

Editorial: Thinking with Decolonial Disability Studies:**Invitation to the Special Themed Issue**

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In “Thinking with disability studies,” a provocative statement on the epistemic terrains of disability studies, published in *Disability Studies Quarterly* in 2014, Nirmala Erevelles invites readers into the “eternally changeable borderlands” of disability studies, challenging us to critically reflect on conventional boundaries of disability theorizing. Foregrounding her historical material analyses of disability at the intersections of other marginalized oppressive categories and social relations, Erevelles (2014) urges readers to move beyond disability/crip/queer politics by situating disability theory and praxis at the intersections of seemingly opposing and complicated domains of social inquiry. She argues for a more accountable approach which re-imagines disability futures in specific historical contexts – something she endeavors to call a “living theory.” As she unequivocally states: “I do not want to dream of a future that is more edgy, more abstract, more dazzling. Instead, I want to end [this essay] by dreaming about a future that is simply more accountable” (n.p.).

Traversing these borderlands ten years later, we are convinced Erevelles’ argument continues to hold its original force by provocatively and powerfully challenging disability scholars to push the conventional boundaries of disability studies as an epistemic and

political terrain that welcomes new ways of disruption, transgressiveness and transformation of Western disability studies. Like Erevelles, we take the very essence of disability studies to be a constant interrogation and disruption of normative assumptions and standards. We concur with Goodley and his colleagues, who posit that critical disability studies is a critical and reflexive project that invites us to pose further questions about the purpose and inclusivity of disability theory (Goodley et al., 2019). Our understandings of disability studies as theoretically and contextually-driven praxis challenges us to reflect on new forms of inquiry, inviting disability studies scholars and activists across the global North and South¹ to engage with disability studies as a decolonial praxis that is epistemically and socio-politically informed and transformed by specific contexts. Indeed, we call for the need to reflect on the historical emergence of (Western) disability studies as a field of inquiry that, unsurprisingly, has privileged Western disability theories and activist approaches, at one level, and the historical/contemporary social conditions in which we – disabled, racialized, and chronically ill activists scholars – have engaged, resisted, and spoken back to this Western hegemony through our collective work of writing, editing, publishing, on the other.

In fact, as the three of us unequivocally argued (Padilla et al., DDSC webinar, 2023), *the* socially constructed boundary between academia and activism set forth by Western

¹ The phrase ‘global South’ references distinct spaces outside Western European and North American contexts. The global South signifies systemic inequalities geopolitically constructed by the history of transnational colonialism and imperialism (Dados & Connell, 2012). We decided to use the capitalised ‘S’ for the South because we deploy the South as a political concept, not as a territorial determinant/compass direction. However, when we use ‘global’ with a lower ‘g’, we intend to “crip” the North American use of the “Global South” as merely a distinct geopolitical space that stands in binary relation to the “Global North” and instead, recognize complex relations of power within the South itself because of colonialism and coloniality that have taken place in the global context. This concept has enabled us to discuss disability experience and theory related to the precarity, vulnerabilities and instabilities signified by the political usage of the ‘South’ in different parts of the world under distinctive socio-economic and politico-cultural circumstances.

academic institutions is, in itself, a Western construct that tends to limit our relationship and capacity to think and act together. As global South disability scholars and activists, we take this themed issue as a decolonial praxis that, we hope, allows us to challenge the colonial/modernist imaginings of disability as a means to socio-economic development in a global neoliberal context where the colonialities of rules have been reinforced (Abay & Soldatic, 2024). By decoloniality, we mean to rethink, revisit, reclaim, and re-centre knowledges and praxis from historically marginalized spaces, and to create a more radical space for disrupting what may have been taken as truth about disability in the global South. We ask ourselves, then: How may we refuse to accept this normative boundary and re-build our relationships by thinking *from* and *with* the South as a form of epistemic disruption? How may we shift this conversation about disability in the global South in ways that create alternative venues and possibilities for re-imagining decolonial disability futures? To this end, we argue for a decolonial disability studies approach which centers debility processes, voices and relationalities of the most marginalized disabled people in the global South *within* and *across* distinctive geopolitical, socio-cultural and historical contexts. Through this editorial, then, we also want to reflect on and interdependently articulate the cross-coalitional power of our collective positionality as global South scholars and activists with extensive decolonial experiences in transnational contexts.

In thinking with disability in Southern spaces, we contend that while critical disability studies scholars have increasingly argued for disrupting the boundaries between academia and activism for decades, the conventional boundaries between global North/South in the politics of disability theorizing and activism have remained relatively unchanged, and, in fact,

untroubled. Following Helen Meekosha's provocative critique of disability studies as a "form of scholarly colonialism," Jasbir Puar (2023) cautions that "disability studies may unwittingly function as a handmaiden to US empire if we do not interrogate the genealogies of the field that exist not despite the occluding of race and empire, but because of such elisions" (p. 119). Furthermore, we are concerned that global North scholars and their Northern epistemologies have continued to hold powerful positions as knowledge producers, whereas global South activists, scholars, and practitioners have been positioned as applicants/passive consumers of such knowledge (See, Connell, 2007; Nguyen, 2018). This themed issue, thus, aims to tackle this epistemic injustice by re-positioning global South scholars and activists as knowledge producers, thinkers, and activists in their own contextual and epistemically relevant ways. We, therefore, ask: Who does the work of disability theorizing, and who is positioned as practitioner or applicant of this pre-given theory while also serving as empirical data for the theorizing to happen? It may be important, then, to recognize that, despite growing recognition of global South and disability in this ever-evolving field of disability studies, the "coloniality of knowledge" (Maldonado-Torres, 2007, p. 23) continues to instill and hegemonically governs the politics of disability theorizing today. How can we do disability studies differently, outside of this assumed binary? How might we be accountable, respectful, and fully open to global South knowledge contributions and reformulations?

Situating the Themed Issue

Current transnational struggles against settler colonialism in different parts of the globe, is reflected in students' protests and decolonial movements against Western colonial policies and practices, that include acts of genocide, land occupation, colonial dispossession,

and the killings and maiming of global South bodies across geopolitical borders such as Palestine, Haiti, Kashmir, South Sudan, Afghanistan or Indigenous peoples in Turtle Island. All these sustained struggles against the politics of Western colonialism and imperialism are witnessed in so-called post-colonial spaces today. Even as we write our editorial, we are shaken by the escalation of genocide as Israeli tanks have entered close to the border crossing of Rafah, intensifying military operation and mass destruction of the Indigenous land and bodies (AP News, 2024, May 7)². Ongoing socio-political, ideological, economic, and epistemic struggles against debility (Puar, 2017) and vulnerable people's exclusion across global Southern spaces necessitates that we think together about ways of researching disability that are true to these contexts of disablement. In the face of massive destructions caused by the colonial invasion, displacement, disablement, along with housing, climate, ecological, and social crises across the globe, we hope that this themed issue represents a constellation of "knowledges born out of struggles" (Santos, 2018), elevating spaces for decolonial conversations and reflecting on ways in which disability scholars, academics, and activists can collectively resist (neo)colonial, (neo)imperialist, transnational capitalist, and neoliberal ideologies and practices that produce disability and debilitation (Anand, 2022; Erevelles & Nguyen, 2016; Minich, 2014, 2023; Puar, 2017).

This themed issue is not the first one about the politics of the global South, disability, and decoloniality; the collective of work informed by disability studies scholars such as

² AP News (2024, May 7). Israel begins military operation in Rafah, hours after Hamas agrees to a cease-fire. Available at https://apnews.com/live/cease-fire-israel-hamas-updates?user_email=254a73e5e980fc09da3bda2e30ab7053005aff3e54fab1e710cd000ce9580802&utm_medium=AfternoonWire&utm_source=SailthruAP&utm_campaign=AfternoonWireMay62024&utm_term=Afternoon%20Wire

Karen Soldatic, Robel Afeworki Abay, Shaun Grech, Tsitsi Chataika, Helen Meekosha, and Sara María Acevedo, to name a few, has opened pathways for rethinking the Western and Eurocentric foundations of disability studies at the intersections with colonialism and coloniality (see, e.g., Abay & Soldatic, 2024; Grech, 2015). For example, in a special issue of *Disability and the Global South* in 2019 guest edited by Reed-Sandoval & Sirvent), the co-editors spelled out their aims to: (1) “demonstrate (particularly, but not exclusively, to decolonial theorists) ways in which decolonial theory may lend itself to the ... analysis of disability,” and (2) “provide an overview of some key themes of decolonial scholarship for disability studies scholars who may be unfamiliar with this literature” (p. 1554). In other words, Reed-Sandoval and Sirvent sought to bridge the two bodies of literature to find ways for both to inform each other reciprocally. Likewise, in the *Preface* to their recent handbook, Chataika & Goodley (2024) explicitly expressed a similar desire to bridge disability studies and post-colonial studies, while noting that “[b]ringing together two transformative arenas of knowledge production should not be confused with fusing or collapsing the two interdisciplinary fields together...” (p. xii). Alternatively, Puar (2023) argues that a radical orientation of global South’s politics of locations must not bracket the global South and Southern disability studies, but rather, “take seriously that no singular ‘disability analytic’ exists” (p. 120). By this, she points to the need to theorize the biopolitical project of disability and whiteness within the context of settler colonialism, arguing that it is impossible to disaggregate the epistemological project of disability outside of its colonial and imperialist contexts. We believe that this is a good illustration of trends in this rapidly growing body of post-colonial, decolonial, and anti-colonial disability studies. At the same time, what this new

themed issue does, we hope, is to situate our writings within historical and contemporary contexts in ways that inform our decolonial praxis. In this praxis of thinking and doing disability studies, we invite our contributors and potential readers to think with disability decolonially. Thinking with disability decolonially, we posit, means unsettling conventional forms of knowledge production on disability which operates as a form of coloniality, and to co-create and co-design more transgressive spaces and possibilities that enable scholars and activists to think and act with disability from a non-Western epistemic paradigm. This is the kind of place-based set of practices that Mignolo (2007) calls delinking, insofar as one moves intentionally away from the epistemological links of Eurocentrism that chain oppressed communities, disabled communities in global South contexts most pre-eminently, to alienating modes of knowledge which perpetuate their sense of powerlessness and passive acquiescence.

To do this work decolonially, we share the desire to bring tension into the transformative potential of these sub-fields. We are also convinced that it is time for decolonial theory to embrace disability as a core matrix of intersectionality with a rank similar as well as closely intertwined to the coloniality of power as it expresses and unfolds through race, gender, class, sexuality and caste extractive and marginalizing dynamics. Agreeing that conditions are finally maturing for the sub-field of decolonial disability studies to come of age, our aim with this special issue is closely aligned with Erevelles & Abay's (2024) call "to actively work towards disability futures... across borders ...beyond metaphor...beyond affect...beyond innocence and towards a transformative political economy of care." (p. 46)

Indeed, this themed issue is the fruit of our collective efforts to sustain and build relations among global South scholars and activists in the context of grief, unwellness, and vulnerability in ways that affect our crip bodies and minds in precarious social relations. We have learned to unlearn Western academic regimes of productivity and performativity by learning how to accommodate each other in a non-linear manner and by challenging ourselves to make space for one another. Working on this collection in a context of our precarity and unwellness in the face of the neoliberal push for “high impact” journal publications reflects our struggles to resist colonial/neo-liberal/neo-imperialist forms of academia across (colonial) universities in the global North and South. To quote once again Erevelles (2014): “disability studies epitomizes disruptive vulnerability that refuses to disappear.” (n.p.). This entails proactive disruptions of ableist academic norms by being mindful of crip time as much more than an accommodation, as a form of liberation (Samuels, 2017).

Engaging with this unique kind of “epistemic decolonization” (de Sousa Santos, 2018), we asked each contributor in our themed issue to state their positionality and understanding of the global South as a way of putting forth the South as a critical concept that goes beyond geographical locations and to critically engage with its geo-political, historical, and epistemic foundations. We recognise that as we, contributors and editors, proceeded to define our global South positionality, it was inevitable that we encountered many ways in which the colonial politics of knowledge production operates to undermine and discredit global South knowledges and practices as inferior and unworthy of academic recognition. We thus invite readers to pause and ponder critically about the content and form of academic

coloniality that are resisted through the open-access publication of this journal and this issue. Contributors to this issue engage deeply with these decolonial, discursive and material practices that seek to cultivate an innovative constellation of liberatory futurities radically grounded in our everyday situated knowledges, challenges, and spheres of opportunity. We invite readers to re-imagine the global South in line with a genuine sense of epistemic justice – re-positioning the global South knowledge production in an equal power relationship with that of the global North.

While critical disability studies has sought to challenge the fatalist linear nature of neoliberal futurity (Fritsch, 2016), a decolonial conversation would have to do harder work. It needs to be more transgressive by questioning the foundations and hidden (often overt) connotations of knowledge, epistemologies, and praxis that have been produced about and even against global South actors, or for the consumption of the global South from a global North perspective. Decolonial disability studies raises epistemic and political questions: what is the social location of knowledge? In what contexts have such knowledges been produced? What are specific geo-political conditions associated with the production of disability and the ableist epistemic spaces where these production dynamics rest? Furthermore, as apparent from the articles introduced below, this themed issue presents a wave of thinking about disability, coloniality, and decoloniality that create spaces for re-imagining decolonial, anti-colonial, and anti-ableist futures.

Introducing the articles

In what follows, we provide a snapshot of each of the articles in this collection. They have been selected to be published in this themed issue based on their engagement with

disability studies from a decolonial standpoint. The conversation between Laura Jaffee and Lara Sheehi in this themed issue, for example, demonstrates the transgressive implications of decolonial work, and sheds light on what we seek to develop in this issue by showcasing ways in which anti-ableist transgressiveness can be enacted and embodied. In particular, they approach decolonial disability work as the enactment of transformational dialogical and dialectical engagements with the politics of decolonial feminist praxis towards disrupting colonial and ableist ideologies. They openly critique our common tendency to fixate our knowledge on such issues as access and accessibility. The authors challenge ableism as a “logic of violence” that renders not only the individual body but also an entire nation disabled. Joining each other from a Palestinian student movement as a part of their everyday praxis, the authors call for a politics of solidarity that consciously tackles the tensions and struggles between disability and decolonial movements through their collective work for social justice and liberation.

From his positionality as blind/disabled scholar and activist, Alexis Padilla invites readers to ponder about the value of theorizing decolonial disability futurities. To this end, he draws on Glissant’s decolonial work. Padilla refers to relational ontologies as “understandings of being and becoming which, almost always situated in spatial politics, engender knowledges and diverse modes of truth-telling from “habits born of the imagination in place.” (p. 3). In other words, he elevates place-based dynamics, contextualizing disability futurities within the inter-imperialist spaces of transmodernities that constitute Black, disabled/Latinx and Caribbean identities as spaces for coalition building and transgressive possibilities. Furthermore, he argues that Glissant’s decolonial relation to the historicity of

place has a potential to elevate “sentipensante/ pluriversal politics,” which he conceptualizes as “modes of knowledge creation and distribution along with their imaginative value” (p. 3), thus opening the door to imagine disability otherwise within inter-imperial spaces of precarity and debility as those faced by disabled inhabitants of the Caribbean and beyond. In her article, Ai Binh Ho advances Southern disability studies through her provocative critique of “beautiful debilitation,” which she defines as “the visuality of war-produced debilitation” exemplified in the international relations between the United States and Vietnam. Her powerful critique begins with the medical journey and visual representations of Phan Thi Kim Phuc – the young girl exposed to severe burns by a napalm rain on her Trang Bang village 50 years ago, as captured in the “Terror of War” photograph taken by artist Nick Ut. She argues that “[t]he power of beautiful debilitation remains central to Vietnam and US political relations today, [...] as war injuries continue to act as a bridge between the former enemies within the context in which reparation and accountability remain out of reach.” At the same time, she does not shy away from critiquing the Vietnamese post-colonial nation in utilizing beautiful debilitation as a weaponizing approach in perpetuating violence. As she maintains, “[c]ritiquing the production of worldwide disability by the violence and wars provoked by the North cannot alone advance the lives of debilitated people in the South.”

Meanwhile, Shehreen Iqtadar and David Hernandez-Saca develop a different yet equally provocative dialogue between global South and decolonial disability theorizing. They invoke the legacy of DisCrit in intersectional educational spaces where racialized and ableist dynamics of oppression coexist. Their argument is crucial because it strives to elevate the concept of global South informed DisCrit. They enrich and transform an intersectional

framework which until now has primarily explored the interlocking matrices of oppression which rely on race and disability dynamics within global North educational contexts. By recognizing the transnational nature of teacher training within higher education institutions as well as the immense significance of migration dynamics of understandings of both ableism and racism, these authors open the door for revolutionizing how academic teacher education spaces in global North and global South alike can start sensitizing their epistemological assumptions regarding global South informed realities when it comes to propelling anti-ableist and antiracist inclusivity for both teacher educators and teacher candidates. In turn, they aim at impacting classroom level ecologies of micro-aggression, various modes of pathologizing disabled students of color, especially those of immigrant origin, and myriad forms of social exclusion (Annamma, 2018; Annamma & Morrison, 2018; Bell, 2006; Leonardo & Broderick, 2011).

Nguyen et al.'s paper on young disabled women's leadership initiatives gathers together a series of insights from youth organizations across the world from a transnational project that generated South-South knowledge exchange. The paper centres on the overlap between disability activism and disability studies scholarship as it contests dominant Eurocentric knowledge circulation through the work undertaken by young women's groups in organizing community research and outreach in three sites, Empangeni in the KwaZulu-Natal province of South Africa, the West Bengal region in India and A Luoi district in Vietnam. Emphasizing the significance of knowledge produced by young disabled women's participation in everyday matters of disability governance, the paper highlights the need to attend to specific contexts of the global South while developing social strategies of resilience

in the face of disablement caused by distinct circumstances of vulnerability. In addition, it shows how decolonizing methodologies become actionable by empowering these young women to own their disabled and local knowledges as epistemic dreams which allowed them to transcend everyday struggles and envision alternative futurities whose roadmap is intrinsically activist and participatory (see, e.g., Hale, 2006; Speed, 2006).

The article by Tirtha Pratim Deb and the co-authored work by Nandini Ghosh and Suchandra Bhaduri foreground disability conceptualisation in the Indian context by destabilizing historical assumptions and revisiting terminological standardizations, respectively. Deb studies the coloniality of oralism and how it operated in the nineteenth-century British-colonised Indian context while a range of hearing scholars and policymakers deliberated on the benefits of oralism. Deb's critical excavation of a Bengali book on deaf pedagogy in the early twentieth century contributes to existing scholarship on disability history of the Bengal region while consolidating interventions made by Indian professionals working under British rule. Continuing the theme of the Bengal region under British colonial rule, Ghosh and Bhaduri trace the politics of naming disability while considering that concepts pre-exist terms, as in the case of regional terms invented to mean disability. Additionally, their paper underscores the need to reflect on changes in disability naming in multilingual contexts, drawing attention to a significant feature of erstwhile colonies like India that are internally diverse in terms of linguistic orientation, social composition and religious orientation.

One of the most significant insights of the articles combined in this volume is their potential to resist the homogenizing of the global South and disablement profiles of the

regions that characterize global North scholarship on places of the global South. Drawing on a variety of qualitative research material and adopting methodological approaches that suit the sites under study, the articles foreground the limitations of global North disability studies ideology and methodology. The articles in this collection offer a direct response to many disabling consequences resulting from genocide, mass displacement, transnational humanitarian crises, and historical modes of subjugation. This special themed issue hopes to make a timely intervention into understanding and counteracting the disabling consequences of geo-political conflicts and violence taking place in many transnational contexts, particularly in the global South. As a constellation of decolonial works, they not only urge readers to re-imagine decolonial and anti-ableist futures; they articulate actionable ways to start moving in those directions. Therefore, through the articles in this issue, we encouraged readers to engage with contributors to connect theory and praxis in ways that set the stage for decolonial enactments of delinking (Mignolo, 2007, 2021) from hegemonic modes of disablement within coloniality, forging a radical politics of writing, theorizing, conceptualizing, organizing, performing, and teaching which model the alternative knowledges and futures born from the heart of our collective struggles (de Sousa Santos, 2018).

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**Beautiful Debilitation: War Injuries as Political Currency
in Vietnam and U.S. Relations**

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Abstract

War-produced disability acts as political currency between the United States and Vietnam. The United States engages with “The Terror of War” and Phan Thi Kim Phuc through the lens of beautiful debilitation. Vietnam salvages beautiful debilitation, borrowing its global power to improve diplomacy and receive post-war aid when reparation is unreachable.

Keywords: disability, Vietnam War, atrocity photography

**Beautiful Debilitation: War Injuries as Political Currency
in Vietnam and U.S. Relations**

In July 2022, Phan Thi Kim Phuc, “the napalm girl,” received her 12th and final round of laser treatment at the Miami Dermatology and Laser Institute, 50 years after napalm rained on her village Trang Bang. Notably, the treatment center is in the U.S., even though Phan resides in Canada. Her last treatment was widely covered by major U.S. newspapers and magazines, demonstrating her staying power within the U.S. imagination. Although the photograph “The Terror of War” has been widely discussed, especially within visual culture studies, I want to explicitly place it within a disability studies context. Within what Helen Meekosha (2011) calls a “southern theory of disability,” Phan’s war-produced debilitation reveals “the role of the global North in ‘disabling’ the global South” (p. 668). Southern disability studies have repeatedly called for the examination of the debilitation produced by global injustice and the war machines of colonialism, occupation, and U.S. imperialism. This article shifts the focus beyond the production of debilitation on racialized, gendered, and poor bodies in Vietnam to show how the visibility of war-produced debilitation—particularly one that I name *beautiful debilitation*—becomes a political pawn in international diplomacy between former enemies. It is through beautiful debilitation, which promotes the visibility of war injuries through a humanitarian rhetoric of international solidarity and friendship, that the U.S. remakes itself, again and again, as a nation that heals disabled people even as it maims and kills. Despite desires to name the U.S. as a colonialist that utterly devastated Vietnam, Vietnam salvages beautiful debilitation through a *guerilla visibility* in order to promote diplomacy with the U.S., particularly during the postwar economic crisis, food shortages and

an uneasy relationship with the Soviet Union. The power of beautiful debilitation remains central to Vietnam and U.S. political relations today, I argue, as war injuries continue to act as a bridge between the former enemies within the context in which reparation and accountability remain out of reach. Beautiful debilitation grounds the staged retelling of traumatic past, in which the war-injured bodies become ideological battlegrounds. By illuminating on the suffering, Phan endures as a pawn between the U.S. and Vietnam, I call southern theory of disability to also hold the global South accountable for its role in harming its subjects. Decolonization cannot simply return to the past or practice fast economic progress that produces mass debilitation (through sweatshops, toxic factories, cash crops, etc.). Postcolonial countries participate in the exploitation of their brown and black subjects and the natural world in the relentless quest for wealth accumulation for its elites and global status. Critiquing the production of worldwide disability by the violence and wars provoked by the North cannot alone advance the lives of debilitated people in the South.

The Beautification of Debilitation

The U.S. (and other western nations) created beautiful debilitation—a humanitarian engagement with disability—through its response to “The Terror of War” and Phan’s medical journey. It is through beautiful debilitation that the U.S. lays claim to the infamous photograph and her curative experiences even decades after the war. More than revealing information about the disabled subject, beautiful debilitation explains the viewers’ orientation towards the subject, who is often othered. It is the potential to heal Phan that makes her a ready symbol. Healing her through surgeries and sending money and gifts provides hope for self-healing and suturing the disruption of U.S. notions of wholeness, beauty, and humanity.

Thy Phu (2022) names this liberal spectator's orientation as "*transpacifism*—which consists of humanitarian initiatives carried out under the ethical guidance of the 'civilian gaze' conjured by atrocity images, and whose significance reaches across the Pacific and binds the United States to these sites—served as a means of symbolic reconciliation, acceptable only because it did not seem to do so" (p. 86). Connecting transpacifism to material debilitations politicizes the humanitarian gaze as one that sanctions mass impairments produced by racial-oriented wars. Recognizing beautiful debilitation, then, resists Western theories and epistemologies of disability. Beautiful debilitation narrows the field of vision—there's nothing more to see except this intervenable event. The trace of violence forever marked by the iconic photograph is mitigated by her recoverable body. To be clear, viewers presume a healing within the theater of reconciliation without acknowledging her daily experiences of intense chronic pain, her shame, her rage, her mothering as a burn survivor who cannot feel her children's touch, and her everyday movements and knowledge that result from the napalm burn.

The simultaneous visibility of her pain (mouth-opened screaming, complete nudity, unfolded arms running towards the audience) and the possibility of obscuring her injuries allows Phan to be placed within an individualistic, linear narrative of healing (injured/cured), which the U.S. can readily "fix." The napalm missed her face, and her scars could be hidden under clothes. Because the war—not her—triggers shock, disgust, and grief, she can embody forgiveness and hope. That is, the napalm injury can be detached from Phan's body to obscure the imperialist war fought in Southeast Asia by the U.S. and its allies. Despite her ability to hide her scars, onlookers can demand to look at her disfigurement. Phan recalls

being forced to prove her identity when reporters have located her: “‘*You* are the girl in the picture?’” ... ‘Yes,’ Phuc replied to the men. ‘I am the girl in the picture’ ... ‘But, you look very – *normal!*’ Phuc understood. She drew up the sleeve on her left arm” (Chong, 2000, p. 190). People with disabilities, especially invisible disabilities, know well the demand to prove our disabilities. Within the context of violence, the demand to see her wounds is also a need to see injustice—to admit to a crime against humanity that ruptures a sense of morality within viewers.

Entering living rooms, “The Terror of War” pushed the war in Southeast Asia into the intimate sphere. The photograph, often credited as the image that ended the war, claimed the middlebrow imagination that upholds the U.S.’s identity as a world leader (Ono, 2022). Moving across national, media, and temporal borders, Phan’s war-produced debilitation attached to narratives beyond the confines of her body. The symbolization of her napalm burns requires the production of intimacy. Since the initial publication of “The Terror of War,” the western media has been obsessed with learning Phan’s name and healing trajectory, emphasizing individualism and intimacy, rather than the reality of mass debilitation. The use of her first name, Kim Phuc, in academic and popular writing goes against standard style of using an individual’s last name after the first reference. “Kim Phuc” is how she is known around the world, suggesting an intimacy between Phan and anyone who speaks her name. Guy Westwell (2011) shows that *The New York Times (NYT)*, in initial publications, promoted “a redemptive ending for the photograph in which U.S. aid and infrastructure results in Kim Phuc's survival, recovery and recuperation”: on June 11, *NYT* named the girl in the picture as nine-year old Kim Phuc. Then, on August 9, it featured a

picture of Phan smiling at a nurse at the Barsky Center in Saigon on its front page. With the headline “Napalm girl recovering in Saigon,” *NYT* declared that Phan “has almost recovered from her burns as a result of the work of U.S.-trained Vietnamese plastic surgeons working at the United States Agency for International Development (USAID) funded hospital” (p. 413). The mention of “U.S.-trained” surgeons, U.S. money, and the name of the medical center indicate that Phan’s healing is only possible through U.S. intervention. The Barsky Unit, named after Arthur J. Barsky, the lead surgeon in the Hiroshima Maidens project, was constructed in 1969 to treat Vietnamese children and train Vietnamese doctors and nurses. When *Life* magazine published its annual “The Year in Pictures” issue in December 1972, it featured a single entry related to the war: a two-page spread of a portrait of a smiling Phan inset with the famous picture of her running naked as napalm seared into through her flesh under the headline “The War and Kim Phuc, Memories Masked by A Smile.” *Life* declared “Her scars are healed, and she is going to school again,” indicating a return to normal (pp. 54-55).

The medical interventions, from the initial treatments in Vietnam to the final laser treatment in Florida, fulfills the fantasy of the U.S. liberal savior within a medical humanitarian framework. The declaration that Phan was “healed” seems fictitious given the fifty-year span of her treatments. The emphasis on “recovering,” “almost recovered” or “healed” suggests a promise of cure to heal and beautify the subject *and* the onlooker. This healing relationship between Phan and individual viewers allows Americans to see themselves as paternalistically responsible to the rest of the world, holding tightly to its liberal identity.

Beautiful debilitation positions maiming within a neoliberalist framework that prioritizes a linear and individual rehabilitation, obscuring accountability for collective injuries and deaths.

According to Samuel Moyn (2010), “a genuine social movement around human rights made its appearance” only in the 1970s.³ One of the key catalysts, he explains, was the U.S. “liberal shift in foreign policy in new, moralized terms, after the Vietnamese disaster” (p. 8). Moyn adds that President Jimmy Carter adopted human rights as the guiding rationale of foreign policy.

The urge to name, personalize, and gender one victim of war reduces the war into a manageable intervention, providing a promising future for a single individual rather than taking responsibility for the millions injured and dead. The effort to individualize war-produced debilitation creates intimacy between Phan and the spectator, which domesticates the disabled subject and encourages a relatability that many maimed people cannot access. That is, the beautification of disabled people simultaneously others and domesticates them. There is only one “little girl” in need of help, as evident in Hariman and Lucaites’s (2003) description of the photograph:

The little girl is naked, running right toward you, looking right at you, crying out. The burns themselves are not visible, and it is her pain – more precisely, her communicating the pain she feels – that is the central feature of the

³ Moyn argues that while the Universal Declaration of Human Rights was introduced in 1948, human rights remained on the periphery, “failing to interest many people . . . at the time or for decades” (7).

picture. Pain is the primary fact of her experience, just as she is the central figure in the composition. (p. 40)

Despite the presence of other children in the photograph, the description repeats the singular pronouns of she and her. The paternal gaze on Phan falls under what Rosemarie Garland-Thomson (2009) categorizes as the sentimental visual rhetoric of disability, which invokes pity, inspiration, and contribution by positioning the disabled subject in a diminished or childlike role.

