroyed crops, disrupted rice paddy production, and caused vast damages in the soil, lake, and river systems (Meding and Thai 2017). Local people who lived in this community saw the disabling impacts of Agent Orange on their lived experiences—the food they ate, the water they drank, or the field in which they played with their peers. Furthermore, ethnic tensions between the Kinh majority groups and ethnic minorities who are indigenous to this land intensified the latter’s experiences of oppression (see McElwee 2008; see also Nguyen and Stienstra 2021). The majority of girls and women in A Luoi are Ta Oi, Pa Co, and Co Tu minorities, who are invisible in the state’s discourse on disability. Despite the “inclusion” of ethnic minorities into the nation-state, ethnic minority women and girls with disabilities faced continuous struggles in terms of access to food, health care, and livelihoods, as reflected in Meo’s story:

MEO: We often don’t have money and borrow from them [family members].

We can borrow money from the grandparents, because they have monthly retirement pension.

FACILITATOR: What do you use the loan for?

MEO: To buy rice.

FACILITATOR: Do you often or sometimes ask for money?

MEO: We do that constantly.

FACILITATOR: Money from farming is not enough for your family life?

MEO: We cultivate a field but it takes some months until we can harvest crops.

In their conversations, participants shared that they were in dire need of access to health care but could not get the certificate to be qualified for social assistance (Nguyen and Stienstra 2021). They also felt that they were invisible in

community activities such as festivals because their difference was not valued or welcome. Meo told the researchers that she could not participate in her community's social events because she was worried about being looked down on by others due to prejudice against her disability.

Another TDKRA participant is Thanh, an ethnic woman who had a brain tumor believed to be caused by her father's exposure to Agent Orange during the US-Vietnam War. Thanh was able to go to a neighborhood school; however, her sight weakened and her body was debilitated, requiring numerous hospitalizations. She remembered being called "crazy" and encountered violence in school due to her difference (see also Nguyen 2019). Her experiences with intersectional oppression as a young woman with disabilities and a poor ethnic minority member illuminate complex layers of oppression in her everyday struggles.

Interestingly, however, her drawing (figure 10.2) shows a vivid reflection of her community survival through her desire to go to school.

The drawing shows a one-story house with yellow walls and a red roof. In front of the house, three children appear to be going to school. Critically, Thanh illustrates disability in her picture through an image of a child holding a cane. There are trees on both sides of the drawing. Thanh described her drawing to her audience: "I would like to present my dream. The topic of my painting is 'Hope.' It has a dream house with green trees. Students with disabilities are going to school. Their dreams will be fulfilled some day in the future" (drawing workshop in A Luoi, 2017). Through her art, Thanh expressed her desire for schooling. She seemed more willing to talk about her future than to recount her pain and trauma in the past. This is an example in which decolonial framing enables researchers to eschew the damage-centered approach, with participants instead centering their own perspectives. This does not mean that she does not remember or no longer wants to recall historical memories that caused her entire family pain; however, it may mean that she wants to reimagine her story of disability in a way that marks disabled children's presence in schools and communities. Decolonial disability studies reconfigures the dynamic of research and centers the voices and perspectives of participants, illuminating the internal strengths these communities possess.

In their gatherings, participants expressed the willingness and commitment to engage with one another to share their stories as a starting point for building broader social movements. One such praxis was a movement-building activity named Five Fingers, organized by our local partner, the Bac Tu Liem Organization of People with Disabilities in Hanoi. The activity began with participants slapping their one fingers from each hand against each other to make a sound. They then slapped two, three, four, and five fingers against each other, collectively, making loud, crisp, and forceful sounds with their hands. Figure 10.3 provides a snapshot of our act of engagement. We came together, worked together, and built



Figure 10.2. Art produced by Thanh, A Luoi, 2017.

Image description: A one-story house with yellow walls and a red roof. In front of the house three children appear to be going to school. The child in the middle is holding a cane. There are trees on both sides of the drawing.



Figure 10.3. An image of the Five Fingers activity, Bac Tu Liem District, Hanoi, 2018.

Image description: A screenshot of a group of women and girls holding their hands upward. There is an ASL interpreter on the bottom left of the screen. The term on the upper left of the screen reads: “Activism.”

collective struggles to amplify the voices and power of women and girls with disabilities in the Global South.

We must still ask who participates in this space, why, and who is missing from it. A decolonial disability studies approach requires us to make visible the forms of exclusion and marginalization that have been sustained within these communities. For example, not all girls with disabilities equally participated in our space due to experiences with ableism, racism, classism, and patriarchy that they had had in various social locations. Some participants only partially participated because they had to work to sustain their livelihoods. Furthermore, while the DPOs took the main responsibility for recruiting participants in their communities as part of a decolonial approach, access to research and activism continued to be the privilege of those located in less remote areas who could be reached by the DPO staff members. This challenges us to make decolonial spaces more accessible for those unable to engage in the project because of their class, gender, disability, or ethnicity.

Furthermore, power dynamics emerged through the movement building. At a national workshop co-organized by the TDKRA research team in collaboration with the Hanoi Organization of People with Disabilities, we saw tensions arising between nongovernmental organizations (NGOs) and the disability community. We brought together representatives of DPOs and disabled women and girls in three project sites to articulate and frame their perspectives on inclusion. In the midst of a discussion, an NGO representative took center stage and recommended that disability communities be more “open” to nondisabled people, like herself, as a path toward their “inclusion.” In response, one DPO partner resisted, saying that her community does not function in a charitable manner and challenging the NGO to see the difference between charity and community struggles for rights.

This material practice illuminates the challenges of applying Western ways of knowing to the Global South. There is a deep-seated assumption that international NGOs can assume power to “include” disability communities in the Global South through colonial and ableist practices such as seek foreign funding and overcome obstacles themselves. Within the context of the United Nations Convention on the Rights of Persons with Disabilities, rights-based discourse is contentious, as it has transnationalized the Western regimes of governance onto the local communities. At the same time, DPOs have utilized this tool in order to negotiate power with the governments and international development agencies. This illustrates another aspect of decolonial struggles.

Conclusion: Decolonial Disability Studies as an Alternative Option

JosAnn Cutajar and Casimir Adjoe (2016, 507) interrogate the one-way transfer of knowledge from the North to South, arguing that “while our everyday

experiences are situated in the local context, the landscape we read and learn is based somewhere else.” In contrast, a decolonial turn in disability studies pushes us to revisit the conceptual limits of Western and Eurocentric frameworks in rendering certain bodies of knowledge from the South invisible (Reed-Sandoval and Sirvent 2019). In this chapter, I propose that a decolonial approach to disability studies is important because it creates alternative spaces for knowledge production in ways that negotiate power and challenge epistemic injustice in the South. The example of TDKRA sheds light on the possibilities and challenges of decolonial struggles through research praxis. We engaged with research as a way of resisting the hierarchy of Western disability studies and reclaiming our engagement with women and girls with disabilities in the Global South from their ways of seeing. This praxis resists “damage-centered research” (Tuck 2009, 422) by building decolonial spaces and methodologies for these women and girls to engage, to reimagine their difference, and to set a stage for connecting their knowledges and movements.

Decoloniality is an option among many systems of thought and is not intended to be universal (Mignolo 2018, 115). It offers a creative approach for reclaiming crip authorship by centering the stories of women and girls with disabilities in the Global South in ways that resist the Western hegemonic structures of knowledge, thus creating new grounds for decolonial struggles.

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