It is not only Phan's debilitation that becomes symbolic. Phan's gender enhances her vulnerability, and thus impacts the viewer's relationship to her. Her racial femininity is symbolized and weaponized within U.S. military narratives and popular culture, a legacy of colonialist discourse in which the global South is presented as feminine, helpless and childlike, and thus, legitimize the need for paternalistic intervention from the global North. Marita Sturken (1997) explains, "As a young, female, naked figure, Kim Phuc represents the victimized, feminized country of Vietnam" (p. 92). Phan personifies Vietnam as naïve, helpless, in need of paternal protection permitting the "white savior" discourse of not only the "Vietnam War" but also wars and imperialism in general. Writing on disability in Palestine, Yasmin Snounu et. Al (2019), writes, "the U.S. in particular, contributes to the disablement of Palestinian people . . . Then, the United States sends developing countries funding for disability projects" (para. 12). Beautiful debilitation calls on liberal humanitarianism and justifies liberal wars, rather than demands accountability for all people affected by warfare. Phan's feminine vulnerability offers healing and redemption for the emasculated U.S. male veteran and the U.S. at large. While the Vietnam-U.S. War remained a highly contested and

politicized issue in the 1970s, it was subjected to a revisionist project designed to reclaim credibility for the military and rebuild national self-esteem in the 1980s. The focus shifted away from the war itself (and its political, geographical, and symbolic complexity) to the experience of veterans. As Keith Beattie (1998) notes, “healing the wounds” became the dominant metaphor for rendering the war less divisive a decade after its end (p.142). The U.S. news media also transformed Phan from a war victim into a “Vietnamese Marilyn,” according to Judith Coburn (1989) in *The Los Angeles Times Magazine*’s “The Girl in the Photograph: 17 Years Later.” In the same article Coburn adds, “From Kim Phuc’s wounds have sprung a passion to be normal,” by which Coburn means a feminine desire to marry and have children (para. 46). Phan’s Asian feminine beauty directly comes from her racialized helplessness that can secure white masculinity within the military industry that both produces and challenges notions of masculinity defined by the shifting fulcrum of violence and morality. Alongside the 1955 humanitarian project “Hiroshima Maidens,” in which the U.S. financially supported plastic surgery for twelve Japanese women disfigured by the atomic bombs, Phan’s role exposes medical humanitarianism as a gendered, racialized arm of the U.S. war machine. The U.S. engagement with military debilitation—a medical and aesthetic intervention towards normalization—reveals that it reconciles the national wound of controversial military interventions by beautifying Asian female bodies. Significantly, the cosmetic projects foreclosed discussions of massive and ongoing debilitations produced by the war in Southeast Asia and the atomic bombs as well as the Japanese women’s and Phan’s daily endurance of ongoing pain and stigma.

Throughout my discussion on Phan's beautiful debilitation, I have pointed out the length of the medical process, her chronic pain, and mental anguish within the context of imperial militarism. Attending Phan's individual experiences of survival does not depoliticize her napalm injury. On the contrary, the failure to attend to the lived realities of disabled people of color elides their daily experiences of navigating structural injustice. For example, while Mimi Nguyen (2012) cogently shows Phan as an agent of liberal empire, "negating murderous structures of race and coloniality as the present of liberal violence" and "redeeming empire from being held hostage to a shameful, irreversible past," she does not acknowledge the conditions that demand this labor from Phan (p.130, p. 86). Phan did not readily choose to become an ambassador of liberal empire. Poverty, lining up weekly for food, clothes, and diapers for her baby, and her uncertain refugee status motivated Phan to sell her story: "Driven by [her and her husband's] desperate financial straits and their guilt at being unable to send money to their families in Vietnam, Kim Phuc relinquished her plans to 'stay quiet'" (Chong, 2000, p. 357). Phan's biography, *The Girl in the Picture* (2000), opens with Phan hiding, full of anxiety, in her Toronto apartment from journalists who have discovered her address. She laments to her husband that the "journalistic hounds" felt like "a bomb falling out of the sky," equating the trauma of being a propaganda victim with being physically injured by war (p. 6). It seems an unlikely coincidence that she and her husband gained permanent residence in 1995 (three years after they entered Canada) shortly after she re-entered public life (p. 357). The precarious condition in which Phan speaks reveals that she remains under duress in her host country, resisting the teleological immigration narrative from poverty and illness to the wealth and health in a Western nation. The limited framework

of her role—one of forgiveness and grace—also shows the labor demanded of the Vietnamese female refugee to uphold the U.S.’s identity as a humanitarian leader and Phan’s duties as financial and cultural caretaker of Vietnam and her family.

Southern disability studies can simultaneously address war-produced disability (both the direct injury caused by the war in Southeast Asia and the injuries produced by exile, poverty and racism in host countries) as collective by nature and attend to the voices and interiority of people living in pain. I am cautious about how the focus of debilitations produced by the North might not make room for some illnesses, such as cancer, fibromyalgia, and sexually transmitted diseases. The elision of the interior lives of disabled people has ethical and material ramifications, including bolstering negative stereotypes of disabled people, omitting the epistemological value of experiences of disabled people in the global South, and ignoring crucial legal and social infrastructure for disabled people. Furthermore Eunjung Kim (2011) warns that the geographic spatialization might limit discussion of bodies altered by violence to be “symbols of injustice and violence” (p.101). Decolonializing projects must attend to social hierarchies, including gender, class, ethnicities, ableism as it criticizes oppression produced by colonialism. The focus on maiming produced by the North does little to hold the South’s governments and societies accountable towards debilitated subjects. In the next section, I show how the emphasis on national progression as a newly independent nation excludes and harms so many of its subjects, repeating structures of colonial violence and way of being albeit new names, maintaining power and resources for few.

Guerilla Visuality

The communist regime, like western media, exploited Phan through the framing of beautiful debilitation that mobilizes her victim status as proof of U.S. colonialism. As the U.S. detaches its culpability from Phan's body, Vietnam depends on Phan's body as evidence of war atrocity within a victimizing framework that absolves Vietnam of wrongdoing. Rather than outright dismissing the humanitarian narrative of beautiful debilitation crafted by the U.S., the Vietnamese state assembles a guerilla visuality by repurposing beautiful debilitation formed and disseminated by Western media. Guerilla suggests an unequal power relationship within a geopolitical collision that results from necessity and lack. As such, guerilla also implies a temporality of cause and effect, existing as a response *after* a deployment of violence from the more powerful. As the term guerilla alludes to militarism, guerilla visuality operates with the specter of disability as a weapon in the “memory war” (V. Nguyen, 2016, p. 33). Constructed out of beautiful debilitation, guerilla visuality anticipates a humanitarian response. Originally nameless in the Vietnamese public, Phan’s power comes from Western responses (her injury is too common to carry such weight in Vietnam). Debilitation’s visibility in public memory is a relatively new part of Vietnam’s postwar development. Analyzing revolutionary photographs from the Vietnam-U.S. War, Thy Phu (2017) shows that “[b]ecause injured and dead bodies were considered dispiriting and demoralizing, they were rarely seen, and pulled from circulation if not censored outright as unsuitable for revolution, perhaps even as counterrevolutionary” (p. 304). She explains that Vietnamese photographs from the war follow a “revolutionary looking,” which is “a practice that . . . attends to the importance of repurposing salvaged material, making do with the resources

available in one's environment,—and alternately acknowledging and disavowing injury” (p. 316). In postwar Vietnam, I argue, *displaying* injury is a “revolutionary looking” in the memory war, repurposing the hegemony of human rights—the “lingua franca of the new world order”—to court partnership with the U.S. (Douzinas, 2000, p.32).

During and after the war, Vietnam saw the undeniable power of the mobilization of beautiful debilitation on the global stage with international attention and emotional connection to Phan Thi Kim Phuc. While the U.S. extended President Richard Nixon's 1964 trade embargo to all of Vietnam until 1994, the image of Phan and other photographs of victimization brought reporters and humanitarian aid to Vietnam. With the power to maintain Western wandering attention, Phan was made into an official war victim to negotiate a reconciliation between Vietnam and the U.S. and its allies. Phan (2017) recalls a government official telling her, “You are very important now! . . . Your government needs you, and you must comply” (p. 93). Officials tracked Phan down when she was nineteen—nine years after she was captured on camera running from the napalm strike—with the goal of leveraging people's emotions towards her to sponsor a new narrative of victimhood and friendship in order to influence the U.S. and its allies to lift the embargo and provide aid and investments (p. 89). She promoted Vietnam's legibility on the global stage as a symbol of the sympathetic victim in need of foreign aid rather than as a hostile or morally corrupt communist country to avoid. Phan's ambassador role reflects Vietnam's larger effort to court U.S. diplomatic ties. In the same year, Vietnam also invited the first delegation of American veterans to Hanoi (Weinraub, 1981).

Phan's debilitation, thus, became objectified and appropriated by dueling nationalist projects. The Vietnamese government workers provided her with a script that emphasized her happiness and success under communism despite the U.S. produced injury, a narrative from which she could not deviate. While she could speak about the physical suffering from her napalm burn since it was caused by an imperial force, she was chastised "for embarrassing the regime by speaking of the difficulties of life in postwar Vietnam" even as her family did not have enough to eat (Chong, 2000, p. 201). Phan (2017) reflects, "During those interviews, government-assigned translators continued to convey to the journalists views on the war, on the napalm attack, and on postwar life in South Vietnam, none of which reflected my own" (p. 92). The full-time role as official war victim eventually forced her out of college despite her tremendous effort to become a pediatrician and her repeated pleas to stay in college. When she hid from officials, they harassed and threatened her parents. Phan's impoverished life and her struggles as a hostage of the state reveal the exploitation of her war-injuries for a nationalist agenda. The tenth anniversary of the Fall of Saigon, in 1985, intensifies this interest to an intolerable level and Phan finds herself paraded by the Vietnamese government to endless groups of foreign media: "Beginning in the spring of 1985, the pace of Phuc's interviews with foreign journalists intensified as never before....some one hundred and fifty foreign journalists, mostly American, came to Ho Chi Minh City" (Chong, 2000, p. 245). Despite living in Vietnam, Phan performs for American journalists, who document for the U.S. general public. Vietnam deploys beautiful debilitation as a guerilla visuality that echoes strategies adopted during the war, in which Vietnamese people repurposed salvaged U.S. weapons and

materials. As a result, the success is limited as the strategy maintains the U.S. global reputation as a human rights leader. While guerilla visuality might be read through a resistant framework, particularly as a postcolonial deployment of debility as evidence of violence produced by the global North, the interiority of Phan's struggles as a propaganda tool problematizes the dichotomy of global North/South as producers of harm. Furthermore, official recognition of war-produced debilitations does not always extend to Vietnamese civilians or veterans who served for South Vietnam. Pham Van Quyen, Nui Thanh District's Chairman of the Association of Victims of Agent Orange/Dioxin, explained to me in June 2023 that the Vietnamese government only recognizes (and thus, provide aid for) individuals who served on the Communist North military and their direct descendants as potential victims of Agent Orange. Indeed, recognizing and responding to the maiming power of war machines of colonialism, occupation, and U.S. imperialism does not translate to necessary government assistance, disability laws, and social acceptance for disabled people of the South.

Debilitation and Diplomacy

Above, I detailed how the former enemies deployed beautiful debilitation through Phan's napalm injuries before political normalization in 1995. After two decades, beautiful debilitation remained an important political tool when Vietnam became a U.S. strategic partner in 2016, ending the arms embargo. Rendering the "Vietnam War" a thing of the past in the address to the Vietnamese people in Hanoi on May 24, 2016, President Barack Obama named debilitation as an opportunity for reconciliation, healing, and progress:

In this way, the very war that had divided us became a source for healing. It allowed us to account for the missing and finally bring them home. It allowed us to help remove landmines and unexploded bombs, because no child should ever lose a leg just playing outside. Even as we continue to assist Vietnamese with disabilities, including children, we are also continuing to help remove Agent Orange — dioxin — so that Vietnam can reclaim more of your land. We're proud of our work together in Danang, and we look forward to supporting your efforts in Bien Hoa. (para. 13).

Obama's speech highlights the two issues that remained important to the U.S. after the war: the missing U.S. servicemen and the ongoing Vietnamese debilitation from U.S. war materials. The emphasis on U.S.'s "help" in reference to U.S.-produced debilitations masks its own war crimes and ongoing contributions to the killing of Vietnamese people living on the toxic, bomb-filled land even as it acknowledges them. The construction of war, debilitation, and death as "a source for healing" utilizes beautiful debilitation to define the U.S.'s beauty and morality as it accepts Vietnam as a new market for its weapons industry. If there is a perpetrator within the humanitarian rhetoric of this speech, it is Vietnam, who cannot care for its innocent children and has failed to uphold basic human rights, such as freedom of speech and religion. The widespread belief that "Western countries are . . . heaven for disabled people while non-Western countries are . . . hell" supports Obama's tone of superiority and generosity (Kim, 2011, p. 94). Obama's references to children—eight times in the speech—emphasize that only a particular type of visuality can facilitate reconciliation between former enemies—the beautiful debilitation of the vulnerable innocents like

Phan Thi Kim Phuc. He names children as victims of U.S. war remnants as if bombs and Agent Orange, dropped by the U.S. military, discriminate by age. The figure of the disabled child functions as a symbol of Vietnam, needing paternal protection. In the same speech, Obama—like a father—warns Vietnam to uphold human rights in order to maintain normalized relations. He lightens the chastisement by adding that “The rights I speak of I believe are not American values; I think they’re universal values written into the Universal Declaration of Human Rights. They’re written into the Vietnamese constitution . . . That’s in the Vietnamese constitution” (para. 29). The former president’s reference to human rights and, more specifically, Vietnam’s violations of human rights, calls on universal humanitarian ethos and affirms U.S. global dominance built upon its identity as a nation committed to rights, freedom, and capitalist prosperity that is antagonistic to Communism. Obama’s speech rewrites the Vietnam-U.S. War as “we-win-even-when-we-lose” account of the war, in which the U.S. has been recuperated as a moral leader who is “so proud to help train [Vietnam’s] peacekeepers” (Espiritu, 2006, p. 329; para. 36). Obama’s emphasis on U.S. assistance and threat if Vietnam does not uphold “universal values” decontextualizes the history of chemical warfare and imperialism. In *From Enemies to Partners* (2017), Le Ke Son and Charles Bailey explain that “ask[ing] the U.S. government to help overcome the consequences of Agent Orange” and “su[ing] the U.S. chemical companies” are “contradictory and counterproductive.” The authors recommend pragmatic procedures because legal actions are more likely to “trigger adverse reactions from some U.S. government agencies” (p. 17). While humanitarian aid might be the most practical avenue for receiving funding to respond

to postwar destruction, it is not redress, particularly as the U.S. refuses to acknowledge responsibility.

Guerilla Visuality at the War Remnants Museum: A Contemporary Example

In the context of the U.S.'s refusal to accept accountability and asymmetrical political power relations, Vietnam continues to repurpose beautiful debilitation to inspire, to call on an international civic culture, and to embody a postcolonial Vietnamese identity. It is important to note that Vietnam simultaneously continues to pursue legal redress. This section shows how the War Remnants Museum, a state-sponsored museum in Ho Chi Minh City, depends on a guerilla visuality of beautiful debilitation to reveal the epistemic violence that compels postcolonial nations to rearticulate narrow conceptualization of disability. The colonial imposition of Western framework of disability, what Xuan Thuy Nguyen (2023) calls "epistemic injustice," reflects an ongoing articulation power that plays out in both the cultural and political arenas (p. 109). In addition to numerous photographs of Vietnamese debilitated by the war, the Museum includes disabled people to foster tangible interactions between the visitors and disabled Vietnamese, echoing the beautiful debilitation exchange between Phan and Western audiences. At the gift shop in one of the two entrances, impossible to miss, disabled people make and sell beaded items. Unlike the example of Phan, whose injuries can be hidden, their disabilities (presumably produced by the war) must be visible to act as evidence of the war's ongoing harm. This type of evidentiary documentation, which rarely occurs in museums, resembles courtrooms' eyewitness accounts. Phan's scars can be hidden because people already have proof of the napalm strike. The museum director Huynh Ngoc Van explained that since 2011, the museum had integrated a "life exhibition" of disabled

people as another way to convey the consequences of the war. In addition to their presence constructing and selling beaded objects, “On Saturdays and Sundays they come to perform their music, singing to the visitors. And sometimes, we also invite them to see the visitors, tell them their stories and play music for the visitors.” Huynh added:

You know this is kind of . . . a life exhibition, so people can see them and talk to them, can hold them, love them, and share with them. Their life has changed so much after what came in the museum. They became . . . happy, more confidence. They married each other and now we have four children. . . . And they feel . . . helpful because when they talk to other people they can share with them the experience to overcome their difficulties in their life and people can learn from them.

Huynh’s description, which presents the museum as an important place for disabled people to make a living, find romantic connections, heal themselves, and promote change as teachers, hints at the ways their lives exceed the scope of their roles in the museum. They, like Phan, also serve as hospitable and gracious Vietnamese ambassadors, entertaining and sharing stories with visitors. As representatives of Vietnam, they perform the pedagogical work of advancing a narrative of Vietnam’s innocence, pacifism, and victimhood. The labor must remain invisible in order to maximize the emotional power to make visitors feel natural and warm affiliations with them. Instead, the visible labor is their craft-making, which presents their work ethic as a defining characteristic of Vietnamese people (willing to do factory jobs outsourced by developed nations) and marks them as inspirational. Their willingness and desire to work conveys a determination “to overcome their difficulties” rather than a sense of

indignation and resentment. Their roles as craft-makers and entertainers reinforce the notion that it is the role of disabled people to warm the hearts and open the minds of abled people, whose ability to appreciate disabled people serves as proof positive of their compassion and supreme moral compass. Unlike some photographs of disabled Vietnamese that featured the most evocative disabilities to shock viewers into a response, these ambassadors' bodies do not trigger shock or disgust. Beautiful debilitation shows the potential for wholeness and the idealism of family, harmony, hope, and humanity despite the presence of injuries, allowing the possibility for the beholder to identify with the wounded subject. As Anne Cheng (2019) writes, "To be able to identify beauty (in the guise of judging it) is to have already experienced the self-identification and disidentification of beauty" (p. 209). They are, in many ways, just like the (assumed) able-bodied viewers—they work, love, marry, have children. They can be your friend—go on, talk, hold, love, and share with them.

The inclusion of debilitated people creates a museum experience that closely aligns with another museum program that connects U.S. veterans from the Soldier's Hearts with former Vietnamese veterans and war prisoners. In December 2016, Van recounts that the U.S. veterans travel with Vietnamese veterans and stay in their homes: "they became friends. . . . I think my museum is kind of a bridge between former enemies—Vietnamese veterans, American veterans, Korean veterans, Australian veterans." These curated interactions continue postwar Vietnam's diplomacy with the U.S. in the 1980s, during which state officials found Phan and hosted the first delegation of veterans to which Foreign Minister, Nguyen Co Thach announces, "Tell your people we are friends, we are not enemies" (as cited in Weinraub, 1981, para. 4). The museum director recounts that U.S. veterans shared with her

that despite having lived with postpartum depression for thirty years, after “3 days in Vietnam everything has changed so much, and they feel very happy, and they feel open, and they love Vietnamese people.” These curated engagements between Vietnamese war victims and veterans and U.S. veterans that spans decades and the promise to heal Americans in just three days, mirrors the reconciliation between Phan Thi Kim Phuc and John Plummer, who claimed to be the officer who ordered the napalm strike on her village, against the national backdrop of veterans Day ceremonies in 1996. She opened her arms to the sobbing veteran and said, “I forgive, I forgive” (Gearan, 1997, para. 57). The controversy around Plummer’s apology, namely that he did not order the air strike as he had claimed, significantly demonstrates the (necessary) hidden complexity of war-produced debilitations.

The Possibility of Photographs of Debilitation

On the fiftieth anniversary of the “The Terror of War” in 2022, Phan Thi Kim Phuc wrote an opinion article for the *NYT*. Aptly titled “I Am Not ‘Napalm Girl’ Anymore,” Phan pivots her role from a visual object to a teacher. Phan discusses school shootings: “We may not see the bodies, as we do with foreign wars, but these attacks are the domestic equivalent of war.” Phan references the common images of debilitated or dead foreign bodies that have become shorthand for the violence, corruption, and poverty of the global South. Within disability studies, disability in the global South has often been represented as a metaphor for poverty, violence, and colonialism (Davidson, 2008; Sherry, 2008; Shirley, 1983).

The Canadian citizen names the Uvalde, Texas school shooting, continuing her role as an ambassador of “peace, love, hope and forgiveness” within a U.S. sociopolitical context. By placing U.S. gun violence within the context of “foreign wars,” Phan, whose racialized body

registers global South debilitation, emphasizes debilitation and deaths produced in the U.S. The comparison of the foreign bodies and U.S. children challenges the U.S. position as a world leader in disability rights and liberal morality underlining U.S. international diplomacy, especially with Vietnam. Ultimately, Phan destabilizes the hierarchy between the U.S. and “foreign” nations in human rights discourse.

Phan calls for photographs of the “aftermath of a gun rampage,” citing looking as the first step to end gun violence. What types of photographs are necessary to move the audience to act towards gun control? Will the photographs show children spread out on the floor covered in blood and bullet holes? Will the photographs show children in caskets—dignified and beautiful—and utterly immobile? Images of debilitation and death have tremendous political and representational power because the human body is the most universal lexicon. The debilitated body promotes an unmatched intimacy and a visceral disruption of that intimacy as we confront the breaking fantasy of bodily wholeness. The tension between the familiarity of the body and the shock of its rupture triggers a wave of emotions—pity, grief, rage, shame, fear. The visibility of bodily injury carries the weight of truth to give the victim moral authority over the more powerful person, institution, or nation.

Many prominent photography scholars, such as Susan Sontag (2004) and John Berger (1973), express deep suspicion of photography’s capacity to propel political change. And as I have described with Phan Thi Kim Phuc and the life exhibition of disabled people in the War Remnants Museum, the body’s universalism makes it vulnerable to objectification according to the desires of onlookers and curators. In *Regarding the Pain of Others*, Susan Sontag (2004) asserts that the circulation of suffering photographs is racialized: The “exotic—that is,

colonized—human beings: Africans and denizens of remote Asian countries were displayed like zoo animals in ethnological exhibitions” (p. 72). Ultimately, Sontag focuses on the ocular power of Western viewers who fail to identify with the seen object. Sontag’s argument, while cogent and significant to visual culture, is more interested in Westerners’ looking habits than the suffering of others. Sontag describes the other through the analogy of animals.

Dehumanization informed by coloniality and racialization underlies her arguments. The suffering of some people—in and outside of the U.S.—is more photographed simply because we are more exposed to harmful and deadly environments. Staying visible in and traveling through photographs can be the only way marginalized people remain alive even as they are presented as maimed or dead. Justice becomes possible not in the present moment of reality, but rather in the future realm of what Ariella Azoulay (2008) names “the civil contract of photography” as the title of her book. Furthermore, marginalized people from the global South often lack the cultural means (such as literature, film, art) to protest. Even lynching photographs that were circulated as a tool of terrorism and community formation among white oppressors shift to become resistance to this form of violence as Amy Louise Wood (2009) details in *Lynching and Spectacle*. So many marginalized subjects occupy the space of this witnessing residual—unacknowledged but existing.

As Phan suggests, people need more, not fewer, engagements with the photography of atrocity in order to reject claims of propaganda, dismissal, or authorized erasure. Looking must account for the specificity of geopolitical power, racial, gender, age, and circumstance. Eunjung Kim (2011) suggests that we can move beyond symbolization of disability by becoming “intimate with the subcultures of disabled people locally,” learning “how people

creatively navigate their inaccessible environments with accumulated expertise and strategies,” and “make connections among diverse, imaginative, conflicting, and ambiguous self-representations of disabled people around the world” (p. 104). Learning to call out the many debilitating violence of a society and honoring the lives of disabled people as complex and whole might be difficult work, but it is critical to reducing harm to vulnerable people. Photographs of disabled people, to begin with, can reveal sites of violence and permit deeper conversations about the lives of people wounded by such violence. We, too, must be careful with dissemination of injured or dead bodies as they can be triggering to populations already predisposed to harm. This article has demonstrated the problems of using disabled people as symbols of a violent historical event—the dissemination and discussion of atrocity photographs must give space for debilitated people to speak. This ensures that both disabled and deceased individuals are treated with respect, allowing people to access the resources they are entitled to in order to thrive.

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Beautiful Debilitation: War Injuries as Political Currency in Vietnam and U.S. Relations by Ai Binh T. Ho

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Disrupting Fixity: Palestine as Central to Decolonial Disability Justice

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Abstract

This conversation enacts a decolonial feminist intervention, especially in the realm of knowledge production. More specifically, the conversation is a real-time attempt to “disrupt fixity” by insisting that the fight for the liberation of Palestine is central to decolonial disability futures. The conversation takes up issues of ableism, including how it relates to mental health, “access washing,” settler colonialism, and the decolonial present as well as futures.

Keywords: disability, Palestine, settler-colonialism, ableism, Zionism

Disrupting Fixity: Palestine as Central to Decolonial Disability Justice

In responding to the call for papers for this special issue, we challenged ourselves to enact a decolonial feminist intervention, one that is meant to disrupt, in real time, hegemonic structures that otherwise might go unnoticed, or unchecked, especially in the realm of knowledge production. Instead of co-writing an article, then, we decided to be in conversation together. Ahead of our conversation, we generated several questions to guide us, though we did not speak beforehand to allow for non-performative exchange. Some of the questions we thought up were drawn directly from the call, others informed it but written by us. While we chose questions that we thought would guide a generative conversation, we were also committed to letting the conversation unfold organically, an in-vivo enactment of the generativity and fluidity against an “always-already” ableist register that we also discuss. What emerged was an exchange that is both grounded in and critical of our academic traditions and draws on our lived experiences and political commitments. More specifically, we find ourselves discussing ableism, including how it relates to mental health, “access washing,” settler colonialism, and the decolonial present as well as futures.

Importantly, this conversation took place well before October 7, 2023. Rather than deploy colonial time stamps of “before” and “after,” we invite the reader to instead hold space for the violence of settler colonialism that always already saturates any conversation on Palestine, let alone one that takes up decoloniality in disability studies. Through our conversation, then, we invite you to reflect with us on how the structural logic of settler colonialism both predated October 7 and provided the infrastructure through which a

genocide of the Palestinian people in the Gaza Strip could both unfold in real-time and be actively supported by United States imperialism and its twin settler colonial scaffolding.

Why this format?

L. Jaffee (personal communication, prior to October 7, 2023): I was very grateful that you suggested this format. I was feeling overwhelmed by the overwork of academia and this format felt not only more doable but also more enjoyable. Having to communicate an idea to someone in real time forces the use of more accessible language. You're getting live feedback about what you're saying. Even within disability studies there can be a lot of heavy jargon. People don't talk like that, but it's so engrained in academic writing. I'm not saying there's not a place for neologisms or new terminology, but I appreciate a format that forces us to think more about the words that we're using, what we really mean by them, and how to communicate that effectively in real time.

L. Sheehi: I think also, if we're centering disability justice as an orienting framework for our world and for our political struggles, everything we do has the potential to become a practice of decentering ableism that lodges itself in us as like a normative fixture. So, part of the constant challenge is how can I consistently disrupt these processes, all the time, in every space? We live in an ableist world that insists on fixtures of normative being, which includes psychically cordoned off areas to us, even unconsciously. For example, in academic publishing it is about what counts as a publication or what counts as knowledge production, which reproduces structures of domination and epistemological exclusion as a matter of "common sense" academic practice. But, when our entry point is disability justice, as an integral part of abolitionist thinking and enacting, we need to *disrupt* processes that are

regularized, modes of being and doing and functioning-as-normative-academic. Ableism is structurally going to support a very narrow way of engaging with the world, so for me, this type of format is also disruptive in real time. And allows us to experience in real-time something new emerge.

L. Jaffee: I mean that feels truer to disability studies' origins— obviously disabilities studies is an academic discipline—but it's one that grew out of disabled folks' organizing and activism. So, I think this format is both a way of practicing disability justice, and also, a conversation feels apt given that we came to know each other because student activists were having conversations—and organizing— around disability justice and Palestine.

L. Sheehi: You're also highlighting that relationality. This relational space acts as a bedrock both of organizing but also, again, together vs. alone asking, struggling through, and pushing the question and *act*, "how do we penetrate these systems that feel so immovable?"; not just one off, but on a regular basis not somewhere far off in the future? Let's do this now.

L. Jaffee: I was thinking, too, that everything about traditional academic knowledge production is antithetical to challenging intellectual supremacy and neurotypical norms. So I'm thinking about this format as challenging what counts as legitimate knowledge production, and in terms of the working conditions and inaccessibility of academia, this is a format that feels far more accessible and far more manageable in terms of the productivity expectations of academia, say for getting or keeping a job.

I also want to say something about how I came to this work, or how I'm positioned in relation to it. I was initially drawn to disability studies because I had done a lot of inclusion work with intellectually disabled kids in the U.S. Through the course of my graduate studies and conversations with disabled comrades, I came to understand the ways ableism had shaped my own experiences—as a person with a chronic immune condition—too. I'm also a white Ashkenazi, American Jew and was raised in contexts where Zionism⁴ was just in the air; it wasn't something I knew to question. It was really through the immense generosity and patience of Palestinian and other BIPOC educators and mentors in my life that I came to recognize Palestinian liberation as integral to all the political commitments and principles I hold, and Zionism as irreconcilable with my other politics—as a queer, and as someone doing anti-racist and anti-imperialist community organizing work.

L. Sheehi: Thanks for that—I appreciate your invitation to own our entry points, too. I am Lebanese Arab and queer, and a clinical psychologist. Over the years, I have become more involved in the thinking through and active disruption of the eugenicist and colonial “givens” of my field, with a focus on psychoanalysis. The questions for me are necessarily guided by my own experience of living under the settler colonial condition of Zionism, being keenly aware of limitations of space, movement, and the right to fullness and being. This recognition was solidified when I moved to the United States for graduate school post-9/11. The intersection of abolitionist mental health work, revolutionary psychoanalysis, queer of color

⁴ Zionism refers to a Jewish nationalist ideology that from its origin called for the creation of a Jewish state. Today, Zionist ideology justifies and normalizes the existence of Israel as an ethno-state formed and maintained through the colonial occupation of Palestinian land and people.

critique, and disability justice has been a process of coming into that being, and an insistence that there is no separation between the clinic and the street, so to speak. But also, on the question of access and legitimacy, I am really interested in the despecializing of psychoanalytic and psychological knowledge, following Che Guevara or Frantz Fanon's tradition of despecializing medicine. It's this political commitment that allows me to understand why clinicians have a place in the fight for liberation, and especially Palestine.

To come full circle, the knowledge we are producing together is happening *because* we met through a Students for Justice in Palestine (SJP) event, the central question of which was, "how do we think about disability justice when we're thinking about issues of displacement? When we're thinking about issues of erasure? When we're thinking about issues of dispossession? Of ability and debility on a spectrum? When we're thinking of settler colonialism?"

What does ableism look like within transnational contexts?

L. Jaffee: I was thinking generally about how disability studies is so much about the physical site of the body and how the body meets the environment, but Western disability studies has very much been focused on the body as an individual body and not a national or collective body. Part of thinking about ableism within transnational contexts is considering how ableism acts on national bodies—occupied, colonized, Indigenous national bodies—as opposed to thinking about the body as a purely atomized individual entity.

And one way this plays out is in how colonial, imperialist, and settler ideologies use ableism to justify the exploitation of labor, to justify genocide, to justify the extraction of resources by

deeming entire populations— national populations, Indigenous populations, occupied populations— either intellectually or physically or psychiatrically inferior in some way (Sins Invalid, 2019). It's always premised on this blueprint of a hierarchy of ability—which then race, nation, gender can be mapped onto.

L. Sheehi: I am also thinking through a psychology register— is intimately intertwined with violence, if we borrow from Frantz Fanon's (1963; 1986) understanding of the logics of oppression. The organizing framework I am using is that ableism is the structure and the logic through which this type of violence is mobilized while settler colonialism creates the conditions of debility, or the conditions through which ableism can even come to be, all of which is enshrined by capitalism and imperialism, similarly to how Ruth Wilson Gilmore⁵ teaches us that racism is enshrined by capitalism. I think it's seductive for us to think about ableism as a symptom rather than as a structure that aids settler colonialism, and like you said, that settler colonialism comes to rely on.

Sometimes we think about ableism as an after-effect, but what we're highlighting is that it's not accidental that ableism is a part of the settler-colonial condition. You're saying that settler colonialism has to include ableism because it's a structure that is fundamentally based on hierarchies of being, contingent on who has access and who doesn't. This is not passive, but rather an active erasure of those who come to not be *allowed* access under the rubric of settler colonialism. This is done, according to Patrick Wolfe (2006), through an insistence that the

⁵ See the short film "Geographies of Racial Capitalism with Ruth Wilson Gilmore," found at: <https://www.youtube.com/watch?v=2CS627aKrJI>

settler is actually Indigenous, which, of course, makes the Indigenous the settlers; it is a psychic inversion that happens. We see this logic repeated. For example, we build structures that are ableist, and then there is an inversion of blame that dictates that it's folks who are disabled that are blameworthy for not adapting to ableist structures.

L. Jaffee: As you mentioned Ruth Wilson Gilmore's work, I feel like there are parallels to conversations that many have had around race and capitalism in terms of contesting the conceptualization that race is just an accidental outcome of capitalism. Instead, racism is what actually enabled capitalism to develop through the creation of racial divisions necessary for capitalism to operate and be normalized. Likewise, ableism creates divisions along lines of ability—or perceived or presumed ability—that serve capitalism, as a system of production premised on division and hierarchy: bosses and workers, landlords and tenants, colonizer and colonized. By naturalizing the idea that there is a hierarchy of ability—of smartness, of strength, of usefulness—ableism provides ideological infrastructure that all systems of oppression can map onto (Sins Invalid, 2019, Leonardo & Broderick, 2011). So, within transnational contexts, ableism is also playing out on a larger scale than typically conceptualized within Western disability studies. It's not just about the impact of ableism on an individual disabled person, but the way ableism lends credence to imperialist and colonial logics that deem the colonized/occupied less than. As Sins Invalid (2019) has written, "one cannot look at the history of U.S. slavery, the stealing of Indigenous lands, and U.S. imperialism without seeing the way that white supremacy uses ableism to create a lesser/'other' group of people that is deemed less worthy/abled/smart/capable" (p. 18).

L. Sheehi: Racial capitalism is always based on hierarchies of power and that's what creates it.

L. Jaffee: Yes! Lately I've been having a lot of conversations about hope and where we find it. As the brilliant organizer Mariame Kaba famously said, hope is a discipline (Kaba, 2020). I think living in the moment we're in, a lot of folks struggle with a degree of hopelessness or apathy, or assumptions based on the world as it is currently configured. I hear so many assumptions around human nature and the idea that people are just bad and selfish and that violence is inevitable. I think the apathy is not so much indifference but ultimately rooted in or a symptom of hopelessness, being stuck in the belief that things can't change.

I was just thinking about the fact that ableism, anti-Blackness, settler ideologies—all of these ideologies have to be continually reinforced to justify violent practices, to justify extraction, to justify domination, to justify displacement. Because I don't think people are inherently selfish or violent or cruel. Even folks in power, the fact that the ruling class needs to create ideologies to justify harmful behavior or violent social systems suggests to me that people aren't inherently just evil and selfish and trying to better their own situation at the expense of others, right? It's not human nature if the ruling class has to devise ideological systems that normalize state violence, that enable them—as the beneficiaries of the political-economic system—to feel okay about systemic violence and make oppression and control commonsense. These logics are produced, and so just as easily could not be produced.

L. Sheehi: To your point, the immense resistances that come up against *being otherwise*, as Black feminists, and here I am specifically thinking of Gail Lewis (2019), remind us. If selfishness is an intrinsic way of being, a fixed position, other modes of being or the spontaneity with which other forms of being come to exist doesn't add up. We saw this during the beginning stages of COVID. Overnight, everything changes. We go through our lives, thinking that things are just fixtures, ideologically fixed, when really, they've been molded into their fixity over time. Undoing ideological fixedness, that's a practice, that's a skill, to remember that the things that have become fixtures aren't natural. We're back to the practice of disruption! To disrupt the making-of-normativity, it's a good psychological reminder, about alacrity versus fixity.

L. Jaffee: I'm in the field of education, so as you're describing ideological fixedness, I'm thinking about all the attacks on progressive or liberatory curricula within the US education system right now. On Palestine, on critical race theory or whatever gets called CRT by the Right, on teaching issues related to gender and sexuality. This is all part of a very broad and constant effort to maintain dominant ideologies and also quash any imagination. Because there are so many concrete historical examples of the wins that movements have made, and of ways of being and existing that undermine the dominant narrative about what's "fixed."

So, the message is, "this is as good as it gets so don't bother trying to make change." It's part of concealing how social change happens— from movements, from groups of people engaging in collective, direct action. All of the anti-CRT, anti-queer and trans education legislation bent on concealing and erasing non-dominant or subversive histories from textbooks and

from classrooms is about maintaining the myth that human nature is selfish and individualistic, that hierarchies of power are natural, that the world as it exists is inevitable, and that the power structure is fixed and unchangeable.

L. Sheehi: Which is, as you know, is a robust space for ableism to persist. And to persist unchecked. And why part of disruption must include divesting and disidentifying. We—in contradictory and varying degrees—have psychic investments in these systems working as they do. And I think this goes back to the question of transnational ableism. What does ableism look like when we understand it as having a transnational dimension of existence? Based on what we're talking about, there's a logic that repeats itself. Borders of agreed upon nation-states are not disrupting this logic.

How do the conditions of Israeli settler-colonialism reveal the “the struggles inherent in Western disability studies”?

L. Jaffee: I think one of the one more obvious examples is Israel's disability rights rhetoric, which is part of Israel's manufactured image as “the only democracy in the Middle East” and as this liberal progressive oasis, based on a very narrow, individualized understanding of identity, or social identity. I was thinking about, for example, Israel signing the UN Convention on the Rights of People with Disabilities, as well as the framing of Israel's COVID policies, and the haste with which Israeli citizens were vaccinated. The media campaign signifying that this is a progressive nation-state that is making great strides in health access erases and ignores Palestinians living under occupation who were denied access to the vaccine as a result of the Israeli blockade (Asi, 2021).

I've talked about this as *access washing*, which is a term I started using in the early stages of my dissertation work in 2017, and later learned (weeks before my dissertation defense in 2020) that the late disability justice organizer and writer Stacey Milbern had used the term in a 2019 blog post titled, *Notes on Access Washing*, which I didn't know existed.

And I feel like the trained response in academia is like, oh shit, somebody used this and here I thought I was coining a term. But I honestly felt a lot of relief. It felt like ok, this is something other people, and specifically other disabled organizers and writers, are seeing and talking about and finding useful to name. It was reassuring that this was not me trying to make a name for myself with some jargon, but this is actually a phenomenon that other people— a disabled organizer of color who I really respect, in particular— are noticing and think is worth naming.

As a general definition, I think of access washing as naming the ways in which relatively privileged—often white, global Northern, cisgender— disabled groups are made hyper-visible to obscure structural forces that produce disability unevenly among populations, and particularly among the most marginalized disabled folks— Indigenous, Black, global South, trans.

Part of access washing is the hypervisibility of disability— of some disability— to justify practices, programs, and policies that harm or exploit disabled and (non-disabled) oppressed groups. These ideas were very much growing out of being a graduate worker at Syracuse University (SU), which is a private university that has a very prominent disability studies

program and also uses rhetoric around disability and accessibility and disability inclusion as part of its university brand or image.

As one example, in 2016 SU built a “promenade”—a \$6 million dollar promenade— through the middle of campus on what used to be a city road. This was essentially a \$6 million walkway, but it was justified as necessary to make the path ADA (Americans with Disabilities Act) compliant (based on the incline of the road) and as making campus more accessible for disabled students. But it had previously been a city road that public buses could drive on so people could actually access the campus using public transportation. What they did— without the city’s approval—was they just shut down the road and turned it into a walking-only path.

L. Sheehi: They privatized it.

L. Jaffee: Exactly. And it was actually covered in stairs. And it’s named after the donor— the Einhorn Family Walkway. The donor, as an aside, is a Zionist and an Israel Bonds Honoree.⁶ And this was this really expensive project, a beautification project, part of corporatizing the university. It further enclosed this predominantly white, wealthy university on a hill. And essentially it’s gatekeeping, or further closing it off to the community, to the broader population of Syracuse.

⁶ The Development Corporation for Israel (DCI), better known as Israel Bonds, was created by the State of Israel in 1951 to finance the newly formed state. Since their creation, sales of Israel Bonds have generated over \$50 billion to sustain Israel’s economy and colonial occupation. DCI is headquartered in NYC, and many U.S. state and municipal pension and treasury funds invest in Israel bonds.

L. Sheehi: Drawing out these concrete examples that happen so regularly is so important to animating what we're talking about. They are such a vibrant way to see how the logics of ableism become intimately intertwined with class access, and race, like you're saying. That example packs all of that in it. I think it goes back to your point that people aren't inherently "trying to be bad," but rather, there are ways in which things become lodged in us as fixtures that task certain people with always having to be oriented to the world, to seeing all these textures of possibilities and potential catastrophic outcomes while others never have to think about it or engage it with meaningful intention.

To me, that's the ableism in it. When I say, "Who do we imagine in a space as readily as we disimagine?"—this is an example of that. Because there is a way in which people claim innocence (Sheehi & Sheehi, 2022) or get into this reactionary and defensive response of, "well, we can't do anything right then." That's not it. What I'm saying is that, consciously or unconsciously, in this act, there is a way in which the people who you imagined in this space, the people who you imagined could come to use this new walkway, this new part of campus, falls on fault lines that *already exist in the world* and, in their already-existence, they happen to be raced, classed, gendered, and dis/abled.

The regularity with which this happens in a patterned way tells us it's a structure. The regularized nature in which we have these examples points to something systemic. And, the other repetitive pattern is that it's often the same people who get written out of the story.

L. Jaffee: Right. This is surely not unique to SU. It's a dynamic with any wealthy predominantly white university. The race and class divide of the city or town is exacerbated by the relationship to the university. Syracuse is a rustbelt city with extremely high poverty among Black residents. The construction of the promenade is part of closing the gates around who is imagined to be at this university, who is imagined to work at this university. And also, it's about reassuring wealthy white parents. Because part of anti-Blackness is presumptions of violence and danger, of unsafety. The closing off of walls functions to reassure the parents of largely white, wealthy domestic students or wealthy international students—parents of students who can pay full tuition—that this is a safe place for their kids to go. And then university administrations have figured out they can use disability and accessibility concerns to justify it. It's about ADA compliance, not about further cordoning off space.

L. Sheehi: That's the brilliance of the term access washing. Because ADA compliance finds traction, because you've mobilized it through good liberal humanist discourse. Because if you didn't, people would otherwise be saying, "what the fuck are you doing?" But when you're packing it in the idea of, "we're creating access." Who's the asshole that's going to be upset with that?— at least within the realm of liberal humanist discourse, because of course we know and see that issues of access are *always* contested. So that is part of it, the language in and with which fixtures, spaces, foreclosures come into being.

But, I also want to go back to settler-colonialism, because, as we're discussing spaces being imagined and people being disimagined, this example you're giving, and so many others, is also being done on stolen land. Now you have reworked ownership over stolen land. And

when you cloak it in the liberal humanist discourse of access, you're also further disavowing, further dissociating the dispossession that happened, and continues to happen, in that very spot.

The law is used to justify many of these projects, which is why I think there are a lot of disability justice activists who rightfully warn us around the limitations of the law as dictating access, because the law itself is entrenched in systems of violence that will always write people out. There are so many layers to this, and it is a live example of how disrupting processes-as-usual has to mean we are attentive and commute between all these layers as a commitment to ethical alignment with, for me, abolitionist principles.

The way that I see this connecting to Palestine is that the logic of settler colonialism repeats itself regardless of the current modern nation-State in which it's housed. You started us off with the state now known as Israel access washing by signing onto the Geneva Convention. In the same breath, the fascist Israeli government has overhauled their judiciary process—the changes have been aptly called “the reasonableness bill.” Which should give us pause, the way “reason” comes to guise fascism, to include expansion of the Basic Law which enshrines the supremacy of Jewish citizens of Israel. It's codified. Hierarchy and apartheid is codified and mobilized through the law, which includes disproportionate prison sentences, most recently. When we lay it out like this, it is not a jump to understand the intersection of disability justice with the question of settler colonialism more broadly, and in this case Palestine more specifically.

It is another very important and concrete example: you're a settler colonial state, you have just codified apartheid, how do you reconcile signing onto the Geneva Convention for disability justice? You are basically outing yourself saying, "There are certain people who meet these standards and others who never will." *Because of who they are*. Whether they're Palestinian, in this case, or Black or Indigenous in other cases, based on these two examples that we just reviewed.

L. Jaffee: Which to your point about individualized notions of disability rights through the law—which doesn't work for most disabled people in the US, either—I think one of the limitations of law is that disability is conceptualized in an individual sense. The law conceptualizes disability as it affects individuals and not as it affects communities, or as it affects national groups. National bodies have no recourse through disability law. Which, to return to the example of the construction of the promenade at SU, Syracuse is on Haudenosaunee land, as you were speaking to. So this \$6 million walkway has been constructed, ostensibly in the name of disability access, but on land stolen from the Onondaga Nation that's now owned and controlled by SU, which has unilateral power when it comes to decisions about land-use. This walkway can be built in the name of disability access because structural debility or disablement of oppressed peoples—for example, the intergenerational trauma of land theft on Indigenous nations—has been written out of the purview of "disability issues" within a settler-colonial framework or logic.

L. Sheehi: This is why it is extremely important for us to disrupt the seduction and to remember that if we're accessing structures that are part of a settler colonial system, one

which is constitutively violent, these structures, even while giving access to some, will always enact violence on people. Even by virtue, in the most simple terms, of how people access the very systems that are meant to protect them.

L. Jaffee: Absolutely. To that point—because I think this example is really illustrative of what you’re saying—I wanted to talk about how access washing has played out in the Israeli military. Ro’im Rachok is an Israeli military program that includes Autistic soldiers in the IDF, or Israel “Defense” Forces. An *Esquire* headline that describes the program says, “Six years ago, three former Mossad agents launched an experimental Israeli Army program to recruit those on the autism spectrum, harnessing their unique aptitudes—their “superpowers,” as one soldier puts it. The name of this big military success? Ro’im Rachok, Hebrew for “seeing into the future,” and it may bring neurodiversity to the broader workforce.

I’m thinking about the media attention that this program garnered and the way in which it fuels Israel’s image as this liberal inclusive bastion, and the taken-for-granted assumptions within a liberal humanist framework that this is so great. So Israel is including Autistic people in its military and surely—if you care about disability rights—that’s assumed to be a positive development. Zero conversation about Palestinians, zero conversation about why the Israeli military exists in the form that it does, why it’s needed—to maintain an occupation. That inclusion in Israel requires inclusion in the military because all Israelis join the military, because mandatory conscription is necessary to maintain a settler occupation.

So this is celebrated as a symbol of Israel's concern for disability inclusion, as a symbol of Israel's concern for disability rights. This narration ignores that Autistic Israelis' abilities are being capitalized on. Their neurodivergent abilities—or presumed abilities here—are being exploited to maintain a settler-colonial structure. Because the way the program is talked about is that Autistic Israelis have a superior ability, compared to allistics, to visually analyze satellite images “for the slightest sign of enemy activity” (Kuchner, 2019). Their abilities are celebrated and made legible as valuable, as useful to the state insofar as they serve the settler project of more efficiently locating, killing, and debilitating Palestinians. Autism is made meaningful—through a non-deficit lens—based on the settler logic that, because they're Autistic, they can read different maps, read different data sets with extreme focus, and that's valuable to the IDF. So Autistic citizens are made legible, made valuable, through their service to the settler state in the ongoing project of eliminating the Indigenous population, eliminating Palestinians. Disability as an identity is made especially legible through its utility in maintaining Israel's occupation.

Which I think really speaks to the limits of trying to export a particular cultural understanding of disability that ignores that level of the nation-state. That ignores anything about power dynamics between occupied and occupier. And again, this narrow framing for understanding disability doesn't work within the US settler state, either. Because it's based on a conception of ableism that doesn't include any analysis of settler-colonialism or imperialism, and specifically the ways they thrive off of a normalized ableist logic.

L. Sheehi: It's exploitative and coercive. It's mining—I mean, a “super power”! It's so sensationalist, too, and that part of it may be entirely lost in this language of inclusivity. I think that's maybe what you're talking about, the importing of the language of inclusivity—which again finds traction in certain places that espouse liberal humanist values— defangs the actual power relations that are happening.

I was at a talk that Robin DG Kelley was giving at Wellesley a couple years back, and he was reminding people that there's a way in which Kimberlé Crenshaw's concept of intersectionality is so defanged. He said something along the lines of: a reminder to people, intersectionality is not an analysis of identity, it's an analysis of oppression. Just this reminder completely blows the *Esquire* headline out of the water. Because once you transpose it to an analysis of oppression, then there is a reminder to engage, as a mode of necessary disruption, in a reality-testing exercise: there is something else here at play, and that something else is an access to services, access to power, intimate proximity to the means of power. In this particular case of the settler-colonial state that is now known as Israel— Identity is a central piece of that. It's being displaced into disability identity by this media coverage, but what's missing from the conversation is back to the Basic Law; it's what that Law codifies in terms of what constitutes the *most important* identity, above all. In the eyes of the law? In the eyes of the so-called democracy? In terms of access to *everything*, including the land.

Both these examples are very important because the endpoint doesn't change, but the discourse is actually really important and mobilized specifically in order to find traction.

That's the piece for us to be aware of when we're talking about these things, particularly in the context of Palestine, these liberal humanist codes of communicating find their way into people's psyche. And it makes them feel good. But most insidiously, it hides the violence.

L. Jaffee: And it's rewarded. The disability theorizing I have learned the most from and that has most shaped the way that I think is not produced in academia. It's not to, of course, dismiss or diminish academic scholarship around disability by any means, but I feel like so much of what I've learned that fundamentally shapes my thinking comes from disability justice organizations on the ground. And that is not accidental because I think even within more recent, more critical disability studies scholarship (as compared to earlier, more canonized disability studies scholarship) that takes up intersectional analysis, that takes up race and gender and to some degree class, questions of global power dynamics and transnationalism are often still not part of the conversation. I feel like part of that is because anti-imperialism is not en vogue. It's not "sexy" within academia.

“What does it mean to do disability justice transnationally while avoiding imposing epistemologies of the North on Southern contexts?”

L. Sheehi: Which is what we're trying to disrupt today. I think that ties into the next question about what possibilities can be reopened for decolonial disability futurities. I think that you are speaking to that directly. I cannot see a decolonial disability movement that doesn't firmly plant itself in anti-imperialism, anti-capitalism, anti-racism— which includes anti-Zionist discourse. How can we imagine our struggles being decolonial if they're not centered in internationalist solidarity movements? Or in rooting ourselves in practices of the global

South and not engaging in saviorist models, but saying, and *meaning*, and knowing, folks have been actually thinking through these ideas and finding ways to maneuver and create life, which is also at the heart for me when I'm thinking about a decolonial disability movement. How do we sustain life-making and life worlds, despite the structures that are meant to snuff that out? How do we even begin to seriously think about this, let alone act, if we're not talking about imperialism or capitalism?

L. Jaffee: Backtracking a little bit— “What does it mean to do disability justice transnationally while avoiding imposing epistemologies of the north on southern contexts?” has to do with how disability studies, and maybe too disability rights, has been concerned with the claiming of identity as a badge that you wear. I'm certainly not the first to say this. Many disabled theorists and activists of color have said things along the lines of not being primarily concerned with who calls themselves disabled because they understand that the implications of claiming identity or having that label differ based on race, on nation, on gender or sexuality (Bailey & Mobley, 2019; Mingus, 2011). The end goal of disability justice is not necessarily that you need to claim this identity. It's about the practice of it and the work that you're doing, and in what we can recognize as a disability issue. I was thinking about disability as a political identity in Palestine as something that is often also a product of resisting the occupation. For example, amputations sustained through Palestinian participation in the Great March of Return. The uneven distribution of particular disabilities as a result, not only of Israeli settler-colonialism, of the occupation, but also of resistance to occupation and the way in which disability emerges as a result of that. In the U.S., thinking

about Indigenous peoples who have become permanently disabled from teargas or rubber bullets while protesting pipelines.

The point of which is not that you necessarily need to claim disability as an identity, but recognizing as people invested in disability justice, who we see as disabled and what we're able to recognize as a disability issue. Schalk and Kim (2020) describe this in an article introducing feminist-of-color disability studies, where they write "feminist-of-color disability studies likewise understands disability as a relationship to power rather than a legible identity to which one can lay claim" (p. 38). This idea of disability theorizing and analysis as about relationality—including one's relationship to power on a global scale—to me is more generative and clarifying than thinking of disability solely as an identity to be claimed.

“What possibilities can be re-opened for imagining decolonial disability futurities?”

L. Sheehi: Right—what the purview of disability justice is. I think you were saying that before, too. Both about what types of models, maybe of thinking or engaging this, are we bringing into certain spaces, but also the expansiveness in which we're thinking and engaging, too. I think this links back to where we met, Students for Justice in Palestine (SJP) is talking about disability justice. Borrowing from Robin Kelley's (2018) idea of solidarity not being a market exchange, if the endpoint is liberation, how do we *not* imagine or know that disability justice is a part of the Palestinian struggle, and the Palestinian struggle is part of disability justice?

That feels like a very simple expansion of the purview because we're talking about liberatory processes. The details, are like you're talking about, creating debility or maiming, like Jasbir Puar (2017) has talked about, policies of shooting people in the knees with the explicit intent to debilitate, all the ways in which you debilitate people or create disabilities in order to keep that settler-colonial structure running the way it's meant to. These concrete examples help animate us what we are discussing. I think I offered this example in the SJP talk we did together of the pregnant Palestinian woman whose husband had an ID card under the Israeli apartheid system that would allow *him* to drive through the checkpoint, but she did not, the ID did not extend to her. Their car was stopped on her way to give birth, and because of the apartheid system, codified in IDs, and enshrined within the settler-colonial condition in Palestine, she was made to get out of the car and walk through the checkpoint, rather in the car. If we were to follow the logic of "reasonableness," people might deploy justifications of state and national laws to explain away the raw violence of that moment. But, in terms of the absurdity, the violence, and the regularity with which this happens, it becomes abundantly clear why disability justice is a Palestinian issue and vice versa.

L. Jaffee: I feel like the existence of the State of Israel is also an example of the danger or implications of not thinking of the ways in which liberation movements are inextricably linked. Zionism was one response to antisemitism, which is premised on ableism because part of antisemitism is the narration of the weak Jew, the sickly Jew. The Zionist response is: we need to build our own nation-state around this notion and ideology of a hypermasculine, hyper able-bodied, strong, Jewish identity. And while part of the Israeli-Jewish identity is hyper-ablebodiedness—thinking about Israel's arms industry, military might, and mandatory

conscription, all of which are part of maintaining or entrenching the settler-colonial structure—with Ro'im Rachok, we also see how these logics are adaptive, malleable. In that example, autistic soldiers are now being written as valuable to the extent that their abilities render them useful to the settler-colonial state-making project.

This is the risk when our understandings of freedom or understandings of liberation are not looking at how all of these logics work in tandem; then you end up reproducing the same sorts of violence. As a part of the Jewish diaspora whose ancestors were killed in the Holocaust, the degree to which the state of Israel perpetuates ideologies that in some ways mirror or mimic Nazi logic is horrifying. The logic of elimination and the way in which Palestinian mothers are talked about by Israel's political leaders as a threat to the state. It's replicating these racist, settler logics about population management and elimination. The idea that Indigenous reproduction is dangerous—it's just another iteration of eugenic logic.

This is the risk of thinking about freedom in such a narrow, unimaginative way, to be on top of the hierarchy instead of obliterating the hierarchy.

L. Sheehi: Instead of getting rid of the conditions that would create the hierarchy to begin with. It's a displacement which also erases the conditions that created the extermination, persecution, and displacement of Jewish folks: a pernicious, racist capitalist, ableist process that came into being and as a European invention. It's a European imperialist, capitalist, colonial invention.

I hear you saying that these narrow ideas conscript us to forget. To forget how these systems came to be, to forget that hierarchies are not fixtures, to forget the roots of these conditions and instead see things as symptoms that then need managing.

Going back to this reopened imagination of decolonial disability futures: what would it be like for us to recognize, in every action, in every intervention, in every thought, that the very systems we live in rely on debility and disability? This may be a truism to some of us, but the practice of remaining connected to that truth becomes hard. They rely on debility and disability not only to drain life force and make people alienated individuals disconnected from collective struggles, but to sustain white supremacy, which is based on purity, productivity as it's seen by capitalism, exploitation, domination, and hierarchy that is enshrined in imperialism and settler-colonialism.

For me, decolonial disability futures means divesting from all those systems, which means divesting from all forms of exploitation and domination. This goes back to your point about the danger in using narrow frameworks because they might divest from one form of domination and exploitation, but actually shore up another one. That's what's incumbent upon all of us who are engaged in disability justice as part of a larger liberation movement, to be attuned to all the ways that domination and coercion can show up. You can't cherry pick one for the other and trade off one for the other.

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**Decolonial Disability Futurities From the Global South:
Radical Relational Lessons From Glissant**

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Abstract

This essay explores decolonial disability futurities through the lens of Glissant's notions of creolization and opacity. The author pursues bridging of global South and global North contexts, stressing the need for relational cross-coalitional⁷ approaches for ethics, epistemology and politics meaningful across various intersectional subalternity⁸ categories, e.g., disability, race, gender, caste and class.

Keywords: decolonial disability, agentic intersectionality, relational becoming

⁷ By speaking of cross-coalitional, I not only mean cross-disability collaborations. I am especially interested in collaborations between cross-disability and other forms of activism by oppressed groups, e.g., racialized and gendered minorities, caste and underclass marginalized segments of the population, etc.

⁸ See note #8 below for a discussion on the origins of this expression and its relevance to the present essay.

Decolonial Disability Futurities From the Global South:

Radical Relational Lessons From Glissant

I am a disabled scholar of color born and raised in the Spanish-speaking Caribbean. My own work reflects the features of a disabled of color organic intellectual, to use Gramsci's famous category (Salamini, 2014; Srivastava & Bhattacharya, 2012). Therefore, I deliberately focus throughout the present essay on relational elements which pertain to body/mind issues. These issues are important because they align with what Michael Oliver designated more than three decades ago as disablement (Oliver, 1996). They are intrinsically connected to micro and macro identity trajectories within colonial and neocolonial configurations. These trajectories need careful examination to elevate the intersectional and complexifying explanations within existing and emerging articulations of critical disability studies.

My purpose in this essay is to link intersectional disability and decolonial/inter-imperialist theorizing (see, p. 6 and following in this essay for definitions) from the global South (Padilla, 2021a; Edwards, 2003; Gordon, 1995). Importantly, the expression global South does not circumscribe its meaning to geographical regions placed in the southern hemisphere. Its meaning primarily relates to marginalized knowledges, even if they flourish within global North nations, i.e., United States, Canada, Germany and so forth. By contrast, when I talk of global North or global North contexts throughout the essay, I allude to Euro-American spaces of knowledges which, especially since the 15th century, have controlled the production, distribution and hierarchization of knowledges that matter, at the expense of every other kind of knowledge outside of such prescribed spaces and ways of knowing (see, e.g., Quijano & Wallerstein, 1992). My approach elevates analytical contributions from

Édouard Glissant. Glissant was a late 20th and early 21st century decolonial global South Caribbean thinker/poet who emphasized relational ontologies (see, e.g., Drabinski, 2014, 2019; Glissant, 1989, 1997. See also, Escobar, 2020b). As one of the essay's reviewers aptly points out, Glissant was also for long periods part of the intellectual life of Paris and New York, among other global North, i.e., Euro-American epistemic centers. Since the global North/global South divide is not fundamentally geographical but rather linked to the politics of knowledge marginalization, this feature in Glissant's intellectual trajectory may help elevate the dialogical potential of his perspectives for transcending global South knowledge marginality. At the same time, this may emphasize the power of relational, place-based ways of thinking, feeling and creating as intrinsic to disability-based modes of decoloniality. Some authors regard Glissant as a post-postcolonial or second wave anticolonial thinker (Drabinski, 2019; Prieto, 2010). This differentiates Glissant from other global South postcolonial figures such as Fanon in the French Caribbean, Guevara in Cuba and throughout Latin America, or Senghor and Césaire, in the first wave of anticolonial movements which germinated throughout Africa in the 1950s and 1960s. In Glissant, one finds a much more complexified picture of agency and futurities. He is particularly attentive to political economy dimensions of material relationality. His approach is strongly grounded on a radical poetics of relationality.

My reference to relational ontologies in the previous paragraph alludes to understandings of being and becoming which, almost always situated in spatial politics, engender knowledges and diverse modes of truth-telling from “habits born of the imagination in place” (de Freitas, 2023, p. 200). In this sense, these understandings express poetic ways of

being tied to place and imagination. Among Glissant's many conceptual contributions associated with radical decoloniality, I focus on the concepts of opacity and creolization (which I define below, see, p. 11 and following in this essay). This entails elevating their sentipensante/ pluriversal politics, modes of knowledge creation and distribution along with their imaginative value. The term sentipensante was coined by Orlando Fals Borda (2016) in Colombia. It alludes to knowledge creation and dissemination paradigms which give preeminence to feeling and relationality in the articulation of thought processes. The expression pluriversal politics, on the other hand, was coined by Arturo Escobar (2018, 2020a; see also the introduction for Mignolo, 2021). It stresses the idea of pluriverse as antagonistic to the monolithic idea of universe with its hierarchical, Eurocentric ways of knowing and doing. Instead, it emphasizes multiple forms of knowing which operate relationally, in a political ecology of close interdependence and strict horizontality. As Glissant (1997) puts it: "thought usually amounts to withdrawing into a dimensionless place in which the idea of thought alone persists. But thought in reality spaces itself out into the world. It informs the imaginary of peoples, their varied poetics..." (p. 1).

I use these analytical categories to enrich the exploration of possibilitarian⁹ modes of intersectional disability futurities. I thus aim to bridge global North and global South knowledges and contexts, fostering through this bridging cross-coalitional agency. Here is my core thesis. Recent Eurocentric epistemologies such as those of Heidegger and Nietzsche

⁹ Senese (1991) uses this qualifier to describe critical pedagogy thinkers who, like Giroux (1983, 1988) tend to be under the influence of Paulo Freire and Antonio Gramsci. Instead of mere critique, these thinkers prefer to use transformative approaches to resistance that open up possibilities for the oppressed. These possibilities are unique insofar as they often seem impossible at first glance when one considers structural barriers and power dimensions.

are fundamentally grounded on an imaginative ethos of ruin and disaster (See Miller, 2009; Drabinski, 2019, especially Ch. 2; & Mendieta, 2012). Possibilitarian¹⁰ decoloniality approaches from the global South such as those of Glissant are instead grounded on relational ethics and hope. This is revolutionary. It allows to forge equity-driven intersectional subalternity¹¹ futurities centered on antiracist/anti-ableist and disability justice concerns.

In the next section, I start by tackling decolonial/inter-imperialist theorizing from the global South. I examine it in terms of its relevance for critical disability studies regarding relational ways of being and becoming. Next, I turn to Glissant's analytical contributions. I highlight their intersectional disability justice significance. I do so by approaching being/becoming as well as relational/ experiential knowledge production and distribution through the innovative lenses of decolonial opacity and creolization as sentipensante/pluriversal¹² politics and knowledges (Padilla, 2021b, 2022a, 2022b; Escobar, 2018, 2020a). I then conclude by linking these analytical discussions with the configuration of cross-coalitional, intersectional disability futurities. In so doing, I emphasize the search for

¹⁰ Throughout the essay, I use the adjective possibilitarian to qualify multiple conceptual and action-oriented categories. Apart from possibilitarian decoloniality, I talk of possibilitarian modes of intersectional disability futurities, possibilitarian justice-seeking thirdspaces, neocolonial sociopolitical spaces of possibilitarian futurity, inter-imperialism's hybrid possibilitarian spaces for both hegemony and counter-hegemony, and the possibilitarian contours of creolization and opacity. In every instance, I emphasize the situated emancipation power of possibilitarian modes of agency, especially in terms of cross-coalitional movement building and collective action that learns from the global South even within global North contexts of ableist, racialized or other kinds of intersectional subalternity/oppression.

¹¹ Through this particular expression, I build on the work of J. D. Saldivar (2012). Saldivar is unique in his interrogation of the subaltern, making an explicit connection to the coloniality of power while also emphasizing the location of these categories within postcolonial studies. In his 2012 volume, Saldivar analyzes writings by Jose Marti, Sandra Cisneros, Toni Morrison, Arundhati Roy, and others, addressing issues such as the "unspeakable" in subaltern African American, U.S. Latinx/Chicanx, Cuban, and South Asian literature as well as constructions of subaltern identities. The latter is particularly relevant to my discussions of decolonial and intersectional disability dimensions.

¹² See my previous explanation on their origin and definitions.

practical ways to bridge global South and global North contextual and agency considerations. My aim is to forge the building of alternative movements centered on equity-driven situated modes of emancipation. These are complex and relationally rich alternatives. They, like global North disability justice (Minguz, 2011) endeavors, have the power of placing subaltern/marginalized agents with disabilities and their experiential/ sentipensante articulations and multiple knowledges at the core of new agency dynamics. However, through decoloniality, these alternative endeavors bring disabled global South knowledges into the emancipatory equation. In this sense, I am trying to find ways to turn the tables of changemaking so as to put destiny in the hands of those who until now have been deemed without power or without spaces for decision-making.

Decolonial Disability and Inter-Imperialist Theorizing from the Global South:

Interrogating Critical Disability Studies via Agency

Goodley et al. (2019) formulate a set of questions to assess and shake by means of provocation the state of critical disability studies (CDS). They elevate various crucial considerations which impact the future development of the field. The last two of the questions proposed by these authors read as follows: "what matters or gets said about disability; and how can we attend to disability and ability?" (p. 972). Goodley et al. claim to come into these critical considerations through a reflexive paradigm. This paradigm is said to privilege an understanding of disability framed as politicized and filtered by precarity, crisis and uncertainty (Goodley et al., 2019, p. 972; see also, Jones, 2018). Their provocations are valuable. However, by failing to elevate relational dimensions, particularly as experienced in the global South, they only scratch the surface when it comes to addressing the political

nature of decolonial and intersectional disability matters. Within global South contexts, these matters are so politically grounded and immersed in micro-macro transgressions that they demand for activism and research to blur boundaries to make a difference in terms of justice-seeking endeavors.

Elsewhere, Goodley and his colleagues touch on the links between disability, ableism and empire (Goodley, 2014; Goodley & Lawthom, 2011). A careful survey of CDS makes evident the need to sharpen our understanding of the complex relational, politicized and material precarity roots of ableism, ability and disability in terms of decoloniality and intersectional subalternity (for expanded discussions, see e.g., the essays in Afeworki Abay & Soldatic, forthcoming, 2024). I aim to supplement these ongoing and emerging developments. I thus explore connecting and divergent points regarding decoloniality and inter-imperialism.

Introducing Inter-Imperialism

As used in this essay, inter-imperialism is both cause and product of domination and emancipation elements which interact in complex ways. It thus depends on fluid transmodernities, to use Dussel's (1997, 2008a, 2008b) terminology. Dussel's idea of fluid transmodernities operates within and beyond the limits of colonial and decolonial spaces of modernity. As such, it allows one to understand how, for example, in trans-Latinx and trans-Caribbean intersectional identities, there is a coexistence of African, Asian and uniquely American modes of oppressive marginality, what I call subalternities throughout the essay. These subalternities from the global South subvert the Eurocentric coloniality of power, knowledge and being (Maldonado-Torres, 2007; see also, Mignolo, 2021; Quijano, 2000,

2006; Quijano & Wallerstein, 1992). The concept alludes to the othering power of Eurocentric coloniality. Resting on Levinas, a Jewish survivor of the Holocaust, the coloniality of being was for Maldonado-Torres fundamentally a critique of ontology, namely the metaphysical engagement with being in time, in the manner spelled out by Heidegger (Levinas, 1989). To be sure, ontology became for Levinas “a philosophy of power ... ultimately complicit with violence. Conversely, a new starting point presented itself for him, one that would make sure that philosophy would not lead, be complicit, or provoke blindness¹³ in respect to dehumanization and suffering” (Maldonado-Torres, 2007, p. 241). Therefore, Maldonado-Torres’ coloniality of being is especially important within the purposes of this essay. It helps analyze disability in global South and global North contexts, explaining othering/abjection as expressed through anti-ableist and racialized processes (Padilla, 2021b). These processes are intrinsic to late capitalist modes of existence (Padilla, Forthcoming, 2024). For instance, Maldonado-Torres (2007, p. 253) indicates that for “Fanon, the black is not a being or simply nothingness. The Black is something else. The enigma of blackness appears as the very radical starting point to think about the coloniality of Being.”

Likewise, disabled Latinx and Caribbean folks (many of whom self-identify as Black or afro-descendant) represent radical beings who subvert the coloniality of being. They

¹³ The use of the word blindness by Maldonado-Torres in this quote has ableist connotations. It is consistent with what blind scholars such as David Bolt (2014), among other CDS authors have criticized as ocularcentric, that is, a tendency to equate blindness with one’s inability to know or to have consciousness. Nonetheless, in this passage, the meaning of the word attempts to counteract philosophy’s colonial tendency to desensitize folks from the dehumanizing hierarchization of suffering. This is something that gets enabled through the othering power of Eurocentrism. Borrowing from Levinas’ concerns as a Jew, Maldonado-Torres is warning all of us about the danger of remaining oblivious to such othering dehumanization as a respectable approach to knowledge and knowing.

embody possibilitarian, justice-seeking thirdspaces (Waitoller and Annamma 2017; Soja 1989, 1996). Soja (1989) developed the term thirdspace to disrupt the binary between spaces of existence and spaces of non-existence. In this sense, thirdspaces are possibilitarian, hopeful ways of creating new futurities. They can emerge precisely where spaces of non-existence and annihilation were once prevalent. Subaltern thirdspaces are made up of waves and wakes of converging diasporas. They are dynamically constituted in Latin America and the Caribbean by what Robert Young (2001) calls tri-continentalism (alluding to Africa, Asia and Latin America as neocolonial sociopolitical spaces of possibilitarian futurity). Often, no doubt, these diasporic waves and wakes are filled with mixtures of extreme violence and pockets of hope. Nonetheless, insofar as they embody decolonial alterity through spaces of non-Eurocentrism, they are constantly becoming and discovering complex modes of relational interdependence. In other words, they are the very making and unmaking of continuous birth and rebirth against the wakes of suffering which have plagued these global South contexts with their unique knowledges. Their colonial suppression was not able to extinguish the vitality and generative creativity of these knowledges. They work through their fluid transmodern (Dussel, 1997, 2008a, 2008b) ways of being and becoming. They operate in their transformational emancipatory power through constant real and symbolic border-crossings.

In addition, the powerful knowledges of Blackness and negritude dynamics make possible to start understanding inter-imperialist legacies and complexities. This is because coloniality makes up LatDisCrit's¹⁴ and disabled trans-Caribbean contemporary modes of

¹⁴ This term alludes simultaneously to Latinx disability and critical race readings and experiences (see Padilla, 2021a, 2021b, forthcoming, 2024).

being and becoming. Their decolonial sense of collective action unfolds, for example, in global North and global South pedagogical experiences (Dei, 2017; Dei & Hilowle, 2018; Dei & McDermott, 2014). For example, U.S. global North classrooms, especially in urban areas, are being reshaped by the relational presence of Black Latinx and Black Caribbean students with and without disabilities. At the same time, one must remember that neo-colonial forces are still at work. For instance, in trans-Latinx embodiments of indigeneity and mestizaje, one finds vestiges of anti-Black and ableist sentiments. They often proliferate as micro-political and sociocultural oppression coming from teachers and White students (Padilla, 2021a, ch. 6; see also, Gudmundson & Wolfe, 2010).

In the tri-continental making of trans-Latinx and Caribbean experiences of disablement, there are pervasive macro-political forces as well. For example, their configuration of coloniality translates at the micro level through internalized racism. This manifests as deficit thinking and learned helplessness for most subaltern Latinx of color with disabilities, their families or guardians, and even for many of their self-proclaimed advocates. Within global North contexts, it is quite common for anti-Black sentiment to drive intra-Latinx interactions among communities and white dominated disabled people organizations in these racialized settings (Padilla, 2021a, especially chs. 6 and 8). Furthermore, in many global South contexts disabled people are subject to various forms of institutionalization or street-bound existences (Ferrante & Joly, 2017) and this gets justified as natural.

As a disabled Latinx engaged scholar, I am highly influenced by decoloniality thinkers from Latin America (Padilla, 2021a, 2021b; forthcoming, 2024). One of their grounding premises is that one needs to distinguish between coloniality and

colonization/colonialism. They do so on the basis of Quijano's (1992) ideas on the coloniality of power. Quijano's coloniality of power underscores much more than colonization as the root of today's imperialist order. Quijano highlights a tripartite conflation of components emerging from colonization, modernity and Eurocentrism. All of these components work together in a complexified fashion. They always operate within an extractivist model of production and reproduction. Although going back to the 15th century, this model has reinvented itself with each imperialist venture of the British, French, and all the rest of European and Euro-American superpowers. All of these inter-imperialist forces and systemic relations have engaged in multifaceted yet intrinsically congruent and mutually edifying ventures. They build upon ecclesial and secular doctrinal principles (Mignolo, 2021, Preface). Likewise, they build on Eurocentric knowledge assumptions that perpetuate white supremacy, ableist, gendered and class and caste-based modes of oppression (Padilla, 2022a; Grosfoguel, 2006).

Exploring Glissant's Contributions: Toward a Decolonial Disability Approach to Intersectional Subalternity Theorizing

Many scholars and even activists explore disability issues without any sense of place-based contours and in a de-historicized manner (for recent exceptions, see, e.g., the essays in Mintz & Fraser, 2024). Furthermore, this happens in an individualistic and non-relational fashion. I thus open this section with the following quote from Drabinski. It demonstrates the revolutionary nature of relationally grounded and place-based decolonial approaches such as Glissant's philosophy as applied to global South and global North intersectional experiences of disability:

What does it mean to think geographically? That is, what does it mean to locate thinking in a place, which is at once space and time, rather than outside our location? Historical experience ought to be our first leading clue. The question of geographic thinking is not mine, but native, as it were, to the question of language and home. No matter the shattering effect of transcendence, we all come from somewhere in our words, the words of the Other, and the dismantling effect enacted in the encounter between those words. (2014, p. 247)

The question of thinking geographically takes us directly into Glissant's formulations. It opens the door to a decolonial destination. This also interrogates place-based disabled experiences, particularly as tied to political economy notions such as productivity (Hartblay, 2014) which determine who is deemed as disposable and why across global North and global South contexts. Policy actors in these contexts deem the disabled as non-productive from capitalist and extractivist standpoints, especially as notions such as productivity are placed at the center of policy concerns in capitalist and post-socialist societies (see, e.g., Blayney et al., 2022; Hartblay, 2014).

Due to space limitations, I can only provide a very preliminary and illustrative reading of Glissant. My conceptual framings are hence quite circumscribed. The exercise nonetheless highlights the Eurocentric connotations of universalizing the thought of authors whose post-metaphysical quests were also born geographically but which are framed as eternal and all-encompassing.

The worthiness of being lies in its specific temporal-historical force of nihilation, which enables possibilities and opens being as the ongoing and future unfolding nexus of

relations, to human others, things, and animals, and thus to the ceaselessly reenacted world...

The dignity of being is the singular possibility of the freedom of its event, its release from the historically determining metaphysical frameworks, that is, its “freedom” from power.

(Drabinski, 2014, p. 241)

In other words, there is decolonial force in the eventfulness of events. Their relational becoming accentuates this (Raffoul, 2020) by humanizing our geographical grounding in feeling and thinking. Our relational becoming gives poetic, that is, *sentipensante* (see, page 3 for the origins and definition of this term) fluidity to our place-based disability knowledges in global South and global North contexts alike (Fals Borda, 2016). As such, it liberates us from the historical powers which have so far imposed their oppressive grip on our thinking, self-identity, our views on ethics and politics as well as our sense of hope/futurity.

Decolonial Disability as Creolization and Opacity

In terms of its power to liberate, opacity means not throwing away our complex relational engagement with a suffering past while we build anti-ableist, antiracist and decolonial futures. The Atlantic slave trade, for instance, is for Glissant intrinsic to the poetics of whatever emancipation future one forges within Caribbean contexts. I emphasize the poetic nature of Glissant’s thinking/feeling because it breaks at once with rationalistic and non-relational modes of thinking or collective emancipation pursuits (Glissant, 1997). In fact, many of Glissant’s insights are expressed through poems. The opposite to opacity in Glissant’s poetic feeling/thinking is transparency, i.e., linear non-relationality. Transparency not only means non-relational, linear ways of understanding reality. It also includes complex yet individualistic and exploitative realities of colonizing oppression through the over-

simplification of inter-imperialistic dynamics. Glissant's idea of opacity is thus closely tied to his conception of creolization. For him, creolization is not mere mixture, as in *mestizaje*. It is a complex coexistence where difference remains relationally intact. In turn, creolization also becomes crucial to understand the complex enactments of inter-imperialism in “postcolonial”¹⁵ spaces such as those of the Caribbean and Latin America. This certainly includes the Latinx geographical territories which are now absorbed into the geopolitical confines of the U.S. (e.g., New Mexico, California, Texas, Florida, etc.) which were taken by force from Mexico in the 19th century (López, 2006; Minich, 2014; Nieto-Phillips, 2004).

In terms of opacity and creolization, inter-imperialism's role is to bridge micro and macro dimensions of resistance against colonialities of power, knowledge and being (Maldonado-Torres, 2007). The global South/global North divide is thus powerfully articulated through the ambiguous political economy and identity contours of inter-imperialism. Inter-imperialism plays out in power and knowledge dimensions. It is present in both sides of the transnational divide between global North and global South environments. These environments are fully infused in their emancipatory synergy. Inter-imperialism's hybrid spaces for both hegemony and counter-hegemony¹⁶ make this possible.

¹⁵ Decolonial thinkers such as Mignolo (2021), Quijano (1992) and Segato (2022) object to the term postcolonial to describe these contexts. They point out that (1) the formal achievement of independence among some Latin American and some Caribbean nation states (Puerto Rico being a notable exception in the region) colonialism ended but global relations of coloniality became even stronger; and (2) decolonial intersectionality dynamics must transcend the nation state, involving cross-coalitional movements which operate at the level which Mignolo calls political society (citing the work of Chatterjee, 2011).

¹⁶ Antonio Gramsci coined these terms. “Hegemony ... ‘describes the practices by which some greater uniformity is sought’” (Backer, 2023, n.p.) between what Marx calls structure and superstructure, namely, economic relations of production and the rest of societal, cultural and political components within capitalism. Counterhegemony in turn opens up emancipation avenues. It emphasizes the fact

In the Caribbean, for instance, this dual tendency between hegemony and counter-hegemony manifests through the linguistic configuration of Creole language. Creole exists within a subversive mingling of old imperial languages (Portuguese, Spanish, French, English, and Dutch) combined with African vestiges. Creole expresses the freedom of the oppressed to counteract the canons of orthodoxy and aesthetics imposed by empires. It also expresses a sense of trans-geographical mobility. This in turn transgresses the imposed limits of imperial place-based hegemony. Of course, it is not simply that speaking Creole provides a magic pathway to emancipation.

In the kinds of non-European and anti-rationalistic modes of reality construction afforded by Creole there are potential basis for opening innovative emancipatory resistance avenues through alternative ways of being and knowing. The enactment of these emancipatory forces depends on two simultaneous tendencies: (1) a sustaining articulation gap; and (2) a crucial, often non-linear movement toward rupture with the vestiges of inter-imperialist oppressions, very much in line with what Glissant calls opacity.

The metaphor that Stewart Hall (1996) uses for representing this complex functional duality of inter-imperialism's opacity is that of an articulation. As in the body, articulations unite and divide. They at once bridge and demarcate. Their real force resides in not being as rigid as bones, in bridging, in not being core. Thus, they are especially vulnerable to ruptures and to the creative coordination of further subversive links and spheres of mobilization. The notion of articulation is crucial because it combines the structural and the discursive

that the relations between structure and superstructure are characterized by "massive disjunctions and unevenness" (ibid. See also, Johnson, 2018, p. 71).

possibilities of these disruptions. It also has an important flip side: societies organized around dominance are also the ground of cultural resistance” (Edwards, 2003: 12).

In the sociopolitical, sociocultural and socio-historical contexts of LatDisCrit’s¹⁷ and trans-Caribbean modes of inter-imperialism, these dual forces are at once generative and generated by inter-imperial immediacy and exchange. For instance, large Latinx enclaves are in the borders of the imperial realities imposed by the U.S. This is true even if they do not reside within the limits of the American state of the union. Yet, at the same time, the vestiges of many other empires are intrinsic to their Latinx and Caribbean identities and to their sociopolitical embodiments of creolization and opacity (Castro-Gómez, 2005, 2007, 2008, 2011; Padilla, 2021a, 2022a).

Inter-imperial proximity, continuity, and discontinuity exacerbate what Edwards (2003) calls a “*décalage*” dimension of Diaspora. This refers to the residues of untranslatable discourse. It also involves cultural, institutional, peoplehood/nationhood and structural perception differences. These coexisting relational differences are such that they open the door to the uncertainty of concrete, context-based change articulation among various imperial actors. For this reason, Glissant stresses that creolization is not the same as static modes of *mestizaje*:

Rather, and this is Glissant’s final and most emphatic concept, the Caribbean is simultaneously local—hemispheric, specifically historical, particular in its memories—and global—the crossroads of the world, from the beginning. That is, Caribbeanness is *tout-monde*, not as an aesthetic or ethical idea or ideal, but as a

¹⁷ See previous note #8 for a definition of this term.

direct description of the material histories and memories of the archipelago... The shoreline of the Caribbean. Landscape of pain, landscape of beauty. Black salt.

(Drabinski, 2019, n.p.)

Creolization is for Glissant intrinsic to this complex geographical and poetic specificity. It cannot be separated from Caribbeanness. It is tied to Glissant's foundational ethics, politics and epistemology of the archipelago. The archipelago is for him a relational way of being and becoming which paradoxically departs from the ashes and ruins of inter-imperialist devastation and oppression. "Thinking in ruins, which is productive rather than (solely) melancholic, is already thinking the archipelago as a geography of the globe and the geography of thought. The archipelago is already the crossroads of the world, so the Caribbean of Caribbeanness is already tout-monde in memory, history, and experience, if not word and concept" (Drabinski, 2019).

Thus, the difference between creolization and mestizaje in Glissant's relational thinking/feeling consists of doing away with the comparative and hierarchical components of mere mixture. In mestizaje, the process of wanting to know leads to Eurocentrism which almost always gets the upper hand. This leads to a perpetually cautious sense of measure and reciprocal reproach.

Meanwhile, in place of "measure, creolization puts excess. Glissant's relation to White Western philosophers, and indeed philosophy more broadly, is precisely that: the movement from measure to excess, a writerly embodiment of what he comes to call the thought of tout-monde. Excessive thought, excessive relation and Relation, is not threatened by its Other, even the colonial Other (Drabinski, 2019; see also, Az rardt, 2012). To be sure,

Glissant calls us to think like an archipelago, not just frame thought as an archipelago.

Relation is therefore dynamic, productive, dangerous, and alive with fecund engagement and appropriation (Drabinski, 2019).

Implications of Creolization and Opacity for Decolonial Disability Futurities

All of this may feel too abstract. However, it may help to switch the lens by thinking specifically of oppressive archipelagos which harm disabled people in both global North and global South contexts. Think for instance of the institutional or the carceral archipelagos that are indeed layers within the same colonial archipelago, harming in a cross-sectional way disabled, Indigenous and many other racialized, gendered and underclass communities (Stele, 2020). How can we proactively resist these colonial archipelagos? First of all, we must realize as activists that by becoming a thinking archipelago, we also become relational, that is, beings complexified, full of paradox and opacity features (Wiedorn, 2017). Disabled people, along with racialized, gendered, queer and other subaltern communities share the intersectional label of problematic people (Gordon, 2020). They embody the chaotic amalgam of what in the global North has been designated as the underclass (Wacquant, 2022). The disabled underclass is thus mingled with an expansive multitude of disposable, marginalized segments of society in global North as well as global South contexts (Goodley et al., 2019; Grech, 2017).

Nevertheless, the power of the ambiguous nature of opacity toward a creative imagination centered on relational ways of knowing is crucial. It breaks the chains of despair for those subaltern collectivities imprisoned within the certainties of intersectional oppression. Furthermore, opacity in tandem with creolization enact radical decoloniality

through the contours of inter-imperialist epistemic encounters. To bring the discussion even closer to issues specifically tied to decolonial disability, it is helpful to examine here Sami Schalk's (2016) critique of the blanket use of the term *supercrip* in critical disability studies which, as will be seen, does not seem to take into account the realities faced by disabled folks in global South contexts, presuming them as invisible categories for all intents and purposes. There is a positive dimension in this critique since Schalk's aim is to bring radical complexity, that is a form of opacity into this representational debate. Thus, in this sense, Schalk elevates dimensions of agency and creativity. Schalk stresses that one needs to give disabled groups the power as an audience to forge their own futurities in critical interaction with the strategic modes of emotionality derived from representations of who they are and who they should aspire to become like in the future (Schalk, 2016, p. 76).

Schalk's critique involves several layers linked to three main dimensions: narrative mechanisms, typology, and representational context. First, the focus on narrative mechanisms entails understanding that the *supercrip* is not a character but rather a narrative which creates a stereotype. It is not something static. Its core triggering representational components are: (1) the use of superlative language; (2) close analysis of body/mind/behaviors through scientific lens; (3) constant comparison to an abstract nondisabled norm; (4) suppression or masking of negative emotions, e.g., stress, anger or depression tendencies; and (5) emphasis on personal, individualized attributes such as willpower and determination (Schalk, 2016, pp. 76-77). The first three triggering mechanisms come from Silva and Howe's (2012) research on Paralympians as *supercrips*, while the latter two come from Catherine Scott's (2006) analysis of Christopher Reeve's memoir, a clear case where White privilege and celebrity

status conflates with the perceived success of their undertakings. Hence, Kafer (2013) is right to point out the intentional depoliticization of disability when it comes to supercrip representations.

Schalk, following Kama (2004) distinguishes between supercrip designations applied to disabled people who are presented as extraordinary for doing something ordinary versus representations of disabled people who are presented as extraordinary for doing something exceptional or rare. This distinction is important to understand the contours of regular versus glorified supercrip representations as well as dimensions tied to the reception of these representations by disabled audiences of various kinds.

I found Schalk's discussion interesting yet insufficient when it came to examples specifically able to speak to disabled audiences in global South contexts. It was almost as if supercrip typologies apply exclusively to global North standards of success. Perhaps, in terms of decolonial disability, it might be helpful to bring in Glissant's opacity, examining the supercrip construct along with a poetics of the disabled underclass in a relational interdependence with the contours of the representational debate as it is addressed by and within disabled global North contexts. What about the link between this representational debate and issues of disability justice? How can the discussion become genuinely relevant to both global South and global North audiences of disabled categories of individuals and groups? Failing to do so means that we might simply engage in a recolonizing process for representational spaces where only successful white disabled individuals residing in the global North or genres developed for their exclusive consumption are worth tackling in analytical exercises.

Concluding Remarks: Engaging Creolization and Opacity in Place-Based Decolonial Disability Futurities

All countries in Latin America and the Caribbean have ratified the UN Convention on the Rights of Persons with Disabilities (CRPD). Despite this, thousands of disabled individuals are condemned to mendicity and other extreme modes of material precarity (Ferrante & Joly, 2017; Grech, 2015; Meyers, 2019). Glissant's relational poetics demonstrates that in these places of diaspora and emerging spaces of hope, the dichotomy between what Kama (2004) calls supercrip versus "pitiful handicap" is not at all binary. It is a rich plethora of relational possibilities. As such it contains potential for resistance and transformational synergy.

The preliminary conceptual explorations of intersectional disabled decolonialities I presented in this essay are conceived as an invitation. I hope they propel further critical research of the possibilitarian contours of creolization and opacity as sentipensante ways of knowing and enacting change. The aim is to elevate relational freedom and sociopolitical interrogations of the poetics of place as far as disability is concerned. Furthermore, I hope that they stimulate intellectual and strategic curiosity into the prospects or cross-coalitional futurities of disability justice. This should be approached in tandem with other spaces of intersectional subalternity (see, e.g., Ben-Moshe, 2020) in ways that bridge global North and global South place-based emancipation. My invitational vision involves respecting place-based ethics and ways of knowing/acting. In turn, this would mean refining decolonial disability and agentic intersectionality while opening imaginative avenues for transgressing

political clichés as they have been so far dictated by Eurocentric, transparency-based (in the sense of antagonistic to opacity and creolization) non-relationality.

How and to what extent can these imaginative approaches help reshape current anti-ableist and antiracist modes of anti-capitalism in global South and global North contexts? How much of these emerging innovative assemblages of decolonial disability will help expose the coloniality of power, knowledge and being? How will they help put intersectional decoloniality concerns at the center of disability justice endeavors in alignment with those of other subaltern segments of the population? Only time will tell. For now, I just hope that Glissant's work can be noticed and carefully analyzed by disabled critical disability students/researchers/activists and other interdisciplinary actors toward radical transformational aims.

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**Transnational Global South Informed DisCrit in Teacher Preparation:
Boundary-Crossing Between Disability Studies and Communication Sciences**

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Author Note

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Abstract

This paper explores how global South informed DisCrit (GSI-DisCrit) can serve as an analytic tool and praxis within teacher preparation programs in higher education. Using methods of self-study, the co-authors exemplify how teacher preparation institutions may create inclusive education access through interdisciplinary boundaries-crossing and objects when preparing pre-service teacher candidates for inclusive classrooms.

Keywords: DisCrit, global South, disability studies, teacher preparation

Transnational Global South Informed DisCrit in Teacher Preparation: Boundary-Crossing Between Disability Studies and Communication Sciences

Students of color are and have been disproportionately represented in segregated special education classrooms (Artiles, 2011, 2013). Approximately 85 percent of U.S. public school teachers are White females while 40 percent of their students belong to racial and ethnic minorities (Ferri & Connor, 2005). Teachers recommending students of color, especially Black students, for special education are mostly White female teachers who have never been identified with a disability themselves (Perouse-Harvey, 2022). In addition, the entanglements with language, immigration status, and disability are another system-wide problem that requires systemic-change efforts and teacher positive responses (Artiles et al., 2005). This student-teacher cultural and racial mismatch may result in interpersonal misunderstandings leading to special education referrals (Santamaría Graff et al., 2020). This is especially critical with more special education teachers leaving the field every year and being replaced by novice teachers, where these new coming teachers feel less prepared to teach in diverse inclusive classrooms (Edgar & Pair, 2005).

Teacher preparation programs in special education attempt to prepare pre-service teachers for the complexities of the profession (Santamaría Graff et al., 2020). Yet, preparing teacher candidates for increasingly diverse inclusive classrooms remains an area that needs reimagining the educational structures, practices, and priorities (Stolz, 2021). Since the special education eligibility process typically begins with teacher referral, teacher education scholarship is increasingly calling for (a) engaging the silenced histories of people and

students of color in teacher education and (b) global dis/ability frameworks and intersectional analyses within the teacher preparation programs (Rodriguez-Mojica, et al., 2020).

This is especially significant in today's growing immigration from the global South (Peguero, 2009) and the demographic imperative. In the current U.S. education system, the demographic imperative is understood as a system-wide problem related to: (a) increasing immigrant and refugee student population in U.S. public schools, (b) the differences between these students and their white middle class teachers' backgrounds and lived experiences, and (c) the educational debt between diverse students' and their peers' educational outcomes (García et al., 2009; Ladson-Billings, 2006).

This is not to undermine the fact that most immigrant children experience cultural and social challenges in their country of resettlement (Jhagroo, 2011). Some of these challenges may include making local friends, becoming familiarized with new school culture and society, and acquiring new language skills (Mthethwa-Sommers & Kisiara, 2015). These social and cultural challenges may cause barriers to learning experiences. However, the role of teachers is paramount for students in this transition phase, which requires educators' understanding and unpacking of personal biases and assumptions toward students migrating from global South countries. The purpose of this article is to engage in such transnational disability justice (Berne et al., 2018; Invalid, 2016) analyses and exemplify how the authors engaged a global South¹⁸ informed Disability Critical Race Studies (DisCrit) (GIS-DisCrit) with their pre-service senior year students at a public university. The goal here is to create

¹⁸ We understand Global South is a contested term which connotes not only geographical locations (referring to the 32 countries below the equator) but is also historically grounded in the colonial era and to the cultural, political and economic power relations between the metropole and the peripheries. We further acknowledge that there is a Global North in the Global South and vice versa and that the Global South is non-monolithic.

inclusive education access for students of color migrating from global South countries, by supporting future teachers through boundary crossing and object creation at the boundaries between traditional special education and Disability Studies in Education (DSE). As a result of this framework, we entered into *critical boundary crossing and object and artifact praxis* with self and each other relative to the curriculum, assessment, instruction, and pedagogy we co-created alongside our pre-service teachers that centered a GSI-DisCrit framework.

According to Akkerman and Bakker (2011) “boundary crossing usually refers to a person’s transitions and interactions across different sites, [and] boundary objects [are the] . . . artifacts doing the crossing by fulfilling a bridging function,” and hence serving a collaborating function (p. 133). By boundary-crossing and objects, we center the importance of interdisciplinary special and inclusive education teacher voice and practice (i.e., objects) regarding the needs of diverse learners such as emergent bilinguals with and without disabilities at the system-level boundaries between the master narratives of disabilities encoded in the Individuals with Disabilities Education Act of 2004 (IDEA) (Hernández-Saca, 2017) and the discursive, emotive and material realities of diverse students such as immigrant and refugee students with and without disabilities in education (Voulgarides et al., 2023). According to Kerosuo and Engeström (2003) “while the focus of implementation is the tool-creation [e.g., boundary object] for collaboration in the interorganizational context, boundary crossings between providers from different organizations are a precondition for the study of learning and development” *despite* sociocultural differences (p. 346). However, we underscore the importance of honoring and radically loving those sociocultural differences, emphasized in our course tenets (See Table 1 for a list of all the course tenets), which were

developed in our co-teaching of the course that we share as an example of enacting a GIS-DisCrit in special education. Specifically, in this article, we ask:

In what ways can teacher preparation institutions create inclusive education access through interdisciplinary boundaries-crossing and objects when preparing pre-service teacher candidates for inclusive classrooms?

Within this article, we share boundary crossing and object creation that we co-created regarding a collaboration between our Department of Special Education with a faculty member from the Department of Communication Sciences and Disorders. We included our pre-service teachers within our minor in special education course, *special education law, assistive technology, and advocacy*, and our colleague's Assistive Technology (AT) and Augmentative Alternative Communication (AAC) artifacts. We centered the value of interdisciplinary collaborative special and inclusive education work and the spirit that both general and special educators can serve all children such as emergent bilinguals with disabilities by collaborating with speech and language pathologists through Critical GSI-DisCrit Continuum Pedagogy for Classroom Engagement (Iqtadar et al., 2021).

Theoretical and Conceptual Foundations

We situate this study in the interdisciplinary and intersectional field of Disability Studies in Education (DSE) (Annamma et al., 2013; Connor et al., 2011). The scholars within the Critical Disability Studies (CDS) community have argued for a global South theoretical and analytic engagement in the field (Goodley et al., 2019; Nguyen, 2018). Building on the work of DisCrit scholars (Annamma et al., 2013), we situate a global South informed DisCrit

(GSI-DisCrit) framework to exemplify how we engaged a transnational approach¹⁹ to disability studies in one senior year course titled: *SPED 4150/SPED 5150 Introduction to Special Education: Legal, Advocacy, and Assistive Technology Practices and Issues* at a predominantly White public university in the Midwest.

DisCrit is an emerging and dynamic interdisciplinary theoretical framework simultaneously engaging the fields of Disability Studies (DS) and Critical Race Theory (CRT); both originated in and retain an indiscriminate attention to the voices and disability experience of global North academics and activists (Grech, 2015). While 80 percent of world disability is created in global South countries, Southern perspectives have mostly been marginalized and/or oversimplified as a monolithic experience of disability within the field of DS (Ghai, 2006; Meekosha, 2011; Meekosha & Shuttleworth, 2009; Munsaka & Charnley, 2013). This leads to an “academic neo-imperialism” (Grech, 2015) embedded within the coloniality of power where the Western and imperial knowledge is considered “the knowledge” and the Southern epistemologies and Southern theory has mostly remained absent, privileging global North theory and experiences (Nguyen, 2018). Arguing about such power relations between global North and global South, Ghai (2012) suggested that

. . . structural and historical obstacles should be identified and be able to suggest practical arrangements that enable both parties to move away from the typical roles of the Global North as a ‘giver’ and the Global South as a ‘receiver’ . . . To be genuinely cooperative, Dufour (2006) emphasises that it is essential that the research questions subsequently posed should equally address the theoretical and applied interests of both partners. Dufour further asserts that both sites should recognise the potential

¹⁹ In the context of this paper, transnationalism represents going beyond nation states and national boundaries and understanding ways in which the Global South is not always the ‘receiver’ of knowledge, and the Global North is the ‘giver’. Instead, the role is bidirectional and beneficial for both. This way our use of the term signifies how learning from the decolonial perspective benefited our students situated in the U.S. to better comprehend global disability politics and feel prepared to support their future students from diverse national backgrounds.

significance of the findings to their respective national settings and to their indigenous knowledge theory building. (p. 262)

Ghai (2012) challenges the “overbearing and sweeping” (p. 273) theories from the global North that are appropriated in the global South without the historical, colonial, and cultural understanding of the South as well as the disability experience in relation to the local practices. Similarly, according to de Sousa Santos (2015, 2018), “cognitive injustice” poses a significant threat to global social justice. This injustice stems from a failure to acknowledge the diverse ways of understanding, wisdom, and existence found among people worldwide, particularly those in the global South. The dominance of Western epistemology, and consequently the global North, perpetuates this imbalance by marginalizing non-Western perspectives.

Aligned with Ghai (2012) and de Sousa Santos (2015), in this paper, we exemplify how we employed a global South informed DisCrit (GSI-DisCrit) to engage DisCrit to a global intersectional disability politics within our course tenets. GSI-DisCrit proposes to engage the systems of oppression in the global South that are most directly impacted by the policies of Eurocentric ideals and affect the everyday life of disabled people with marginalized identities in the countries of the global South (Iqtadar et al., 2021). In other words, GSI-DisCrit contests the Western-based and North American versions of disability politics and recognizes and advocates for the voices and experiences of the subaltern population with disabilities as well as the frameworks and knowledge produced in Southern spaces (de Sousa Santos, 2015, 2018; Chataika, 2018; Goodley et al., 2019; Grech, 2015; Grech & Soldatic, 2016). One such example is to critically investigate the legal influence of U.S. civil rights discourses and educational laws, including the Americans with Disabilities

Act (ADA) and the IDEA, which is approximated by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in global South countries (Iqtadar et al., 2021). We used the following points from the GSI-DisCrit work (Table 1) within our course tenets to help the preservice teachers unpack how nativist²⁰ racism and ableism work interdependently to marginalize newcomer students of color from global South with and without disabilities (See Table 1).

Self-Study at the Boundaries of Disability Studies and Communication Sciences and Disorders

Self-Study in Teacher Education. We employed critical self-study in teacher education (Anderson, 2006; Kosnik et al., 2006) to narrate and analyze our pedagogical practices about the institutional practices, and to present our use of GSI-DisCrit framework within classroom ecology. According to Fraser (1985) “no one has yet improved on Marx’s 1843 definition of Critical Theory as ‘the self-clarification of the struggles and wishes of the age’” (p. 97). We, in turn, adopt this definition as what we mean by *critical* in our critical self-study in teacher education as a way of co-facilitating the self-clarification processes of creating inclusive education access skills, knowledge, and dispositions through a GSI-DiCrit approach. Self-study in higher education research refers to educators researching their teaching practices with an attempt to improve, explicitly narrate their pedagogical expertise, and to contribute to the methodological base of teacher preparation programs (Vanassche & Kelchtermans, 2015). As scholars of color from global South and global North, we came together to reflect, analyze, and co-teach from the lens of GSI-DisCrit, with the hope of

²⁰ The assigning of values to real or imagined differences to justify superiority and dominance of the native White over non-native people and refugees of color (Huber et al., 2008).

identifying how our future teachers can understand and mitigate the challenges that first-generation immigrant and refugee students from global South experience in the U.S. public schools. We also used self-study to help us maintain intensive self-reflection to understand how our normative beliefs and biases remain hidden if not reflected upon, and how we can support each other to identify some of these hidden assumptions by becoming critical friends in the process. Given our research design that centers on introspection and analytical self-reflectivity about *what, how, and why* we engaged in such knowledge claims about the boundary crossing and objects, we choose to not pursue an Institutional Review Board (IRB) at this point.

Researcher Positionality. We engaged in the work of teacher preparation and the co-construction of inclusive education access through an interdisciplinary boundaries-crossing and objects for preparing pre-service teacher candidates for inclusive classrooms by being mindful of our personal, professional, and programmatic researcher and teacher education identities. We situate such work as part of ethics and trustworthiness (Brandenburg & McDonough, 2019) given the boundary work relative to the technical, contextual, and critical components of praxis between traditional special education and DSE. In turn, we operationalized researcher positionality through the researcher self along all of the dimensions of not only the research processes and elements but also regarding the boundary crossing and creation of tools such as the ones presented below and our collaboration with Dr. Jackson²¹. We align such a positionality operationalization with Boveda and Annamma (2023) to challenge the fields of special education and DSE by going beyond a statement in

²¹ Pseudonym used.

the ethical and paradigmatic work of theory, research, policy, and praxis as it relates to one's positionality. For example, above we positioned ourselves as scholars of color from global South and global North, but here we further articulate our positionality, which was central to all our knowledge production, before, during, and after writing this piece.

Shehreen. Within the U.S. education system, I am a South Asian Muslim female scholar of color. Living as a first-generation immigrant woman of color from the global South has shaped and informed my identity in multiple ways. I am specifically sensitive to the issues of segregated education systems for first-generation students, including immigrants and refugee students from global South, teacher education inclusive practices, as well as the neoliberal educational agendas imported from the global North to the countries of global South without nuanced understanding of local contexts or engagement with students with disabilities and their families. I understand that global South is non-monolithic and understand my privileges as a western-based non-disabled educator and academic of color. For this purpose, I build my teacher preparation courses from an interdisciplinary lens of critical pedagogy in disability studies and culturally sustaining pedagogy. Through this self-study, I engaged and continue to engage with the system of higher education as a global South educator of color who has experienced multiple global cultures academically and socially, and has lived as “majority” and “minority” in many contexts throughout life.

David. I am a dis/Abled scholar of color who experienced self-contained settings in special education from K-5 grade and increasingly was mainstreamed in the regular education classroom. Over the last 15 years, I have grappled with the meaning of being labeled with an auditory learning disability, the shame and stigma of being in special education, and how it

impacted my sense of self. I became a teacher educator because I wanted to change the deficit thinking and language associated with special education segregation and labeling practices and policies. Given these personal experiences with the field, and how they have shaped the questions I ask and the research agendas I pursue and the *what, how, and why* relative to the research questions I co-construct with colleagues like Shehreen. In other words, my personal life is related to my professional and programmatic selves and how in turn I engaged with the multiple research processes, and teaching processes with and alongside Shehreen, our colleague from Communication Sciences and Disorders, and our pre-service special and inclusive education teachers. Lastly, in my collaboration with Shehreen, our lens of our immigrant and refugee experiences shaped our conversations in being intentional in the *what, how, whom, and why* relative to a GSI-DisCrit justice praxis at the boundaries and how we wanted to orient our pre-service teachers to their teacher work and voice.

Data Collection and Analysis

Our data for this self-study stems from co-teaching a course over one year (i.e., 2020). We used five key features of critical analytic autoethnography for data collection and analysis. These key features include (1) analytic reflexivity, (2) narrative visibility of the researcher's self, (3) dialogue with informants beyond the self, (4) member researcher status, and (5) commitment to theoretical analysis (Anderson, 2006). We further operationalized these key features through our above definition of *critical*. We maintained analytic reflexivity through after-classroom discussions and kept separate reflective journals to reflect on our co-teaching methodologies. Maintaining reflective journal entries was an important feature considering our differing intersectional positionalities regarding race, dis/ability, gender, culture, and language(s). We discussed these entries during our after-class meetings. Data

collection also included reconceptualizing the course by creating and/or modifying the course artifacts (such as creating assignments, incorporating the Assistive Technology (AT) and Augmentative and Alternative Communication (AAC) lab visit, embedding case studies within course materials and the course tenets, and (re)conceptualizing the course from GSI-DisCrit approach through the creation of the course tenets), our discussions with students and each other as critical friends (Schuck & Russel, 2005), as well as our theoretical commitments to the field of DS. We entered into criticality through our dialogue (Freire, 1970) by a) engaging and activating our personal, professional, and programmatic selves as teacher educators and b) critically reflecting on what we each shared that was going on for us in our hearts and minds. Such a process we later came to describe as co-mentorship. (This has also been documented elsewhere. See Iqtadar & Hernandez-Saca, 2023). This rigorous process of simultaneously conducting data collection and analysis is effective for co-personal, co-professional, and co-programmatic growth and praxis (Kosnik et al., 2006) in teacher educational contexts to prepare future educators for diverse classrooms.

Operationalizing GSI-DisCrit as an Analytic Tool and Praxis

We introduced course tenet 1 by foregrounding global South voices and narratives through podcasts and articles of students of color with disabilities, including recent migrants and refugees from the global South, to disrupt the deficit assumptions about race, migration, and ability as well as to help pre-service teachers re-think, reflect and transform the Eurocentric ideologies embedded within the U.S. based special education curriculum. The classroom discussions involved identifying their own multidimensional identities, the role that the education system plays in creating and maintaining biases and assumptions about

those migrating from the global South, as well as discussing how the educational spaces deem different for first-generation migrant and refugee students from the global South.

We highlighted the second tenet in conjunction with the first tenet to identify the role of “culture” in one’s life as well as review the history of the traditional medical model of disability, the social model of disability, the psycho-emotional model of disability, and intersectional disablism models as primarily embedded in global North context (Iqtadar et al., 2021). Such as Grech (2015) argues, that:

Colonialism matters because as researchers, academics and practitioners, this history frames, positions and legitimises us, our epistemologies and disciplines (e.g., disability studies), methods, practices and the universalising knowledge we produce . . . It also sustains the structures (global North universities and organisations) to maintain this epistemic and material superiority [of global North] and the exportation/imposition of its ‘knowledge’, methods (e.g., the social model of disability) and practice to an undeveloped South space historically (re)constructed ontologically as perpetually deficient. (p. 17)

From a decolonial perspective, our goal was to help our students become critically aware of how these models of disability originated *in* and *for* global North contexts and overwhelmingly discriminate against the voices of disabled people from the global South. Such as in some cultures in the global South, a dis/abled body might not be considered as something to be “fixed” or remedied and/or viewed from the lens of “productivity” in capitalist terms (Rizvi, 2017). In another context, it may be associated with divine blessing, or viewed through the lens of “karma” which views disability as Karmic compensation in this

life or the life of rebirth (Iqtadar et al., 2021). Taking such a decolonial approach to the university curriculum, which acknowledges that knowledge is not owned by anyone and specifically by global North in this particular instance, helps open the avenues of how disability could be viewed from another perspective, in this context the Southern perspectives, which defines disability in historical, cultural, social, political, and economic terms (Cutajar & Adjoe, 2016; Jenks 2017; Johansson 2014). The co-authors brought resources in the classroom to read and discuss (a) how disability might be understood differently in some global South countries, (b) the deficit perspectives about people from the global South, and (c) how cultural understandings of disability may interact with the local dis/ability interpretations for their future new coming students and families migrating from the global South. These readings included texts such as *Disabled Upon Arrival* by Jay Dolmage (2018), and Iqtadar's phenomenological study with first-generation African immigrant and refugee students with disability labels which were in progress at the time (Iqtadar, 2024),

Shehreen has a dual degree in Speech and Language Pathology from Pakistan and a special education degree with a DSE focus from U.S. Shehreen leveraged her background knowledge and experience of working in different professions in the global South and global North contexts to help students explore how constructs from the global North, such as from the American Speech Language Hearing Association (ASHA), have been imported in day to day practice, such as taking patients' history, creating SOAP notes and labeling students in specific global South contexts.

Tenet 3, the global North interest convergence in global South countries makes it particularly important to identify how local education is never detached from global contexts. After reading the GSI-DisCrit text as an assigned class reading, students researched and created a list of inclusive education institutions being run in global South countries and read through their work and contributions in the field of inclusive education. Some of these institutes across regions included *Springdales*, *Pathways*, *Nirmal Bhartia School*, *The Heritage School*, *Kreative Kinder Haus*, *ASAS International School*, *Headstart Kuri*, *Oasis School for Autism* in India and Pakistan, *Tauri Foundation*, *Sylhet Inclusive School & College*, *Baptist Mission Integrated School (BMIS)* in Bangladesh and *Cameroon School News* in Africa. Students were then asked to complete a group activity identifying the new knowledge that emerged exploring the resources in the global South and finding ways how they would use the lessons learned from these resources in their future classrooms. Finally, Tenet 4 humanizes the educational experiences of students with multidimensional identities and identifies individuals as whole.

Table 1*Applying GSI-DisCrit as analytic tool and praxis*

Course Tenet through GSI-DisCrit framework	Applying GSI-DisCrit as analytic tool and praxis
Center the voices of globally dis/abled multiply marginalized people, both in the global South and those migrating from the global South to the global North	Valuing a global multidimensional notion of identity vs. singular notion of identity
Emphasize the social, global cultural (beyond singular understandings of culture), psychological, emotional, material, judicial, political, and historical constructions of race and ability, [that acknowledges the onset of racism and ableism], which sets one outside of the global ability supremacy and racial “norms.”	Multidimensional notion of “culture” and emphasizing the various viewpoints about disability through individual and cultural experiences rather than traditional medical models as used in the global North
Calling out the global North interference and interest convergence and resisting its neoliberal concepts which create a mythical divide of “global North/South” to understand human beings (through racial, disability, tribal, caste identities) that value the economization of human bodies and their productivity through local and global institutions and structures.	Understanding and dismantling the intersection of White privilege and ability supremacy in local and global contexts.
Understanding individuals as whole and learning about psycho-emotional disablism and intersectional disablism to promote social justice, equitable and inclusive educational opportunities.	Understanding that labels do not define a person and that a disability is not just physical. Take the time to learn about the person and their identity without bias (implicit or not). Show care, respect, support, and understanding to the person.

Modified from Iqtadar et al., (2021).

Applying the Critical GSI-DisCrit Continuum to Pre-Service Teachers' Classroom Engagement and Pedagogy

Preparation. We collaborated with one of our colleagues in the Communication Sciences Department, Dr. Jackson, to visit the AT and AAC lab and learn about the use of the AT and AAC devices available. The students read Yvonne's AT case study about her journey towards the use of AAC for literacy education that Dr. Jackson selected and brought it to us for review. Yvonne is a bilingual 10-year-old girl with cerebral palsy of the spastic quadriplegic variety from Puerto Rico. She has non-ambulatory and limited-speaking secondary to cerebral palsy (Harrison-Harris, 2002). We all felt this was representative of the issues of cultural, linguistic, and disability diversity we wanted to explore with our students. Once students read the case study, they reviewed a set of eleven AT and AAC videos developed by Dr. Jackson's graduate assistants explaining the specific devices and their use. Our students then visited the AT and AAC lab and explored these devices hands-on. Once finished, Dr. Jackson and the co-authors met with the students to discuss their tour to the lab and answer the questions that might have been raised during the visit. In addition, we focused on the importance of working as a team with all of the multidisciplinary Individual Education Program team of students with disabilities through a Critical GSI-DisCrit framework, as we outline below.

Example. The AT and AAC lab visit was organized in conjunction with two major assignments for the course. For this paper, we will explain one of these examples. As an IRB was not taken to document students' responses²², we will only share the assignment and the

²² Throughout our research design of self-study in teacher education, we generated the data for this study through the aforementioned tools outlined by Anderson (2006); however, in retrospect, we also honored the critical reflective process through 1) autobiographical reflection as a learner of practice, 2) our students'

examples prepared by the co-authors to help students brainstorm. Following the self-study in teacher education methodology, we used our reconceptualized course boundary crossing and objects and artifacts as data for this article. To begin with, we asked students to collaborate in teams to work on one of the major assignments titled: *Advocacy Project or Plan*, for the course. We created the assignment in two parts. For part 1, student teachers engaged in a classroom workshop with their group partners and filled out the table (Table 2) template. This process helped them re-read Yvonne's case study from the lens of course tenets and embed them within their ongoing discussion about the advocacy and activism module of the course. During the workshop, the co-authors circulated among the groups and engaged in conversations with the student teachers, probed critical questions, and offered insights when requested. Examples were also provided (see column 2, table 2) to help student teachers engage the course tenets with the case study and advocacy skills. Student teachers then brainstormed and listed multiple ways they can connect course tenets to advocacy and activism in their future schools and classrooms. Some of the ideas presented by the co-authors (for columns 3 and 4) included but not limited to: 1) educating oneself about students' multicultural and multilingual backgrounds as well as their political and emotional differences, 2) embedding language components into the AT tools when needed (such as *Boardmaker* through a culturally sustaining pedagogy approach by including the language of the students and representative images for the Picture Communication Exchange System (PECS), 3) engaging in classroom activities/projects that value multiple perspectives and cultures to bring students' language and cultures to the forefront (Kulkarni & Parmar, 2017),

perspectives in our critical self-reflectivity, 3) our colleagues' perceptions and experience and 4) the lens from the empirical and theoretical literature base relative to our research question (Brookfield, 1998).

4) understanding your student as a whole, 5) creating equal opportunities and embedding Universal Design for Learning (UDL) within classrooms, as well as 6) asking different and critical questions within school spaces from a decolonial perspective to better support your students migrating from global South countries.

Once students filled out the template (Table 2), they worked together on part 2 of their Advocacy Project/Plan. Students were provided two options to pick from. They were asked to either create 1) an advocacy project or 2) a plan from the following options:

Advocacy Project:

- Make a “Top 10” List of creative ways to be an advocate for individuals with disabilities from diverse backgrounds (including race, gender, religion, and other identities).
- Create an Advocacy digitally accessible brochure highlighting ways teachers can serve as advocates for their first-generation Black, Indigenous, and Youth of color with dis/Abilities.
- Interview one student, teacher or parent of a student with multiple marginalized identities regarding their role as an advocate.
- Select a particular Special Education issue and make an infographic, poster or PowerPoint to illustrate possible ways to advocate for your position on the issue.

Advocacy Plan:

Write an advocacy plan for students with disabilities that incorporates diversity and include the following:

- identified statement of the need for advocacy
- a projected action plan for advocacy in a teaching or professional environment,
- and a reflection of how to be an advocate on the identified issue.

As co-teachers, we made ourselves available outside of class, via Zoom meetings, to help students brainstorm ideas for their final project. As a final step, student teachers shared the resources with the class on presentation day. We purposefully positioned our pre-service teachers throughout the semester to account for GSI-DisCrit before coming to the signature

assignment of the Advocacy Project/Plan. Throughout the course, we specifically framed the law, assistive technology, and advocacy portions of the course as being interrelated, therefore, during the orientation to the signature assignment we made sure to make this explicit to students. That is, how they could approach their Advocacy Project/Plan assignment through the work that they did in the Collaboration Course Tenets Table Connection to Advocacy and Activism Activity. Consequently, how our pre-service teachers were a) oriented to the assignment, b) the intellectual GSI-DisCrit work they did all semester long c) through the course tenets within and across the assignments, the instructor PowerPoint Slides, lectures, and readings, and d) all of the skills, knowledge, and dispositions that they developed were grounded from a GSI-DisCrit perspective.

Table 2

Collaboration Course Tenets Table Connection to Advocacy and Activism

Course Tenet Example	Yvonne’s Case Study Collaboration Examples provided by co-authors	Connection to Advocacy and Activism:	Given this week’s readings and podcast:
Center the voices of globally dis/Abled multiply marginalized people, both in the global South and those migrating from the global South to the global North.	Centering Yvonne’s intersectional identities, to honor her language heritage of both Spanish and English. How both the Speech and Language Pathologist and Special and General Educators use the PLAAFP statement, to build a curriculum or IEP with supplementary aids such as AAC so that her IEP team can each know her strengths and areas of improvement.	List the multiple ways that you can connect your assigned course tenet (column 1) as a form of advocacy and activism.	How can you add to your ongoing understanding of the meaning of advocacy and activism for students of color with disabilities, migrating from global South, in special education?
Emphasize the social, global cultural (beyond singular understandings of culture), psychological, emotional, material, judicial, political, and historical constructions of race and ability, [that acknowledges the onset of racism and ableism],	Building a culture within the school and IEP team, that builds a positive environment, where we are cognizant of the different ideologies or worldviews, that might come from Washington or other historical periods in our history as a country related to Puerto Rico, and the intersectional ways that Yvonne might benefit from a multicultural AT and State Core		What ideas, concepts, or frameworks were introduced within the readings and podcast this week that you or your partners envision incorporating into your advocacy projects? And Why?

which sets one outside of the global ability supremacy and racial “norms.” curriculum.

Develop an action plan on how you would incorporate the course tenets to your advocacy project.

While you listened to the podcast, please list any questions you might have for our guest speaker for the next class.

Lessons Learned from Engaging in GSI-DisCrit Critical Self-Study in Teacher Education Practice

As co-authors of GSI-DisCrit, we engaged the framework with the methods of critical self-study within teacher education for the first time. Through our analysis of the data, we engaged in the process of self-reflection as learners of practice (Anderson, 2006; Brookfield, 1998). The process helped us continually narrativize and analyze our pedagogical practices as critical friends. Our different backgrounds from global South and global North helped us bring different perspectives, while we also learned from and with each other and our students. The goal was to help prepare our student teachers for diverse classrooms with students from diverse backgrounds learn about their own biases and assumptions and support their newly arrived future immigrant and refugee students from global South through the transition-related challenges.

Importance of Critical Inclusive Education Access through Interdisciplinary Boundary Crossing and Object Work

One of the major goals of this critical interdisciplinary boundary crossing and object tool creation was to support our student teachers to create inclusive education access and practices for immigrant and refugee students from global South in their future schools. This is

critically significant and timely within the U.S. education global contexts. Specifically, the IDEA disability categorization is based on the medical model of dis/ability which identifies a “problem” within the student while placing them at the margins of society (Dudley-Marling, 2015). This approach wants to “fix” the student, instead of fixing the system (Annamma et al., 2013). Hence, it requires schools to locate the student, conduct assessments and/or evaluations, categorize students based on the dis/ability label, place students in more segregated special education classrooms for some or all day and confirm that they receive special education services and protections. This model of identification and sorting of students in the education system follows the medical profession of identifying and “ruling out” the medical needs or emergencies of patients needing medical assistance, such as taking histories, conducting assessments, evaluating, and providing diagnoses (Connor et al., 2008). In alignment with the medical profession, this approach creates a false binary of “normal/abnormal” in the education system, which reinforces who is “normal” and who deviates from “typical,” “normal” “able-bodiedness” and needs “fixing” (Annamma et al., 2017).

Within the western culture and education system, the “normal” is associated with the White middle class “able bodied” ways of being and doing (Leonardo & Broderick, 2011). The newly arrived immigrant and refugee students are often viewed through this lens of “normativity” that fails to account for a southern perspective and cultural and linguistic diversity. This is also represented within the education system when immigrant and refugee students are referred for special education services and are caught up in a difference-to-

deficit-to-disability “web” (Iqtadar, 2022; 2024) contributing to the overidentification of bilingual and or multilingual students into special education (DeMatthews et al., 2014).

Through the decolonial GSI-DisCrit and inclusive education access perspective, the course supported student teachers to identify such challenges of distinguishing dis/abilities from English language proficiency, in current practice, and advocate for their future students in school spaces through a GSI-DisCrit for justice in education (Klingner et al., 2014; Park, 2019). This would have specific implications for students fleeing the economic and political instability in some global South countries caused by global North interest convergence (such as armed support provided by the U.S. and the U.K. in wars in the middle east, as well as mass destruction of the land and economies) causing mass migration to global North countries. While their experiences are catered as similar to the native-born students of color, the very nature of their transnational migration, and the impact of loss of land and capital along with the different cultural and social backgrounds requires educational institutions to prepare future educators from a decolonial perspective. We acknowledge that this paper and our pedagogy has been the first step to engage a GSI-DisCrit lens from the decolonial perspective in this regard.

Since the enactment of our boundary work processes and object and artifact creation and engagement in personal, professional, and programmatic renewal given our GSI-DisCrit teacher preparation approach to conceptualizing and practicing inclusive education access much has happened nationally and internationally regarding global politics, and in particular the Ukraine-Russian and the ongoing military and political conflict in the middle east and the armed support it receives from the western world. Such global instability and conflicts make

the critical work of GSI-DisCrit such a needed perspective to account for the critical, contextual, and technical components of education for historically marginalized youth coming from the global South. We submit that a GSI-DisCrit approach would help current and future special and inclusive education teachers to engage in interdisciplinary and collaborative efforts alongside immigrant and refugee students coming from the global South in co-creating inclusive education access. In addition, such a state of global affairs propels us to further theorize the GSI-DisCrit approach to center the role of ethics in special and inclusive education and teacher education. The fifth GSI-DisCrit point states:

Acknowledge, support, and align with all forms of global activism, resistance and justice movements to counter-narrate the silence, lack of representation, and power within and between multiple levels of global and local civic society and institutions for critical revolutionary praxis (Author et al., 2021, p. 731).

In retrospect, this fifth point speaks to the role of ethics and an ethic of care relative to the emergent critical, contextual, and historical national and international events such as global politics. We then, in turn, consider how such a GSI-DisCrit approach and the roles of ethics and an ethic of care embedded in this last point can provide both teacher educators and pre-service teachers and invested parties in schools a framework to co-construct inclusive education access.

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**Organizing the Youth Leadership Circle:
Lessons Learned across Southern Spaces**

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Abstract

The Youth Leadership Circle is a transnational group of young women and girls with disabilities from across Southern spaces who come together to learn and to develop their leadership skills. In this paper, we explore our experiences supporting this group and the decolonial possibilities and struggles that emerge through this work.

Keywords: Youth Leadership Circle; transnational, young women and girls with disabilities, decoloniality, Global South

Organizing the Youth Leadership Circle: Lessons Learned across Southern Spaces

There are approximately 180 to 220 million young people with disabilities among the estimated one billion people with disabilities in the world, and most of these young people live in the global South (UNFPA & WEI, 2018). Included within this large group are young women and girls with disabilities, who encounter significant barriers within male patriarchal and historically colonized contexts. Despite their active engagements in transnational spaces to mobilize their rights and foster feminist engagement (Nguyen & Johnson, 2017), inquiries into how young women and girls with disabilities in the global South participate in research and organize their activist agendas has been lacking.

Learning with and from the global South: Engaging young women and girls with disabilities from Southern spaces (ENGAGE), a research project involving girls and women with disabilities across three Southern spaces in Vietnam, India, and South Africa, is an initiative to tackle such epistemic issues. Funded by the Social Sciences and Humanities Research Council of Canada (2021-2024), the project aims to examine the ways in which young women and girls with disabilities, along with partners in three communities in the global South, participate, negotiate, build leadership roles, and promote knowledge sharing within these communities. Our explicit use of the term ‘global South’ within this project exemplifies a shift in focus from typical issues of ‘development’ or cultural difference within international work, to one that emphasizes the history of colonialism, imperialism, and unequal geopolitical power relations (Dados & Connell, 2012). The global South, therefore, refers not to a geographical region per se, but denotes spaces and epistemic struggles of

peoples experiencing geopolitical and economic inequalities through the continued impacts of colonialism, neo-colonialism, and globalization.

In this paper, we will reflect on our collective organizing of the ENGAGE Youth Leadership Circle (YLC) transnational workshop – a research event aimed at creating decolonial spaces and conversations among young women and girls with disabilities from Empangeni, KwaZulu-Natal province, South Africa; West Bengal, India; and A Luoi district, Vietnam. Our aim herein is to share our experiences with organizing and creating space for the engagement, networking and knowledge production of girls and young women situated in the global South, while being mindful of our positionality and our different perspectives, in hopes of contributing to a new conversation about decoloniality in disability studies. We argue that learning with and from young women and girls with disabilities across Southern spaces is a decolonial approach that facilitates our collective learning and transnational praxis and that has the potential to challenge epistemic injustices in North American and Eurocentric disability studies (Grech, 2015). It also allows us to re-imagine decolonial futures with disabled girls and women in the global South.

A note about authorship is important here: while the co-authors of this article are researchers working from/with the global South, this work would have been impossible without the engagement and contribution of each and every member of our team. We consider it imperative to resist the Western academic conventions involving the individualization of collective work when publishing. Instead, we call for a decolonial path (Alvarado Garcia et al., 2021) that recognizes intellectual contributions and relationality

among the collective of scholars, partners, and activists from the Southern spaces with whom we have been engaging and learning.

Decolonial disability studies as epistemic struggles

Why learning with and from the global South? Why does knowledge from the global South matter, to whom, and for whom? These questions remind us of the space and locations of knowledge that have been, and continue to be, marginalized in the global regimes of knowledge production (Connell, 2007). This politics of knowledge reflects epistemic struggles within disability studies. Indeed, much of what has been written *about* disabled people in the global South has been taken from perspectives of scholars in the global North (Swartz, 2018). Even as the number of projects and publications addressing issues in the global South has increased, the majority of these continue to be conceived and viewed through a Northern lens, and the global North's imaginings of the lived realities of disabled people in the South have continued to be decontextualized, simplified, and generalized by disability scholars and practitioners.

The emergence of Southern, decolonial, and transnational disability studies therefore reflects epistemic struggles within the field of disability studies - struggles that highlight the need to understand the limits of Western disability studies and to open a path for decoloniality (Chen et al., 2023; Grech, 2015; Nguyen, 2018; Nguyen, 2023; Puar, 2023). Such decoloniality recognizes and problematizes the historic legacies of power imbalances and inequities that continue to inform and fuel global and local structures and relationships,

while simultaneously affirming alternative paradigms that emerge from marginalized communities in the global South (Mignolo, 2011). And, as decolonial scholars have argued, the impact of these North-South power differentials goes beyond the geopolitical, economic and epistemic realms, yielding continued effects on all areas of life, including on peoples' ways of being and living (Mignolo, 2011; Maldonado-Torres, 2007).

Nguyen (2023) argues that Western approaches in disability studies tend to reinforce “coloniality of power” (Quijano, 2000) – the long-standing power and knowledge hierarchies that were spread through colonialism and that continue to influence all aspects of life today – through their uncritical application of the same concepts and theories to historically colonized spaces. Indeed, there are usually generalized assumptions about the situation of disabled people in the global South, whose representations are often described and quantified through numbers or inferential statistics. Similarly, damage-centered research (Nxulalo and Tuck, 2023), which is also very common in the Southern context, does little to benefit communities in the South. Howell et al. (2019) from South Africa argue that, if we are to change the status quo regarding disability in the global South, we must resist such epistemic violence by facilitating new ways of understanding disability from the lived experiences of disabled people and their organizations from such spaces.

Within the ENGAGE project, we therefore strive to create alternative spaces for knowledge production in ways that contest the hegemonic notion of Western epistemic superiority by working and learning *with* and *from* Southern spaces – not through the extractive means that have typically been used by colonialism and transnational capitalism (De Sousa Santos, 2018) – but instead, by implementing a decolonial disability framework

that challenges the hegemonic relationships framed within Western disability studies.

Decoloniality thus asks us to center and reflect on alternative perspectives and knowledge traditions of those individuals and groups who have previously been marginalized, and whose lives, experiences and knowledges have been deemed irrelevant and insignificant by Western modernity. It is our hope that such work may lead to decolonial disability futurities – that is, to collectively reimagine alternative disabled futures in colonized spaces, and to reconsider the notions of what is possible and what could be. In contrast to the neoliberal futures that currently predominate the imaginations of powerful elites in both the global North and the global South, we posit that the concept of decolonial disability futurities has the potential to create new possibilities and lifeworlds that center and celebrate disabled bodyminds (in all their diversity) based on the values and priorities of marginalized disabled peoples. In so doing, decolonial disability futurities can create new spaces for co-theorizing (Nxulalo & Tuck, 2023) – for re-imagining disability futures *from* and *with* marginalized people across historically colonized spaces.

Organizing the YLC: A decolonial process

One of the primary objectives of the YLC was to utilize research as a decolonial praxis – one that acknowledges and challenges existing geopolitical power dynamics by centering the “unique experiences, knowledge, identities, and wisdom of the global South,” particularly Indigenous and ethnic minority peoples (Murillo Lafuente et al., 2021, p. 136). Furthermore, we aimed to support the building of relationships, leadership, and activism among the girls and young women with disabilities. To achieve this, we brought together twelve young women and girls with disabilities and their personal assistants from all three contexts, along

with three disability and youth activists from different provinces in Vietnam. The youth participants (aged 16 - 34) came from marginalized communities in India, South Africa, and Vietnam and represent diverse disability communities, including people of short stature, those with visual, physical, and/or intellectual disabilities, and Deaf people. The majority of the participants are students and teachers, while others work in health care facilities, NGOs, DPOs, or in their homes.

Stage 1: Building relationships through local workshops

In the first year of the project, the local researchers and local Disabled Persons' Organizations (DPO) in each of the project sites co-organized a 2- to 3-day community workshop that engaged and built relationships with and among girls and women with disabilities, communities, disability organizations, and researchers. These workshops were designed to suit the local context and were intended to engage not only the participants, but also the researchers, in the process of learning about disability in the context of the global South. During these sessions, 12-14 young women and girls from each site partook in a variety of participatory methods such as photovoice, cellphilm-making using mobile phones, and creating a local magazine through artistic methods, in order to identify and express their views about issues that are important to them and their communities. The methods used varied from site to site depending on the interests and expertise of the researchers, the DPOs, and the participants. By building these decolonial connections between research and activism, our approach centered the priorities and perspectives of DPOs and women and girls with disabilities in the global South in an effort to underscore their local insights and expertise (Nguyen et al., 2019).

The participants were also empowered to elect representatives, consisting of 2 to 4 young women and girls with disabilities, to join the transnational YLC event in Vietnam. In certain contexts, such as Vietnam, we encouraged the participants to select their best representatives through consultation with their family members. In India, the research team worked closely with participants' families to ask for their permission to allow their girls and women to participate in the workshop. This was because there are cultural and religious factors affecting the decision-making of these families and consequently the ability of the girls to travel. The team in South Africa was elected by their peers and schoolteachers. The selected representatives then took on leadership roles and served as the community's voice in making certain decisions involving, for instance, how to represent their communities at the YLC, and in providing consultation to the research team members in the project's subsequent stages.

Stage 2: Transnational Virtual Space

Once the youth leadership group was established, they participated in three monthly meetings with technical support/coordination from the research team in each community. Using Zoom, this group actively engaged in the planning process for the YLC event in Vietnam. The online sessions focused on setting the proposed agendas for the YLC, establishing long-term and short-term goals, and exploring possible participatory activities. This virtual platform became an effective approach for building relationships among the girls and young women in different global South locations because it provided multiple opportunities for the youth leaders to initiate and develop cross-border relationships, laying the groundwork for their direct engagement at the transnational event in Vietnam.

Stage 3: Youth Leadership Circle event

The results of data analysis from local workshops and virtual meetings in the first and second stages served as the foundation for the research team to identify the objectives of the YLC. We then developed an agenda in coordination with each of the local teams, as well as with the partners, stakeholders, and participants. In addition to transnational networking, the YLC research event focused on the process of knowledge production and on the generation of shared understandings of the issues that disabled women and girls encounter in their spaces, thus promoting collective action among the young women and girls with disabilities (McAdam et al., 1996).

The three-day event was designed around interactive discussions and participatory arts-based methods of engagement, including several activities such as collage-making (wherein each participant created their own collage to tell their stories of leadership and activism), creative zine-making (wherein participants identified issues facing young women and girls with disabilities in their communities and developed their advocacy strategies), and the development of a *Disabled Girls' Manifesto* (a declaration created by young women and girls with disabilities at the YLC 2023). Following these activities, we created an exhibition to showcase the artwork produced by all the participants; this was an effort to facilitate dialogues within and beyond their communities. As Vanner et al. (2019) suggest, art productions have the potential to create dialogues with the community, and this work increases the “possibility of being seen ‘over and over and over’ again, reaching many different audiences—so that the circle gets bigger” (Vanner et al., 2019, p. 6).

Stage 4: Connecting the global and local YLC

At the time of this writing, we are planning for stage 4, in which the virtual meetings with the YLC group will continue. This stage builds upon the collective strategies and actions established at the YLC workshop in Vietnam. The participants made a commitment during this event to sustain their engagement with one another and to create an active participant network within their communities. The YLC members will therefore continue to engage in transnational online meetings, updating one another on their learning, on the actions they have implemented at the local level, and on the challenges they face. We hope that this will serve as an important tool to enhance the effectiveness of the decolonial learning network established through the YLC.

Learning with and from the global South: A critical reflection on the YLC

The learning network established through the YLC sheds light on the opportunities and limits of decolonial theory and praxis in the global South. Menon (2022) suggests that decolonial theorizing must start with intellection from the South, rather than reiterating a Eurocentric episteme in Southern spaces. Decolonial thinking therefore prioritizes knowledges from the global South beyond what is usually referred to as “epistemological corrective” and the politics of citation (Puar, 2023). That is, beyond citing a plethora of texts produced by Southern disability scholars, our decolonial thinking/praxis has engaged with knowledge produced by young women and girls with disabilities across three project sites in the global South, as part of our struggle for epistemic justice (De Sousa Santos, 2018). This

approach transgresses the global North's treatment of disabled people in the global South as passive subjects of disability rights violations and invites new ways of engaging with the discourses and practices emerging from these spaces.

Thinking with the global South: Girls and young women with disabilities as knowledge producers

From a decolonial perspective, the YLC offers an alternative approach to working with young disabled women and girls that departs from typical top-down, academia-led, and global North-driven approaches that have dominated knowledge production in Western academic institutions. Instead, the YLC has emerged from distinctive post-colonial spaces wherein girls and young women with disabilities are often overlooked within highly disadvantaged communities. As shared by the Vietnamese group regarding the issues that women and girls with disabilities face, "society often has prejudice against women with disabilities...", "they [able-bodied people] will think that disabled women will not be able to do anything." Furthermore, Ly (pseudonyms are used to protect anonymity), a young girl with visual impairment from A Luoi, Vietnam expressed, "... When people said something, I felt abandoned and wanted to cry... I was not accepted by everyone." She felt that she was rejected due to the lack of respect for her disability (Group discussion, YLC 2023).

Across our learning sites, the girls and young women shared their experiences of being denied, disrespected, abused, and excluded. At the same time, using creative tools such as arts-based materials and methods, they found alternative ways to express themselves and to explore and share their stories, experiences and perspectives. This approach ensures that disabled young people's voices are centered in the knowledge-making process. For example,

through her collage creation, a Deaf woman from West Bengal in India, Anika, shared that she encountered exclusion in school as her Deaf experiences were defined by hearing teachers and friends. Importantly, the very fact that her mother became a strong advocate for her child's right to education inspired Anika to become a self-advocate for her rights, as well as for the educational rights of Deaf children more broadly. As she said, "girls come together to solve the problem."

Figure 1

Collage created by a young woman with disabilities collage created by a young woman with disabilities, aged 27, at the YLC 2023.



Image description: A white poster board lays on a wooden surface. The words “MY COLOURFUL LIFE” are handwritten in multiple colors in the center and lower half. There are images of a sewing machine, paintings, a teacher and student, and work and social gatherings attached to the posterboard.

While Anika’s narrative of exclusion from education may share some common experiences with other girls and young women with disabilities in the global North and South, her journey to leadership and activism for the educational rights of Deaf girls emerged from a specific space in the state of West Bengal in India where disabled girls and women have experienced multiple forms of marginalities. Ghosh (2020) found that disabled women and girls in West Bengal tend to internalize the social impositions of traditional gender roles and responsibilities that are ideologically enforced upon their bodies, where (able-bodied) girls are trained to fulfill their gendered roles as wife and mother. Thus, the presence of a disability is usually seen as a catastrophe within the family, since the disabled girl is deemed less capable than other girls. Yet, through her art, Anika was able to reconstruct her story, and her experience with exclusion was transformed through activism and teaching. This decolonial space thus enabled her to use her expertise to build her leadership. In fact, she took various initiatives to design her group’s zine and other visual products during the workshops, suggesting that she was empowered to take leadership within the YLC.

Another girl from South Africa, Theresa, actively engaged in various discussions and dance performances. She attends a special school for students with intellectual disabilities in a relatively rural area. She shared stories of being seen as a “naughty girl” throughout her childhood, which caused her to internalize ableist notions. We noticed, for instance, that

Theresa sometimes accepted her teachers' assessment that she needs to be in control of her anger to become a "good" student in school. Ableism is implicated in the ideological assumption that disabled girls' anger is "bad" and should be under control. Interestingly, when engaging with the girls from other contexts, however, Theresa appeared to push back against this assumption. On various occasions when we met, she became very forceful in her identification of the stigmas and exclusions that girls with disabilities shared in her school, and this reveals her potential to become a self-advocate by refusing to accept ableism as a given. As she provocatively articulated, "Don't let anyone define you. It's you who define yourself" (Fieldnote, YLC2023).

These examples testify to the need to reflect on the politics of knowledge – that is, who speaks, whose knowledge counts, and from what locations. Speaking from some specific locations in the global South, the girls and young women with disabilities in the YLC shared some similar experiences with exclusion and societal prejudices. And yet, their stories suggest that the embodied experiences in each of these spaces are distinctive. For example, participants from South Africa saw gender-based violence as the most poignant, such that they chose this issue to articulate their desire for change, whereas the girls and young women in India identified collective struggles for their education, enhancing knowledge, and fostering economic inclusion as the most pressing for their communities. The YLC therefore offered an alternative platform for knowledge sharing that enabled the girls and young women to reflect on ableist assumptions and practices that they had encountered in each of their spaces and to articulate their visions on social change.

Re-imagining girls and young women with disabilities as leaders

Through their participation in the YLC event, these girls and young women demonstrated that they possess the knowledge and experience to tackle issues that are important to them and to build this into their leadership-development efforts. They engaged in activist platforms by expressing their views, identifying their networks, supporting their fellow members, and, in some instances, by inspiring others to become leaders through the sharing of experiences. A woman with disabilities from Vietnam, Tinh Tam, for example, shared her experiences mobilizing various informal spaces for youth with disabilities to engage with one another. Recognizing that young people with disabilities have been multiply marginalized in their communities and associations, Tinh Tam established a club for youth with disabilities in the province, successfully mobilizing 88 youth members to join and to engage in various activities and training programs. As she shared upon her collage making: “What I want to share here is not about being in the best ten or the best one. The message behind it is that if you have a dream, make an effort to make it successful. Turn your thoughts to the actions, thoughts create actions, actions create habits, and the habit will be successful. And I believe that we all have dreams, and we will do it in our own ways” (Collage presentation and storytelling by Tinh Tam, YLC 2023).

Tinh Tam’s commitment for action exposes the need for decolonial praxis that can serve as a way of repositioning young women and girls with disabilities from the global South as capable of becoming leaders in their communities. The young women and girls in this project often expressed their aspirations for building their networks by learning to engage with one another and fostering their collective activism. This counters the individualistic

approach to leadership. As Antonio Jimenez-Luque (2021) puts it, while mainstream leadership approaches are characterized by the Eurocentric colonial structures of power that universalize and hegemonize the dominant worldview, decolonial leadership is “the process that aims to decolonize society [by] debunking myths and narratives [of leadership] imposed with the Eurocentric social order” (p. 155). Jimenez-Luque (2021) argues that because subaltern groups’ perspectives have been historically excluded, it is critical to “make visible more distributive and participatory ways of exercising leadership” in ways that empower them to act collectively (p. 155).

We suggest that the YLC creates space for decolonial leadership in an emancipatory process that is informed by subaltern perspectives and politics. It emphasizes the need for relationship building and learning from subaltern group’s learning experiences. For example, in her “leadership roadmap for the future,” Parvati, a young woman with disabilities from India, shared her plan for developing a club of women with disabilities in her own community. Her “roadmap” suggests an aspiration to learn and teach young people with disabilities the skills and knowledge that she had acquired from participating in training workshops (See Figure 2).

Figure 2

“Leadership roadmap for the future,” created by a young woman with disabilities from India, Youth Leadership Circle 2023.

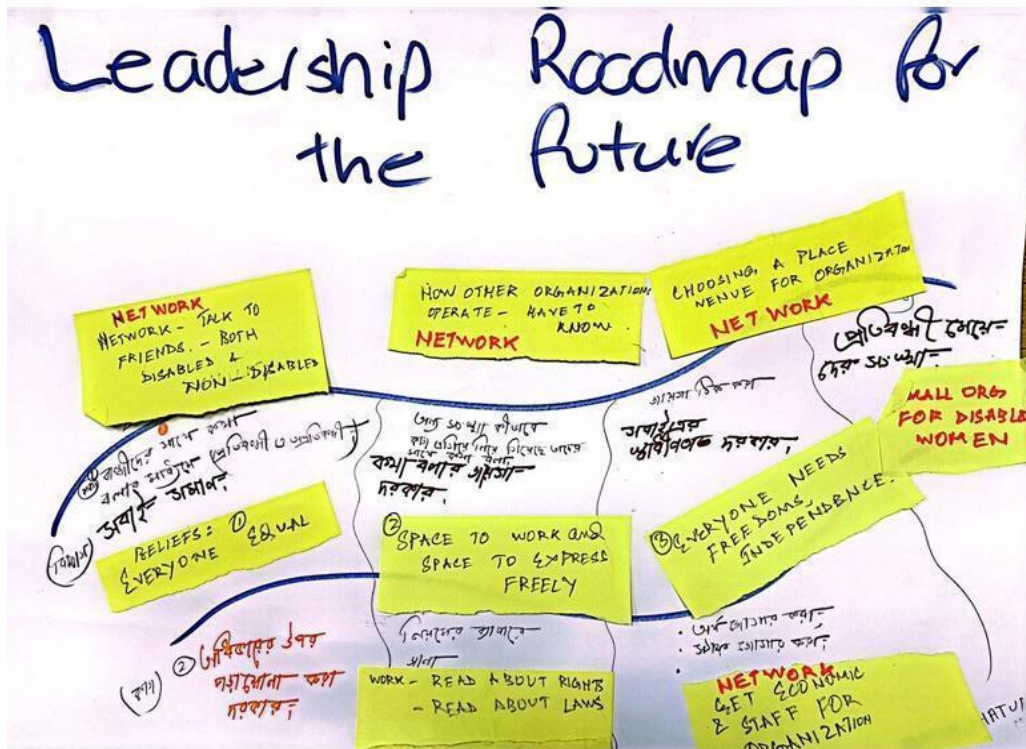


Image description: A white poster board with the words “Leadership Roadmap for the future” handwritten in large letters at the top. A road is drawn across the page with text in Bengali on and below the road. Yellow Post-it notes are attached and provide text in English about networking and disability rights.

Parvati's leadership 'roadmap' reflects her idea of community engagement. For instance, she highlighted the need to be strategic and to talk to disabled and non-disabled friends alike as a way of building her communities. She saw networking as an integral activity, allowing her to strategically support her club for women with disabilities. Alongside networking, she also clearly communicated a desire for knowledge and further learning, including learning how things operate in an organizational structure. And all of her planning was informed by a set of beliefs including "everyone [is] equal," "everyone needs freedoms and independence," and everyone needs a "space to work and space to express freely." This belief system demonstrates her firm values for equal rights for young women and girls with disabilities. Also interestingly, rather than striving to become an individual leader, her community-engaged approach to leadership seeks to be *in relation with* others to achieve her goal for establishing a club of women with disabilities in her community.

As another example, during the zine-making workshop entitled *Bringing about Change*, a girl and young woman in India created their stories for change by first identifying barriers that they had encountered, such as difficulty accessing education due to the lack of accessible language. They also discussed difficulties related to accessing healthcare services, since doctors do not have enough time to effectively communicate with them. Through this activity, they visualized particular solutions together and they advocated for constructing their own network by "com[ing] together, learn, and do something new" (Zine production presentation, YLC 2023). As they articulated, "Everybody stands together. These girls are not alone" (Zine production presentation, YLC 2023).

Thus, while the group had different experiences with exclusion based on their disabilities and social locations, these discussions generated some collective stories about exclusion, enabling them to develop advocacy strategies that reflect these experiences. This suggests that such decolonial spaces and opportunities can empower younger women and girls with disabilities to recognize their potential for leadership within their communities. This approach is “decolonial” because it works to unsettle the colonial/modernist and individualistic approach to leadership, which is male- and able-bodied-driven, and which systematically excludes women and disabled young people from engaging in leadership building. In contrast, the participants recognized that collectively, they can strategically build their networks and inspire young, disabled people to think with one another and take collective actions to bring about change.

Our learning from this space also suggests that opportunities for leadership building among these girls and young women with disabilities tend to be uneven. Factors such as class, gender, disability, caste, and social status all play an important role in affecting girls and women with disabilities’ opportunities to engage and sustain relationships with one another. For instance, not all participants in the three project sites were able to travel to the YLC due to limited resources and opportunities. Furthermore, among those who were elected to attend the YLC workshop, not everyone has had the opportunity to take leadership positions in their own schools or communities. Some girls and young women shared that they were relatively isolated from the community in which they live or study. In fact, a workshop participant raised the question about who is privileged to take leadership positions, indicating

that some women and girls with disabilities may not have the institutional support and conditions they need to create change (Personal communication, YLC 2023).

As decolonial researchers, we believe that her argument was critical as it can help to unsettle and challenge power dynamics usually ignored in colonial and neoliberal approaches to leadership building. Specifically, it reveals that leadership capacities and opportunities may be conditioned by an individual's class, race, gender, disability, caste, religion, which result from centuries of colonialism in distinctive spaces in the global South. In the case of leadership building for women and girls with disabilities, we are mindful of the modernist regimes of development, wherein the discourse of leadership tends to be institutionalized as a modern standard which categorizes who fits into the colonial/modernist norms. These colonial implications of leadership, we argue, can be unmasked through a crip narrative of leadership that refuses to conform to the modernist standards that define who can be a leader and what leadership should look like. A crip narrative challenges dominant narratives about leadership, and instead, recognizes the power relationships among the girls and young women with disabilities within their specific spaces. We believe that, while the YLC is still far from being fully accessible, it is an example of decolonial praxis that is crucial for connecting girls and young women with disabilities in the South and for redefining understandings of leadership, while simultaneously building knowledge and sharing their stories (which have yet to be heard within the North American disability justice movement). And, by creating spaces for disrupting the normative assumptions about leadership as male, able-bodied, and global North-driven, our research with girls and young women with disabilities creates possibilities for collective organizing and theorizing about decolonial leadership from the lens of young

women and girls with disabilities in Southern spaces.

Further reflections on our learning experiences

We acknowledge, with caution, that our reflections herein are a discourse of knowledge in the making – something that cannot be universalized or assumed to be the *only* form of knowledge that represents the perspectives of girls and young women with disabilities from the global South. As Mignolo and Walsh (2018) remind us, taking such a universalizing approach would simply reproduce coloniality. Indeed, our ongoing learning experiences were often filled with tensions, debates, and sometimes frustration and incompleteness. As researchers engaging in disability studies from the global South as a part of broader epistemic struggles (Nguyen, 2023), we are cognizant of, and sometimes frustrated about, the colonial structures within which we function. Moosavi (2020) argues that global North scholars need to “recognise how we are privileged by coloniality and even implicated in its enduring structures of inequality” (p. 333), and so we grappled with navigating through this (de)colonial process with a critical reflexivity on our privileged position. The resulting epistemic and political discord evoked “crip feelings” (Chen et al., 2023, p. 2) – the recognition that coloniality has continued to morph into decolonial research in ways that impact our feelings and embodiment, such that it is entangled within the colonial and ableist regimes of Western academic institutions and operates through issues such as funding, resources, and power relations. And yet, through our positionings and experiences across these spaces, we found that the YLC provided us with an opportunity to work towards epistemic justice by centering knowledge, perspectives, and praxis from the global South,

recognizing our privileges in research relations, and examining how this may impact our efforts to build relationships with participants.

Furthermore, through our organizing experiences we learned that individuals have different timeframes when processing things such as language and expressing ideas. For example, our Deaf participant experienced language at different paces and modalities because her communication required different processes of interpretation between Bengali, Indian Sign Language, and English. As such, we must cater for diverse access requirements, rather than “bend[ing] disabled bodies and minds to meet the clock” (Kafer, 2013, p. 27). Crip time thus helps us to reshape our understanding of time, orienting it towards diverse abilities and the needs of disabled individuals, and becoming conscious of, and resistant against, the colonial/neoliberal regimes which circumscribe our crip experiences. And, as Ellen Samuels and Elizabeth Freeman (2021) argue, “Even as crip time is a space of frustration and often of loss, then, it is also a space that offers new kinds of connections and presence that are fundamental to imagining a new world into being” (p. 250).

Conclusion

At the core of decoloniality is the agenda of shifting the geography and biography of knowledge, bringing identity into epistemology – who generates knowledge and from where? Decoloniality’s point of departure is existential realities of suffering, oppression, repression, domination, and exclusion (Ndlovu-Gatsheni, 2015, p. 492).

An important goal of decolonial theory and praxis is, as Ndlovu-Gatsheni observes, to shift the locus of enunciation in relation to its epistemological vantage point from the Euro-North

American centric as *the* epistemic locale from which the world is described to the “ex-colonized epistemic sites as legitimate points of departure” (p. 489). This intellectual project does not merely involve theory from the global South (e.g., Connell, 2007). Rather, it emerges from praxis that exposes the ways in which the coloniality of power has sustained modernity and it creates tools for re-imagining a different side of humanity.

The development of the YLC offers a unique way of learning with and from the global South. This transnational praxis, implemented through different learning platforms such as Zoom meetings and transnational engagements among girls and young women with disabilities, creates several opportunities for researchers to reconsider different possibilities for knowledge construction with these girls and women. By supporting them to see themselves as young leaders with valued experiences and insight, the YLC becomes a space of knowledge generation and transnational activism that unsettles the global North’s assumptions about women and girls with disabilities in the global South. Instead, what we have seen in the YLC is a range of potentialities for re-imagining the spaces in which decolonial knowledge can be constructed, learned, and shared among disabled girls and women, as well as with their networks and broader communities.

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Reading Mohini Mohun Majumder's *Muk-Shiksha*:

Special Education in Colonial India

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Abstract

The paper studies a 1903 text titled *Muk-Shiksha* to make three arguments. It examines the colonized deaf subject as shaped by discourses of oralism, the role of hearing advocates in consolidating oralism, and the ways in which deafness is mediated in local contexts of educational reform.

Keywords: Oralism, Reform, Pedagogy, Colonial Bengal

Reading Mohini Mohun Majumder's *Muk-Shiksha*:**Special Education in Colonial India**

In the 1904 issue of *The American Annals of the Deaf*, Jamini Nath Banerji wrote a review of a book titled *Muk-Shiksha*ⁱ. Described as a “copiously illustrated book on the education of the deaf” as well as the “first publication of its kind in any Indian dialect” (Banerji, 1904, p.390), *Muk-Shiksha* was written in Bangla by Mohini Mohun Majumder and printed by a press in College Square, Calcutta, India in 1903. Alongside Jamini Nath Banerji, Srinath Sinha, and Girindranath Bhowse, Majumder was one of the earliest proponents of teaching methods for deaf students in colonial Bengal. They were all involved with the founding and the workings of the Calcutta Deaf School. In his review, Banerji measures *Muk-Shiksha*'s importance through the “contribution” that it makes where the public discourse on deafness was limited (Banerji, 1904, p.390). *Muk-Shiksha* was among few textbooks to supplement a state-approved curriculum, which had been designed for hearing students, and which was required to be followed even in deaf schools (Vasishta, 2021). However, by describing some of the concepts, approaches, and methods in use at the Calcutta School, most of which discussed certain practical ways in which the Deaf^{fi} student could be taught to ‘speak,’ *Muk-Shiksha* was also produced with a larger readership in mind. This readership included students, instructors, as well as parents, presumably both deaf and hearing, who could learn about oralist methods in Bangla. Thus, the intent was to bring within the colonial

public and print sphere what was ostensibly ‘specialised knowledge’ about teaching deaf students. By the time of the book’s writing, oralist methods had not only made their way into the colony, but also been in use at schools such as at the Bombay Institute for the Deaf (Miles, 2001, p. 310). Even though other methods of communication had been used with deaf students outside the formal confines of schools, the preference for oralism signifies two important things. One, in their use of oralist methods, Indian educators perpetrated what was an essentially colonizing perspective of deafness as difference. And secondly, its deployment was also emblematic of a modernizing imperative in educational reform, with the colonized Deaf subject at its helm.

The problem with this figuration is that, in the absence of any consolidated political consciousness of disabled persons, it was not so much modernity as was the case with other social groups. During this period, there was no substantial literary or cultural output by disabled persons themselves, except for some isolated instances such as Subodh Chandra Roy’s *The Blind in India and Abroad*; nor were there any significant inroads made as far as a disabled identity goes. Disabled people were not at the forefront of any sustained claims to a political constituency. This sense of ‘becoming’ modern through educational reform was steered by nondisabled advocates rather than disabled persons themselves. Thus, the instrumentality of education was a more pressing concern and its consequences on persons deemed ‘infirm’ and ‘defective’ more immediate, rather than any subjective questions of what disability had meant to the students.

This leads us to ask what was it about deafness in the colony that these educators had thought to make ‘modern’? What role did education have in such imaginations, and was this idea of a modern, socially capacitated Deaf subject influenced by developments in the metropole? Was there any space given to sign language within the predominately oralist methods used in schools? If oralist principles were mostly followed, how do we conceptualize Deafness within the socio-cultural context of the colony? Majumder has been described as “a brilliant exponent of the sign language” (S.N. Banerji, quoted in Miles, 2001, p.310) and yet for its entire length, *Muk-Shiksha* relies on oralism as guiding its pedagogical content. Could the formative moments of Deaf identity be located and historicized in life histories of students at the Calcutta School, a textual trope which closes Majumder’s text? We do not know if cultural identities had formed around signing in the colony. Existing literature documents the prevalence of signing communities (Miles, 2012), while isolated moments of signing as pedagogical practice emerge in the colonial archive. But where any cultural consciousness had not emerged around signing as linguistic practice, what were other ways to conceptualize Deafness? I pose these questions to point the major thematic turns this paper will take in its discussion of *Mik-Shiksha*. This is a text which was produced, I argue, with the purpose of familiarizing its readership with deaf education in general, and with the oralist pedagogy of the Calcutta School in particular. It elaborates on the forms that oralism takes in the immediate context of Bangla, all the while underscoring education as social intervention.

For all its adherence to oralist methods then, *Muk-Shiksha* can also be understood as an instance of early advocacy by teachers at the Calcutta School. Threading through it is an

awareness of pedagogical as well as cultural practices of Deaf communities in the metropole and the implementation of oralist education in the context of the colony. Its attunement towards ‘becoming’ modern, when read against the social reformist landscape of late colonial Bengal, thus positions deafness as the site upon which such imaginations are inscribed. Yet, such interventions come at the cost of integrating deafness within a normative, hearing world. How then, does reading *Muk-Shiksha* provide decolonial possibilities of understanding deafness in the colony? I argue that these emerge in how Indian educators negotiate with colonial structures and imperial knowledges to rewrite the cultural terms of deafness.

This is a complicated position, a glimpse of which is present in the final section of the book which documents, through brief personal histories, the lives of former students at the Calcutta School. Such was the kind of advocacy which included the formation of groups such as the Convention of the Teachers of the Deaf in India (Vasishta 2021) and concerted lobbying on the part of educators and relief workers for aid, acknowledgement, and resources from the colonial state (Majumder, 1940, p. 233). Thus, *Muk-Shiksha* encapsulates some of the prevalent notions on deafness in the context of colonial education and reform. Through moments of narrating the past and present of deaf pedagogy, and by imagining Deaf subjectivity in the histories of students, *Muk-Shiksha* intervenes into a public space where information about deaf education was scarce, and where deafness was equated with the colonial logic of ‘infirmity.’ This does not mean that noncolonial configurations of deafness subscribed to the same, as native forms of signing had persisted in the colony, outside of governmental and reformist intervention (Nair, 2020, p. 86). Even though *Muk-Shiksha* had relied on oralism, it had displayed an awareness of impairing regimes of colonial production.

It had worked around the reluctant stance of the colonial state regarding disability reform. In the context of its socio-cultural location, therein lies its decolonial imagination.

In my reading of *Muk-Shiksha* then, I proceed in three primary sections. The first briefly discusses oralism's imperative to assimilate the variability of deaf experience within a colonizing and culturally disqualifying discourse. Oralism was premised upon the "disenfranchisements of deaf people" (Esmail, 2013, p. 10), and in the process of gaining ideological ground over forms of pedagogy in the west, had aligned signing with social and political exclusion. In the second section, I think through historical moments where oralism was consolidated in the context of the colony, primarily by hearing advocates and educators. I look at certain scattered instances of signing, and trace how it had been gradually replaced by oralist pedagogy within formalized settings such as deaf schools. The final section critically reads *Muk-Shiksha* as embracing oralism in its contents, and yet not decrying signing as inferior. Rather, it presents certain possibilities for Deaf subjectivity and records Deaf history, contained as they may be in the context of educational reform in the colony.

Advocates and Instructors: The Figure of the Teacher in Colonial Deaf Schools

It is important to note that the colonial state had pushed the matter of education for disabled persons outside its immediate purview. Passive in its welfarist engagements with disability, it had constructed disabled persons as a class whose educational interests were beyond the state's immediate concerns. This had led to interventions from other stakeholders in the matter of social reform and education, such as missionaries, landed and merchant

classes, and native educators. What was common in their responses to an emerging trend of reformist intervention, was a “curative imaginary” of disability, that is, the understanding that disability “not only expects and assumes intervention but also cannot imagine or comprehend anything other than intervention” (Kafer, 2013, p. 27). Such intervention was differently located for colonial actors, localized in their intent and agendas based on what they had imagined the role of disability to be. Missionary engagement with disability, for example, may have had “a strong religious motivation,” but it was “far from being a monolithic or coherent force” (Miles, 2001, p. 292). The conditions of charity by merchant classes may have been influenced by “filial piety and obligation, driven by family and religious motivations” (Kaul, Sandhu and Alam, 2021, p. 12), but it had also brought under its fold those who required economic and social aid, such as the old, sick, and disabled, across community lines. But most prominently, where the state’s approach to disability was careful and selective, present on paper but rarely actualized, there had come up schools for disabled (primarily blind and deaf) students, mostly but not always helmed by Indian educators. Requiring resources, financial support, and social patronage had caused educators to correspond with one another, leading to the formation of associations and groups which had, in turn, lobbied with the colonial state.

This becomes an important point of contention in the discourse on education of deaf persons. Much like how Jennifer Esmail describes oralism as being consolidated by “hearing parents, hearing educators, and hearing governmental representatives,” the role of hearing individuals in the context of the colony also belies a conflation of difference and the scale of its reform. Some historical accounts note that the initial efforts at teaching disabled children

started out of personal concerns, and then took the form of schools. Such was also the case at the Calcutta School. Girindranath Bhowse and Srinath Sinha, two of the founders, had deaf family members (Banerji, 1949, p.5). A 1906 editorial in *The Association Review* mentions P.L. Desai and his “noble efforts ... to educate his own deaf son” had led to the “one or two other deaf children” being “brought to him for instruction” (“An Interesting Letter,” 1906, p. 199). Desai, who had started a school at Kadia near Ahmedabad, Gujarat, was also a proponent of the oral system, a point we will return to in this paper. However, leaning towards oralist methods may have been more than simply ideological. It may have also been influenced by the difficulty of using sign language in classroom settings, or the designing of course materials using the same. For instance, an 1897 review of Jamini Nath Banerji’s *Visit to the Institutions for the Deaf and Dumb [sic] (and the Blind) in England, Ireland, and America* describes this mediated approach in the early years of the Calcutta School:

Where success by the oral method is not possible, he favors the manual alphabet, but finds it difficult if not impracticable to adapt a manual alphabet to the native language of India. Signs he would use freely with all pupils, but only “such signs as can be understood and are used by hearing people. (“Notices of Publication”, 1897, p.339)

During his time at the ‘Normal Department’ in Gallaudet College between 1895 and 1896, where hearing persons were trained in methods of deaf education, Banerji had been exposed to manual signing. The idea of combined methods may have appealed to him, as he had also encountered oralism during his visit to England, specifically the work of Van Praagh, an oralist advocate (Cleall, 2022, p. 176). Yet, Banerji’s approach to both was mediated at first, as its oralist pedagogy had not entailed the complete removal of signing at

the Calcutta School. However, Banerji had eventually moved towards oralist methods. This was very likely a consequence of the colonial logic of reformism, compounded by the formalization of oralist methods in the colony and thus, the ease in disseminating information on them. While signing has been documented in some instances (Miles, 2012), it was eventually sidelined due to the absence of any significant cultural presence of Deafness in the colony, unlike how it was in the metropole. This was, once again, an issue with early instances of advocacy in the colony, where its paternalistic proponents were persons who were nondisabled and hearing. Any political constituency that disability had accrued, was not because of a changing critical consciousness, but rather, because of a tendency among nondisabled advocates to conflate reformist modernity with the difference upon which it was premised. Thus, while *Muk-Shiksha*, for the most part, works as a treatise on oralist methods reiterated in Bangla, it also discusses signing and fingerspelling, however briefly, as concurrent forms of expression for Deaf persons. Which leads to the question of what factors and conditions had pushed oralism into the mainstream of deaf pedagogical methods in the colony. However, before that, I will briefly discuss how the political construction of deafness was contingent upon oralist discourses in the metropole.

Between Oralism and Manual Signing in the Metropole

Oralism and manual signing had occupied inequivalent positions within narratives of deaf subjecthood from the nineteenth century onwards. Manualism advocates for signing as a form of linguistic, cultural, pedagogical, and thus, political expression for Deaf persons. Oralism, on the other hand, premises itself on speech and hearing as capacitating features of a

rational, autonomous self. Douglas Baynton argues that manualist methods were focused on individual moral reform, while oralism emphasized the “creation of national unity and social order through homogeneity of language and culture” (Baynton, 1992, p. 218). Oralism understands deafness as inherently negative and signing as a ‘primitive’ form of expression, meanings which were also conflated onto ideas of nationhood and language, resulting in political exclusion. Amid debates on the use of both within educational spaces, the “oralist victories of the 1880s and 90s” (Esmail, 2013, p. 16) were significant moments. This was not only because the decision-making bodies they were a part of had consolidated oralism in pedagogic spaces. But conversely, such moments also saw strategic attempts at establishing and publicizing the variability of Deafness and signing as lived experience through forms of cultural production such as art and literature by Deaf and signing persons, what Esmail calls “counternarratives to oralist denigrations of signed languages and signers” (Esmail, 2013, p. 46). Thus, despite the segregationist consequences of the “ascendancy” of oralism (Fleischer and Zames, 2011, p. 17), such as the banning of sign language as a medium of instruction, at The Second International Congress on Education of the Deaf at Milan in 1880, it had persisted within “a countervailing ethos vigorously supporting the teaching of sign language” (17).

Despite its “political attempt to erase an ethnic group” (Davis, 1995) and its fixation with eradicating the cultural variability of Deafness, oralism’s discursive expansion was not without responses from Deaf communities who had contested it. Thus, while oralism may have attained a certain significance, both within and beyond pedagogical spaces, manualism, signing, and fingerspelling were not without its advocates. Signing was understood to be an

inherent, naturally realized element in the formation of Deaf identity and community relationships. The work of Deaf Scottish artist William Agnew is important in this regard. Agnew has been described as a “strong opponent of the oral system” (Stiles, 2011), whose stance on signing is evident in a series of paintings he had made between 1883 and 1900 “which recorded a conversation between a hearing person and a deaf person that took place in signs” (Esmail, 2013, p. 1). The subject of these paintings was a deaf woman, Elizabeth Tuffield, who is depicted lying in her bed and conversing with Queen Victoria in signs. Curiously, it was Agnew from whom Majumder had procured printing blocks for the illustrations in *Muk-Shiksha*. Further, a brief biographical sketch of Agnew also appears in the final section of the book, as does an account of Victoria visiting Tuffield.

Mainstreaming Oralism in the Colony

By the late nineteenth century, some of the early schools for deaf persons had been established in the colony of India. The Calcutta school was one of the earliest, alongside others at Bombay, Mysore, and Palamcottai. While oralism was more pronounced in these places, other methods of teaching deaf students were also prevalent. Take for instance, the school at Palamcottai in the Madras Presidency, which was started by Florence Swainson, a missionary-worker for the Church of England Zenana Missionary Society. The complex nature of teaching methods used here is observed by Lilian E. Bishop: she writes teachers engaged with their students “by the use of charts, maps, pictures, black-boards and other means, together with sign language and wonderfully expressive faces,” the results of which were “as successful” as the means “were ingenious” (Bishop 1904, p. 294). The adoption and

use of complex methods is also documented in records produced by the colonial state. H. P. Jacob, the Educational Inspector of Sind, a province in the western part of the colony, observes in 1890 that a fourteen-year-old boy at “an indigenous school” in Hyderabad (Jacob 1890, p. 8) was taught using “gestures both of lip and hand occasionally.” This boy, who was taught by the “worthy Bawa and his wife” (‘Bawa’ refers to the teacher) at the school, had eventually learned to write in the Gurmukhⁱⁱⁱ script. Jacob also mentions another person named Chellaram who was taught to write in Sindhi alphabet by a “Mohammedan Akhund” (‘akhund’ is a Persian title for an Islamic scholar) using “manual and other signs” (Jacob 1890, p.8). It is important here to establish the terms which had distinguished such forms of teaching from those adopted at the Calcutta, Bombay, and later, Palamcottai schools. Surely, the two teachers mentioned above had not subscribed to any oralist principles, at least not in the ways its use had been mandated in the metropole at the end of the nineteenth century. They may have used a mixture of pedagogical methods, even though the knowledge of the alphabet and writing was an important step. In Jacob’s observations, the question of speech appears secondary to the ability to read and write, such as when he notes that Chellaram would communicate with hearing persons using signs and written words (Jacob 1890, p. 8). It is also pertinent to note that both persons whom Jacob mentions had been left to the care of their respective teachers, suggesting a more complex, longstanding, and sustained relationship between the deaf student and the hearing teacher. Such forms of pedagogy, isolated as they are in historical records, foreground deafness as contingent upon specific contexts, where the terms of responding to it had varied from the oralist inclinations of the metropole. There was no formal political imperative guiding such moments of deaf

pedagogy, but only attempts at fashioning a subject who could be capacitated through education. With “the growing professionalization” (Miles, 2001, p. 310) of formal teaching methods in newly established schools in the colony, especially with such methods already in use in the metropole, a discernable direction had emerged. This was not so much a turn, simply because there was no prior formal system of teaching deaf students from which to turn away. Rather, the increasing adoption of oralist principles in these schools signified an outlook towards deafness where speech seemed to be the only way to ‘recover’ what was deemed to be lacking in nonspeaking and deaf persons.

Writing how “the tide was strongly contrary” in debates about the use of signing (Miles, 2001, p. 311), Miles locates signing methods as gradually giving way to an oralist hegemony in pedagogical methods. What could have one of the ways to work through the scarcity of funds, or to bring schools into circuits of social relevance, was the adoption of what was formalized in the form of existing resources, methods, and, simultaneously, trained teachers to deploy them. Indian educators, in their attempts to draw from such ideas, had corresponded with oralist institutions and organizations to seek resources and teaching materials for their deaf students. The eighth volume of *The Association Review*⁴ had printed an excerpt from a letter by Pranshankar Lallubhai Desai in 1906 (“An Interesting Letter,” 1906, p. 199), describing his attempts at teaching his son in “the art of speaking” using the Gujarati alphabet. Desai had created a book “containing small sentences involving names of articles of daily use” (“An Interesting Letter”, 1906, p. 199), which his son would read daily, while the latter’s method of “lip-reading” would include writing “to dictation detached and connected small sentences containing verbs representing ordinary actions done by him” (“An

Interesting Letter,” 1906, p. 199). A. H. Date, who had established a school at Thakurdwar in Bombay in 1907, designed what he describes in a 1935 newspaper article as a “vernacular system of teaching” (Date, 1935, p. 15). Date used “vernacular” to distinguish from what he called the “English System,” which he claims to have been used at the schools in Calcutta, Madgaon (Bombay) and Palamcottai. Date then goes on to mention a book in Marathi he had published called *Mukam Karoti Wachalam*⁵, before noting that a “complete course of books” was needed to design a curriculum “specifically” for deaf students (Date, 1935, p. 15). Incidentally, *Mukam Karoti Wachalam* roughly translates to “making the mute speak,” and much like the title of Majumder’s book, centers speech as the subject of its instruction. And much like Desai and Majumder, Date also produced instructive texts in a native linguistic context. However, unlike Majumder, Date never uses the term ‘oralist’ in his article to denote his approach to teaching. It may very well be that by 1935, he was aware of the methods in use at the three schools he mentions, the ‘English system’ in his words. By this time, the use of oralist methods in the colony was common knowledge, bolstered by the justification that oralist resources and oralist training was easier to come by and implement in the form of curricular materials, rather than the specificities of signing as pedagogy. The Calcutta School had a teacher training program which was started in 1897. In what was a “paradoxical” (Vasishta 2021) move, Jamini Nath’s adoption of oral methods has been attributed to reasons such as the difficulty of using fingerspelling in the Bangla alphabetical context, as well as a broader consolidation of oralist teaching in the metropole (Vasishta, 2021). Thus, oralism had persisted and its principles and methods normalized as teaching practice. In the Bengal Presidency itself, there were eleven deaf schools by 1940 and most of these had a single

teacher in charge of its activities, most of whom were either graduates of the teacher training center, or of the school itself (Majumder, 1940, p. 233). By 1935, The Convention of Teachers of the Deaf was formed in India, and among its agendas was the integration of deaf education into the mainstream of primary education in the colony (Majumder, 1940, p. 234). Such lobbying was backed in strong measure by the convenient adoption and normalization of oralist methods, knowledges, and resources.

Muk-Shiksha: Oralism in the Bengali Alphabet

Muk-Shiksha (translated as ‘Education of the Mute’), was published in 1903 by Majumder himself, and is divided into three primary sections. The first historicizes education for deaf persons by locating some key moments and figures who had fostered it, both within and outside colonial India. The second section is entirely instructive in its contents. It adapts oralist methods in the context of the Bangla alphabet, working through grammatical principles of word and sentence formation using phonetics, pictures, and repetition of vowels and consonants. The third and final section uses biography as a narrative trope to talk about the lives and careers of some former and existing students at the Calcutta Deaf School, among other prominent figures such as William Agnew and Helen Keller.

Muk-Shiksha begins with a note by the publisher/author acknowledging the role of certain individuals in the production of the book. Among them, Majumder mentions the formative role of William Agnew, who had parted with his printing blocks for the Majumder’s use in the book. The teachers at the Calcutta School were aware of developments

happening in the metropole in the sphere of education, which had by then shifted to an oralist ideology, as well as of Deaf artists iterating their political stance on sign language through cultural production. Thus, Majumder's adoption of oralist methods in *Muk-Shiksha* was not so much supplemented by the socio-cultural disqualification of signing, but much more nuanced in its approach and choice. This becomes evident in the first section of the book, in which he historicizes the emergence of signing as pedagogical practice by narrating accounts of educators, authors, and their books which predated the late nineteenth century turn towards oralism. This is not to say that Majumder does not narrate instances where speech is the preferred modality of teaching, but that his primary concern is with the social integration of deafness, and the ways in which deafness is engaged with in western historical-cultural texts. In Majumder's historical narrative then, texts discussing fingerspelling and signing such as Giovanni Bonifacio's 1616 treatise "The Art of Signing" is mentioned alongside accounts of oralists such as Alexander Graham Bell.

Muk-Shiksha's second section is titled "শিক্ষা প্রণালী", or "teaching methods." Here Majumder expands on his understanding of oralism before mentioning four existing methods: "the manual or sign method," "combined system," "the manual spelling method," and finally, "the auricular method" (Majumder 1903, p. 41). Even though he acknowledges that the 'combined system' may be used where oral methods are too laborious, he does not hesitate to assert oralism as being "the most excellent one," which "is presently used to teach in most schools of the world" (Majumder 1903, p. 40). Before centering oralism, Majumder addresses what he perceives as a pronounced social response to deafness, where it is equated with an inability to speak. He then locates the intervention that oralist methods, and by extension, his

book would provide in such cases where a nonspeaking, deaf person can be taught to speak through careful instructions, sustained care, and the use of ‘specialized’ methods. Thus, in Majumder’s construction of deafness, while it may lead to the absence of speech, such a state can be eventually ‘recovered.’ Using a situation where he describes that a Bangla-speaking and hearing infant understands the language because she heard it being spoken by her family members since childhood, yet the same infant would not understand English because she had never heard it before, Majumder substantiates his claim that it is lack of hearing that causes the inability to speak. Thus, he declares that “the deaf don’t have to be mute forever” (“বধিরগণ আজন্ম মূক নহে”) (35). In this regard, Majumder also explains—perhaps to remind his readers that speech is not out of bounds for deaf students—the biological processes involved in the act of verbal communication and the use of specific methods such as lipreading, or tactile communication by touching the throat (which he describes as an instance of teaching blind and deaf students). He expands on the latter point to bring up the question of homophones, with examples such as “আতা – আদা” and “আঠা – আটা” (both sets of words are similar sounding) (40), which may not ordinarily be distinguished by the deaf student through any oral method. The solution, Majumder contends, is in contextualizing similar sounding words through their use in sentences, writing that “একটি পদ দ্বারা আমরা ভাষা বুঝি না, আমরা বাক্য দ্বারা তাহার অর্থ চিন্তা করি ও বুঝি” (we do not understand language through figures of speech but rather it is through sentences that we understand and think about its meaning) (40).

This section then leads to several pages of pictorial-phonetic exercises where Majumder describes grammatical schemes, rules of pronunciation and word formation using

the Bangla alphabet. Further, Majumder includes extensive footnotes which guide the reader/instructor towards properly using the lesson, as well as clarifies certain basic concerns which may develop over its course. Among the teaching methods he uses are sound repetition, and word-picture and word-sound association, where the complexity of words are compounded with increasing number of syllables. Interspersed with pictures of the objects, around which such exercises are written in most cases, there are thirty-two lessons (“পাঠ”) in this section. Not only do such lessons include instructions on grammar, word and sentence formation, they also detail how to read, write, and pronounce numbers, directions, names of objects, and in the later lessons, even short passages. For example, the twenty seventh lesson is titled ‘rose’ (“গোলাপ ফুল”) and has a picture of a rose above it. The passage in the lesson goes thus:

আমি গোলাপ ফুল দেখেছি। গোলাপ ফুলের গন্ধ ভাল। গোলাপ ফুলের রং অনেক রকম। অল্প লাল, হলুদে ও সাদা। আমি হলুদে ও সাদা গোলাপ ফুল দেখি নাই। গোলাপ ফুলের গাছে অনেক কাঁটা আছে। জবা ফুলের গাছে কাঁটা নাই। জবা ফুলের রং খুব লাল। জবা ফুলের গন্ধ ভাল নয়।

Translated into English:

I have seen roses. Roses smell good. Roses have different colours. Some are red, some are yellow, and some white. I have not seen yellow and white roses. Rose plants have many thorns. Hibiscus plants do not have thorns. Hibiscus flowers are very red. Hibiscus flowers do not smell nice. (Majumder, 1903, p. 56)

With its emphasis on repetition of words, continuous adherence to sentence structuring and syntax, as well as the use of abstract descriptions and context, the lessons in *Muk-Shiksha* position oralist principles as central to the kind of pedagogy that it presents. It must be recalled that this was a book addressed to not only teachers or instructors in formal schools, but also to a readership who may not have known about such developments. Their dissemination through print, in the local context of Bangla, was thus a focal point of the intervention that Majumder and Banerji had sought to make. This imperative threads through the way in which *Muk-Shiksha* is structured, appended at the beginning and at the end with historical narratives of education, and few biographical sketches of deaf persons, respectively.

Among brief biographies of deaf educators, artists, and authors outside the colony, Majumder also includes some students at the Calcutta School. His recourse to speech as a central tenet of the book becomes most prominent in these biographies of students. For example, he writes about Satyendra Basu, one such student, that “তাহার স্বর অতিশয় কোমল এবং স্বাভাবিক, তাহার সহিত আলাপ করিয়া হঠাৎ কেহ তাহাকে বধির বলিয়া মনে করিতে পারেন না।” (His voice is extremely soft and normal, no one can understand that he is deaf upon conversing with him) (88). Deafness and speech occupy equivalent positions in this instance, where one comes to be used in place of the other. Thus, in his use of biographies, Majumder relies on a thematic trope where the lives of students are qualified by bringing in the role of oralist education and the Calcutta School. Satyendra Basu later joins the Government Art College, Calcutta, after having apprenticed with a photographer in the city for two years, while simultaneously receiving lessons from a teacher at home. Rakhal Chandra Palit,

another student, is described as having humble origins, moving to the city at sixteen and studying at the Calcutta School for six years, also learning art and woodwork alongside the usual curriculum. His artistry had drawn accolades from prominent individuals, as did his work at the office of the Surveyor General of India, who also gave a testimony about Palit's work, which Majumder quotes at the beginning of the biography (90). Employer testimonials were a common feature of the biographies Majumder writes, such as in the case of Nalinikanta Basu, who had joined the school at the age of fourteen in 1898; Basu was adept in mathematics and could solve problems in his mind and was presently working at a jewelry shop in the city (94). However, in every biography, Majumder makes it a point to note the extent of verbal speech training on these students, recording the progress each made in the ability to pronounce words. This is most prominently displayed in the account of Mouli Bhushan Mukherjee, in which Majumder quotes an entire public the student gave (93).

Throughout *Muk-Shiksha*, Majumder uses variations of the Bangla word “বধিরগন” (deaf people) rather than allude to any distinction between deafness and ‘Deafness.’ This brings back a question posed at the beginning of this paper: is there a way to think of Deaf cultural identity in the absence of any significant political consolidation of the same? Signing is mentioned in passing, relegated in favor of the practicality that oralism brings to the project. Are discursive parameters around Deafness then complicated in the specific context of the colony, where oralist methods were predominant, at least in the first two or three decades of the twentieth century? It cannot be denied that the work of educators and advocates such as Majumder, Desai, Date, or Banerji, brought the matter of deafness into the colonial print and public spheres, even though their terms were rooted in a fundamental

understanding of deafness as difference, where deafness could eventually be ‘reformed.’ The histories of colonized Deaf students archived in *Muk-Shiksha* and plotted alongside moments, texts, and biographies from the metropole, thus underscore what social integration means to Majumder, resonating in many ways with the reformist politics of the Calcutta School. I use ‘Deaf’ here to suggest a certain imagination to which *Muk-Shiksha* subscribes. This was an imagination premised on oral education as entailing social emancipation by its integration into a nondisabled space of difference. Graduates from the Calcutta School went on to establish deaf schools in other parts of colonial Bengal, such as Chittagong in 1923 and Rajshahi in 1931, both in present day Bangladesh (Bhattacharya, 2012, p. 14). It was through such mediations by Indian educators that early forms of advocacy were possible. In the absence of any organized mobilization around deafness or any attempts at contesting what was nondisabled, hearing, and normative, the question of a Deaf identity was contingent upon narratives produced by such advocates and educators. Yet, by recording and circulating life histories of Deaf students, by forming and tapping into regional as well as transnational networks, and by lobbying against the colonial state about resources and aid, there was an attempt to bring it into public circulation and thus fashion a political constituency populated by Deaf as well as hearing advocates.

Conclusion

This paper has argued that the incidence of oralism in the colony was distinct from how it had come about in the metropole. Where the colonial state was unconcerned with educational reform for its disabled subjects, it was through the work of missionaries, landed classes, and most influentially, Indian educators and social reformers, that disability had

come to be written about, discussed, and spoken for. Since there was no consolidated mobilization around signing, and because it was deemed difficult to incorporate within classroom settings, the adoption of oralist pedagogy had occurred without much resistance. However, this had entailed the formation of networks among advocates and educators both within the colony and outside it, through which they had engaged with resources, concepts, and methods used in educational practices in the metropole. *Muk-Shiksha* was one of the earliest texts on the instruction of deaf students in the colony, where it had sought to address the absence of any such material for a localized reading public. By adapting methods and principles drawn from the metropole in the specific linguistic-cultural context of colonial Bengal, *Muk-Shiksha* had aligned deafness with processes of educational reform, although such intervention was premised upon the centrality of verbal speech and to bring into its fold deaf students. Building upon the pedagogy of the Calcutta Deaf School, this text had thus, imagined a colonized deaf subject who could be made 'modern' using oralist training, and who could be integrated into a normative, hearing and speaking social sphere. Conversely, it was through such processes that the formative aspects of political representation for Deaf persons were possible in the specific context of the colony, however limited they may have been.

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Footnotes


ⁱ All translations from Bangla to English have been done by the author of this paper, unless specified otherwise.

ⁱⁱ In the final section of this paper, I mention my reasons for using ‘Deaf’ in some places. While ‘Deafness’ is premised around sign language as the center of its political and cultural identity, I argue in this paper that the conditions for any such mobilization were not available in the specific context of colonial India. Thus, I use ‘Deafness’ to refer to moments where Deaf lives are capacitated and written into history by mostly hearing advocates and educators. Their construction of Deafness, even though it comes through as a result of oralist education, is a primary focus in this paper. I go on to argue that such constructions were complicated by the political imaginations of hearing advocates, and simultaneously, by their upholding of deafness as difference.

ⁱⁱⁱ ‘Gurmukhi’ is a script which continues to be used in western parts of the Indian subcontinent, mostly in the Punjab region of undivided India.

^{iv} *The Association Review* was brought out by the American Association to Promote the Teaching of Speech to the Deaf. This organization was instrumental in oralism gaining significant ideological traction around deaf pedagogy, and subsequently the cultural marginalization of manual signing.

^v This phrase is taken from a Sanskrit verse in the Hindu religious text the *Bhagavat Gita*.

 Reading Mohini Mohun Majumder's *Muk-Shiksha: Special Education in Colonial India* by Tirtha Pratim Deb
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Categorizing Disability: Perspectives from West Bengal, India

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Abstract

This paper explores the ways in which disability as a conceptual term existed prior to colonization and was reshaped during colonial and later times, trying to name and capture both human conditions and experiences, which reflect the social attitudes of the communities within which these concepts are used and manipulated.

Keywords: disability, colonialization, postcolonial, decolonial

Categorizing Disability: Perspectives from West Bengal, India

Postcolonial and decolonial studies have engaged with global structures, experiences, and discourses of colonial domination, particularly those of marginalized people, whose experiences, imaginations, and knowledge of the world count less, or simply do not count at all (Gallien & جاليان, 2020). Postcolonial scholars and activists orient their academic work towards the recovery and re-articulation of the knowledges of particular communities that colonialism has displaced. While postcolonialism has been oriented towards theoretical propositions within the academy, decolonial interventions position themselves within political activism and social movements (Colpani et. al 2022). Vazquez (2009) highlight that social struggles challenge and define the oppressive grammars of power, that are often re-signified with meanings that emerge from political practices, alternative forms of justice, and other ways of living.

In India, the colonial project of “modernization” of the native population led to the negation of all that was perceived to be local and indigenous by the process of changing ideas and practices of everyday life and processes of production and consumption. The retrieving of pre-colonial knowledges traditionally diminished by colonial narratives of progress must recognize that indigenous communities also fostered notions of the “other,” which were drawn upon by colonial administrators, that intrinsically altered and mediated their pre-colonial forms. Thus, definitions of disability, which emerged as a distinct category during

colonial rule in India and have been modified by modern global discourses, represent a hybrid co-formulation of cultural identities, wherein the traditional/indigenous blends with the colonial framing and the modernist re-envisaging. This paper argues that this idea of hybridity challenges the decolonial claim that alternative situated knowledges may successfully delink from the colonial matrix of power while acknowledging that indigenous matrices of power also influence ways in which the decolonial project re-envision these concepts. Thus, categories such as disability are constructed through diverse spatio-temporal and cultural frameworks that remain inextricably intertwined and co-exist with one another.

The reconceptualizing of the category of disability during colonial times was further extended in the postcolonial independence period, when the state in India grappled with policy frameworks around disability deeply influenced by western perspectives. This paper explores the ways in which disability as a conceptual term existed prior to colonization and was reshaped during colonial and later times, trying to name and capture both human conditions and experiences, which reflect the social attitudes of the communities within which these concepts are used and manipulated. The first section of the paper draws on historical and archival literature on disability in pre-colonial India and analyzes the ways in which disabled people and disability were included within society. The second section delves into colonial and postcolonial policies and legal frameworks that draw primarily on Western philosophical principles and yet have come to influence and structure thinking around disability in the present day. The third section uses empirical data from the districts of Kolkata and South 24 Parganas West Bengal, primarily personal narratives of five disabled women and their family members, to demonstrate how the dynamic processes of naming have

shaped the everyday worlds of women with disabilities. Data is also analyzed from a focus group discussion with six women with disabilities, where language and identities were debated. All the empirical data were collected during 2022-23 as part of an on-going project²³ with girls and women with disabilities. The paper concludes by pointing out that decolonial assertions of constantly shifting conceptual frames blend traditional/indigenous pre-colonial and colonial understandings of disability, leading to historically specific cultural ideas around disability and disabled people.

Disability Nomenclature: Indigenous Ways of Defining

As India is varied in terms of geographical regions, religions, languages and cultural practices, disability has also been described in various ways. Western scholarship around disability has highlighted the different ways in which people in positions of power use language to represent disability as a discrete category, yet both definitions and attitudes are never simplistic in nature (Garland-Thomson, 1997; Hughes & Paterson, 1997; Lonsdale, 1990; Shakespeare, 1996; Oliver, 1990). Critical disability studies scholarship (Goodley 2013; Meekosha 2011) has also pointed to the fact that, even though 70% of the world's disabled population lives in developing countries of the global South, Western philosophy and ethics define disability almost all around the world, with European terminologies dominating the discourses of disability. Addlakha (2013) refers to how researchers have begun to look beyond medical terms and management and rehabilitation to find experiential reality of disability. Ghosh (2016) argued that the lived experiences of disabled people

²³ Most of the empirical data in this paper comes from the ongoing project titled "Engaging Girls and Young Women with Disabilities across Southern Spaces" (ENGAGE) in collaboration with Carleton University, Canada.

indicate different degrees and levels of social inclusion, although historically socio-cultural ideologies always represent disability negatively, and often are strengthened by the social barriers that are designed to exclude. A decolonial approach here would necessitate juxtaposing such ideologies against lived experiences of disability, to unravel the various levels at which categories are ideologically imposed yet lived, experienced, and resisted.

There is a need to recognize that disability is felt and thought of through language, which is influenced by culturally specific social ideologies. Colonial expansion in India sought to introduce standardized terminology to even out the “outdated” or “barbaric” language and cultural variations and to ensure they were able to use familiar definitions, which was also a technique of asserting power. The writings of European travelers in India highlighted several religious beliefs and repulsive customs they could not interpret.²⁴ These ideas were further concretized into stereotypes with the occidental mentality overpowering the existing narratives (Said, 1978).

Hindu mythological stories are replete with references to disabilities and deformities across time. The Vedas refer to the god Vishnu appearing as a dwarf in one of his avatars, while the epics Mahabharata and Ramayana have the characters of a hunchback Manthara and ineffectual king Dhritarastra respectively (Miles, 1995). All these representations are of either evil or weak people, highlighting that it is about the deficit of the body and mind and the viciousness of these “evil” characters lead to greater misfortune (Ghai, 2018). Disability

²⁴ India was often looked at as irrational, a land where imagination overpowers reality and a land with no sense of history (Sharma, 2003). ‘Superstitious’ practices and sacrificial rituals, ‘dirty’ crowded city life repulsed the British who came to India. For example, the British found the presence of Hijras or eunuchs (a transgender community) starkly in conflict with their Western morality and conception of gender. Other ideas about India, including European superiority, were modeled on these perceptions as well (Hinchy, 2019).

is repeatedly represented as a punishment of the deeds (or a consequence of sins) from the previous life (“karma”), especially as a prescriptive text of the Vedas, *Manusmriti*, highlights (Miles, 1995).

Disability is also represented as a retributive consequence of sins committed.²⁵ For example, one who steals a lamp will become blind (Olivelle, 2005, quoted in Burley, 2013). The story of Ekalavya²⁶, a tribal boy in the epic Mahabharata, illustrates how disability becomes the fate of those who want to climb up the social hierarchies (Ghai, 2018). There is also mention of special powers²⁷ possessed by persons with disabilities as gifts from God (Bhaduri, 2021). What must be kept in mind is, though these religious texts and scriptures depict and prescribe certain ways of life and norms of society, Brahmanical texts or Manu’s laws do not have the doctrinal authority such as the Bible in representing people’s roles or perceptions about different individuals (Tyagi, 2008; Anand 2013). They can be studied as a valuable source of information about changing perceptions in an ever-evolving society or how certain ideological constructs came about (Anand, 2013). The Mauryan times saw the introduction of vocational rehabilitation of physically, socially, or economically handicapped people (Miles, 1995; Anand, 2013). Several rulers throughout history took up benevolent

²⁵ A Brahmanical law book, *Manava Dharmasastra* (c.200 CE), mentions how evil men become disfigured due to the bad deeds they have committed (Olivelle, 2005). A fear of retributive punishment also operates where one must behave well towards disabled or other disadvantaged people in society to assure one will be treated well in the future or not be reborn disabled in the next life (Burley, 2013).

²⁶ Ekalavya had mastered the skill of archery but was punished by his Guru Dronacharya by cutting off his right thumb for breaking social norms and aspiring for skills not meant for his social group.

²⁷ Surdas (1478-1581), a saint and poet, blind from birth, was known for his spiritual insight and encouraged people to seek a deeper connection with the god Krishna. Ashtavakara, in King Janaka’s court, born with eight physical deformities, displayed exceptional intelligence in several philosophical debates showing his knowledge and prowess in the understanding of Vedas and Upanishads (Ghai, 2015). Thus, though stigmatized, people with disabilities are often depicted with significant gifts. Many Southeast Asian, Indian, and African beliefs surrounding disability (and re-incarnation) hint that children with disabilities are often a gift from God or sometimes an ancestor reborn in the family (possessing the spirit of the ancestor) (Kalyanpur, 1999).

initiatives to give aid and grants to build shelter homes for the poor, sick, and disabled (Karna, 1999). Kautilya's *Arthashastra* (4th century BCE) clearly mentions penal provisions in the form of fines for use of discriminatory language, mockery and abuse of people with disabilities. Such penal provisions clearly indicate that impairment was blended with the identity of a person, where disability was seen as part of a mind-body complex (Miles, 1995). The perception of being "defective" meant that persons with disabilities were often excluded from the inheritance laws and denied access to important social positions like king and priest. These lists of exclusion from social positions specifically mentioned impairment categories, where disability was put on a similar footing as being female (Jain, 1947; Raghavachariar, 1965 cited in Miles, 1995). While disqualification based on disability was written about in several texts, special directives are seen for *upanayana* (thread ceremony) of male children who were "blind, deaf, crippled or idiots," not for the purpose of education but for enabling them to marry (Miles, 2006).

The tradition of care and benevolence continued until the Mughal times when there is documented evidence of a deaf woman raising hearing infants who communicated through signs during the rule of Mughal Emperor Akbar in 1578-82 CE. However, such experiments towards the education of disabled people or attempts to better understand their lives were scattered and very few (Miles, 2006). What pre-colonial history presents is a non-prescriptive, non-uniform understanding of disability, couched in speculative language, often open to the interpretation of the people reading different texts of Brahmanical traditions (Anand, 2013). What emerges clearly is the fact that, while there are precise prescriptions and proscriptions that define the ideologies toward persons with disabilities, there is little

evidence that indicate the lived realities were probably different, with disabled people being included within families and communities in varying degrees. It was the European business companies and accompanying Christian missionaries in 17th to 18th centuries who then began to take up charity work with natives to support the disabled, orphaned, and poor women and children with monetary funds (Miles 1997, 2006). This next section discusses how Western concepts of disability, colonial rule, and policies changed the understanding of disability in India.

Colonial and Postcolonial Interventions: Changing Terminologies

British rule in India introduced administrative mechanisms, with a view to control the populace and generate cheap labor for industrial capitalism. Census operations were started in India to gain more knowledge about the people and their various cleavages. The census thus created categories to classify the population into groups. Like religion and caste, a category was created labeled “infirmities” mostly to designate people with disabilities (Waterfield, 1875). The focus on infirmities reflected a capitalist mindset of productive persons as against people in need of support and charity (Oliver 1990), which would enable the capitalistic “civilizing” mission of the colonial rulers. Thus started the formal categorization of infirmities from 1871-1872 whereby “blind, deaf, insane and lepers” were initially identified as relevant categories by the British administration and census enumerators (Waterfield, 1875). The terminology introduced by the colonizers reveal that they were using familiar frames from their own country to categorize the population in India as these groups of people were perceived to be incapable, non-productive, and in need of support within the framework

of industrial capitalism. Thus, colonial, and missionary energies were to be channeled towards the mission to provide for these groups.

According to Davis (2013), the concept of “normal” as conforming to, not deviating or different from the common type or standard, regular, or usual, created the idea of the “abnormal,” a deviation from the statistical average or majority, to arrange people in ways that are socially and economically convenient for society (Linton 1998). By equating disability with the abnormal, of being the “non-productive,” “deviant,” and thus “undesirable” in society, the administration sought to govern them separately. Census operations in colonial India sought to create uniform categories, by using standardized definitions and instructions to enumerate disability that could be comprehended adequately by the British administrators. However, such categories were inadequately defined due to poor knowledge of the social and cultural cleavages of the communities within which they were to be applied.²⁸ For blindness, only blindness in one or both eyes was counted. Also, congenital cases for deaf-mutism [sic] and only ‘black or true’ leprosy²⁹ were in the initial census instructions. The vital nuances that led to the cause of many disabilities were

²⁸ To enumerate and understand the population of India, one of the categories that was introduced was caste. There was confusion among the population of India itself where the general perception was that the object of the census was to impose some new tax (*Report on the Census of Calcutta in 1866*, Calcutta: Thacker, Spink and Co. Press, 1866 p.1). Muslims listed their caste, even though they are assumed not to have caste system in Islam. The colonial administrators categorized caste based on their own pre-existing understanding of caste. Caste names were often introduced by enumerators themselves, e.g., in Punjab members of an indigenous tribe were labelled as being Rajputs, while they were unaware of such a caste itself (*Report on the Census of Punjab, taken on the 17th of February 1881*, Vol I, p. 485). Bayly (2001) writes that most of the people in India gave very limited importance to the formal distinctions of caste, where social identities which were malleable were of importance. It was because of the colonizers attempts to make sense of the Indian culture and its people, enumerating the population through census, that they began categorizing and defining, simplifying complex and diverse systems of faith and social identities for their own benefit (Walby, K. & Haan, M, 2012).

²⁹ Buckingham (2002) while elaborating on Leprosy in Colonial South India writes how the census enumerators were only instructed to note the presence of “true or black or eating leprosy” in the British Indian census. While there were no descriptions given as to what could be the identifying symptoms, it can be presumed to refer to signs of physical deformity.

conveniently ignored.³⁰ The translation of these instructions into regional languages created more discrepancies in counting. For example, the word *kana* in Kashmir meant the loss of vision in one eye only, while *andha* and *nabina* meant complete blindness. The terms had different meanings in other regions. Untrained officials further confused the statistics by wrongly categorizing people in different regions, creating negative attitudes and facilitating the creation of the “other,” the “abnormal,” within the Indian population.³¹

British categorization of the undesirable extended from the ‘unproductive’ disabled people to the labeling of the indigenous tribal population of India as criminal castes because of their “barbaric” livelihoods leading to increasing discrimination, segregation and constant surveillance. Both groups were regarded as challenging the aesthetic of the cities, which affected the modernization process of the British. The perception that beggars with disabilities in emerging towns and pilgrim centers were carriers of the “foulest diseases” (Nair, 2017, p. 193), led to the rise of several institutions that segregated disabled people from the general “productive” population and furthered the colonial and missionary objectives of “care,” treatment, and “cure.” This segregation helped to eliminate the “inferior” population from sight. The effort was to bring India out of its “civilizational inferiority” with medical interventions and technological experiments. The decrease in the

³⁰ The census enumerators were not trained to identify disabilities. Often stereotypical ideas about the “orient” like climate and harsh tropical weather conditions, or lack of organized social organizations would be attributed to causes of disabilities (Bhaduri, 2021).

³¹ With the segregation and confinement of people with disabilities, often being identified as lepers or insane, led people to believe that they were virtual criminals and thus liable to be relegated to prison-like institutions for care and treatment (Bhaduri, 2021). Many mendicants were often looked at as “blots of civilization,” spreading disease and dirtying the cities, and needed to be segregated, confined as the mobile nature of disabled mendicants posed a challenge to law and order as well as the aesthetics of the city (Nair, 2017).

number of infirmities reported in the 1891 and 1901 censuses was used to prove that efforts to solve the “problem” were working (Bhaduri, 2021).

The civilizing mission of the colonial rulers was buttressed by the rampant export of Western ideas and language to the colonies with the British. The colonial administration began segregating the disabled into two categories: one group being dangerous or dependent requiring confinement and the other, as educable, which shaped the legislation and policies for the disabled.³² The identification and categorization process defined by the medical definitions and subsequent segregation, resulted in a concealment of disabilities of women and of people of upper castes. The colonial administration, with its racist prejudices, started labeling certain groups as infirm, as is evident from the categorizing of indigenous fire worshippers or Nat worshippers within the category of insane.³³ Such prejudices encouraged people to conceal crucial information about disabilities, leading to census data being inaccurate in many instances.³⁴ The attitude towards people with disabilities came to be framed in different ways - the colonial administration promoted family care, while missionaries and native elites encouraged cure and care in the form of segregated institutions

³² There were anti-begging laws and also laws prohibiting “wandering” without any “worthy means of subsistence” even if not asking alms was considered a criminal offence. With the Bombay Plague in 1890s, a beggar would be liable to one-month prison sentence and Rs.50 fine if seen “wandering” around the city (Nair, 2017). The Bengal Vagrancy Act (1943) also prohibited begging for alms—as mendicancy was a primary means of livelihood for many people with disabilities in colonial India, these laws were clear display of displeasure by the Colonial Government (Nair, 2017). Some other legislations are Lunatic Asylum Act, 1858, Lunacy Amendment Act 1889, Indian Lunacy Manual 1909, and Indian Lunacy Act of 1912, and Lepers’ Act of 1898 and many more (Nair, 2017).

³³ *Report on the Census of British India taken on 17th February, 1881* (Vol I), “The Highest proportion of insane persons is found amongst Nat worshippers, where it is 1 in 909.” Insanity has also been attributed to the excessive indulgence in ganja and opium (pp. 257, 263, 264).

³⁴ Nair (2017) highlights how blindness was the least concealed infirmity, deaf-mutism [sic] too wasn’t much of a problem when taking the census data in many cases; however, translating the census definitions became an issue initially. The colonial administrators did encourage family care to justify their lack of direct investment. Nair (2017) cites letters from the educational inspector from 1890 (p. 191) to highlight how British interference would “weaken the existing sense of responsibility” of families.

of vocational training, where people with disabilities could be taught to become self-reliant. Here the missionaries also had the agenda of spreading the gospel of Jesus while promoting benevolence towards disabled people. Some of these institutions also attempted to promote education as a worthy means of income. An asylum in Banaras was set up in 1826 by its Hindu ruler for blind and poor people, primarily to restrict their movements within the city in the guise of charity. Voluntary contributions from wealthy native elites and nominal government aid for missionary-run institutions were also popular. Since beggary was considered an “unworthy” form of livelihood, missionaries focused on teaching the gospel to the disabled people brought to asylums and institutions of care. The Braille and Moon system helped in spreading the education for blind people in the Christian scriptures even more³⁵. Several people from these schools later spread the gospel in their own villages (Miles, 2001).

Schools in Bombay, Madras, and Calcutta came up under missionaries and pioneering natives to educate blind and deaf-mute [sic] children. The aim was to provide education and vocational training to enable them to choose professions such as carpentry, turban-making, tom-tom making, painters, typist, blind educators for blind children, etc. which were seen as more civilized means of income (Nair, 2017, Bhaduri, 2021). While these became centers of charity, the British administration also demonstrated that the infirm could be “self-reliant” and “productive.” Segregation of the infirm (especially the lepers and lunatics) into colonies and asylums also helped control spread of diseases, which the census and administrative

³⁵ Moon type or Moon system of written letters was developed by William Moon in Sussex, England, to enable blind people to read. It used Latin alphabets with raised curves, angles, and lines. It was introduced in 1845. Braille, named after its creator, Louis Braille was invented in 1824, where raised dots are used to enable blind people to read with their fingers. Braille is a code which may be used to write in many languages. Source: <https://www.britannica.com/topic/Braille-writing-system>

documents showed as a push towards modernization. The census dropped the category of infirmities in 1941, revealing the shifting priorities of the government and reflecting indifference towards the disabled population in India (Bhaduri, 2021). However, by this time, the disabling language accompanied by the negative ideologies around capacity gained importance, leading to the popularity of the western medical interventions that focused on integrating the disabled into mainstream society (Mani, 1988 cited in Ghosh, 2012)³⁶. Institutionalization changed the ways in which persons with disabilities were treated in India. Informed by the Christian missionary zeal for charity, the institutions for disabled people portrayed the disabled as “unproductive” and dependent, negating the ideologies prevalent in Indian society. These institutions also ignored the actual lived experiences of disabled people and the various degrees of inclusion in different family and community activities. For example, many blind Muslims used to earn a livelihood by acting as a Hafiz, a person who could recite the Quran in religious gatherings. However, the Europeans regarded them as people propagating the Quran without true understanding and thus a regressive profession (Nair, 2017). Based on the premise that many of the traditional professions of the “infirm” were regressive in nature, laws like Lunatic Asylum Act, 1858, Lunacy Amendment Act 1889, Indian Lunacy Manual 1909, and Indian Lunacy Act of 1912 outlined several procedures on institution and asylum management especially for mental illness, ignoring the existing social inclusion of disabled people. Similarly, the Lepers’ Act of 1898 defined lepers

³⁶ Even after independence in 1947, the general attitude towards people with disabilities surrounded that of charity and welfare. The government maintained a reluctance to formulate a disability policy. It was the language introduced by western medical interventions that featured in the first Plan (the Planning Commission in India was entrusted to make plans and programs for the development as well as for different sections of the population of India). The definition of disability had a strong medical bias and sought to influence the state’s stance, bias and orientation of the population of India towards people with disability (Ghosh, 2012). The concerns of people with disabilities were often granted low priority (Mani, 1988, cited in Ghosh, 2012).

as “prisoners” (Buckingham, 2002), who must be incarcerated in asylums or institutions, outside the city beyond the public gaze. Imperial interest in hygiene, infections, and colonial diseases and maladies as the cause for many disabilities led to the establishment of institutions like the Calcutta School of Hygiene and Tropical Medicine in 1922, pushing the discourse of disability into the medical frame, promoting marginalization, suppression, and further segregation of the disabled. Removed from the traditional familial structure of care and subjected to isolating institutionalization, people with disabilities became further exposed and vulnerable within society (Choudhury Kaul et al., 2021). While the colonial administrators reached out to many poor, destitute, and disabled people with their zeal for a civilizing mission (Dalal, 2002), the larger attitude was to ignore the native cultural and indigenous belief systems of Indian society (Mehrotra, 2011).

Thus, the colonial project of identifying and segregating “the infirm,” indicating the people with disabilities and labeling them as being “unproductive” and “dependent” populations, attempted to use uniform standards for identifying and dealing with persons with disabilities, thereby ignoring the huge diversity within India, geographically, culturally, and linguistically. The category of “the infirm,” which subsumes what is presently discussed as disability, as envisaged and postulated by the colonial administration, sought to pathologize persons with disabilities, popularizing the discourse of institutional dependency (Ineese-Nash, 2020), where these “dependents” could be led towards some form of productive labor as prioritized by colonial capitalism. Such an individualistic conceptualization of infirmity and disability by British administrators demonstrated not just the ignorance about local social arrangements, but also the power relations that allowed them to unilaterally define the people

and their social realities. What such magnanimous colonial and missionary interventions largely ignored were the ways in which communities and families in the geographical spread of India structurally and systemically addressed the issues concerning persons with disabilities and the extent to which they were included and able to live within their own communities.

In Independent India, the Constitution framed in 1950 abolished disabilities like untouchability and prohibited discrimination of Indian citizens within the country based on religion, race, language, and sex; disability was mentioned only in terms of care and protection (Advani, 1997). The Constitution of India refers to disabled people only in Article 41, assuring that the state shall “within the limits of its economic capacity and development” make adequate provisions for public assistance in cases of unemployment, old age, sickness and disablement (Ghosh 2016). This is indicative of the general attitude of the state in India towards persons with disabilities, colored by ideas where disability was associated with *karma* and disabled people looked down upon as objects of pity. The welfare approach extended towards all identified disadvantaged sections of society, where people with disabilities were grouped with women, children, scheduled castes, and tribes. The state in India, following the colonial directives, initiated welfare schemes for them and started to normalize people with disabilities to the extent possible (Ghosh, 2012). However, social stigma and the lack of adequate healthcare facilities created an environment of discrimination and the exclusion from society. In the 1950s, the National Council for Handicapped Welfare started to roll out disability rehabilitation programs in the country (Mehrotra, 2011), also

using medicalized concepts, definitions, and ideas of disability, with little input from people with disabilities.

The Census of India operations excluded disability as a category until 1971, reflecting general apathy towards people with disabilities. In 1981, disability as a category was reintroduced into the Census where the terms used — “totally blind,” “totally dumb,” and “totally crippled” reflected the larger mindset of the state administration. The data generated from the Census led to the initiation of education programs for disabled children like the Integrated Education of Disabled Children scheme (IEDC) in 1974 and the Project Integrated Education for the Disabled (PIED) in 1987. Both these schemes however were focused only on the educable categories of people with disabilities: the blind and the locomotor disabled. Most of these programs met little success due to lack of infrastructure or trained teachers, and the negative attitudes of society affecting integration of disabled students in mainstream classrooms (Advani, 1997, Mani, 1988). With the coming of Universal Primary Education in 1997, all children with disabilities were technically deemed to be eligible for education, but the actual implementation of the programs left much to be desired (Ghosh 2016).

In the 1990s, the first legal frameworks specifically for persons with disabilities began to emerge in the form of the Persons with Disabilities (Equal Opportunities, Full Participation and Protection of Rights) Act 1995 (also referred to as PWDA 1995), and The National Trust Act 1999 for persons with cerebral palsy, intellectual impairment, autism, and multiple disabilities, mostly in response to international pressures and the discourses emerging from the West. Thus, these laws borrowed heavily from the social model of disability in terms of individual rights and entitlements guaranteed to persons with disabilities but adopted

medicalized definitions of disability (Ghosh 2022). As Dhanda (2008) has argued, the welfarist approach ensured access to social and economic rights, which were seen as progressively realized based on availability of resources. Entitlements were protectionist in nature, with concessions granted to persons with different disabilities in higher education, and reservation of specific posts in government services and legal guardianship promoted overtly for certain groups of disabled people perceived to be more dependent. On the other hand, the absence of civil political rights from the disability rights discourse with their immediate availability and justiciability meant that persons with disabilities had to continually negotiate for their rights (Dhanda 2008). Yet the PWDA 1995 recognized attitudinal, social, and environmental barriers in its text, which was the result of the efforts of disability rights activists, who promoted the language of the social model during the framing of the law.

Drawing inspiration from the UNCRPD 2007, the Rights of Persons with Disabilities 2016 talks of disability as diversity, yet names disability using medical terms. While the UNCRPD clearly avoids any medical terminology in the definition of disability, Indian laws, even while acknowledging the UNCRPD definitions, prefer to use medical terminology in the identification and labeling of persons with disabilities. The RPD Act of 2016 lists 21 medical conditions as disabilities and lapses back into medical modes of identification, rehabilitation, and intervention, without giving due importance to the stigma and discrimination faced by persons with disabilities in everyday life. What these laws have in effect done is to provide disabled people terminology to refer to themselves, sometimes in a specific manner (cerebral palsy, blind, etc.) and at other times in a generic manner (persons with disability). Both generic and specific terms often are used in conjunction as is illustrated in the next section

where we discuss the ways in which people with disabilities and their families talk about them. As Linton (1998) points out, when persons with disabilities are designated as such by state initiative, it provides them with a tool to identify as a community, to develop a group identity and to function as a basis for political activism.

Postcolonial Identities and Disability Terminology

The present-day discourses around disability in India reflect a hodge-podge of medico-legal terms blended smoothly with communitarian attitudes that imagine disabled people, and specifically women, as weak and pitiable, yet as deserving recipients of support, with complete apathy in situations of discrimination and abuse. The ways in which identities are recounted and represented shift incessantly between the individual and community, between legal and local, and between the everyday and the problematic. This is indicative of the ways in which categories are never wholly rooted in a specific spatio-temporal cultural context but rather are an ephemeral amalgamation of ideologies that retain the inherent negativity while espousing for changing attitudes. Both disabled people and their family members alternate between, using legal terminology to refer to the disability of the person in particular situations, and vernacular terms like *osubidha* or *somossya* (problems) in other situations. As most disabled people and their families have been exposed to and “sensitized” by the legal terminology, there is a tendency to refer to the medico-legal terms “cerebral palsy” or “Down syndrome” to lay claim to power as knowledge. However, the generic term *pratibandhi* (person with disability) is often used as an identity marker that is premised on politics and not on particular embodied conditions. *Pratibandhi*, in Bengali, literally means a person who encounters multiple barriers, which could be interpreted variously. This

application of a generic term could be indicative of a certain consciousness-raising, on lines of the social model that allows disabled people and their families to use such terms as an assay of power, as if claiming the term consciously can erode the social negativity associated with the terms. This is using nomenclature or terminology in a way that helps the powerless to claim power and privilege through an assertion of “knowledge.”

Likewise, Rao (2001) had highlighted the use of colloquial language that supports the inclusion of people with disabilities. Her work on Bengali families, specifically mothers, revealed the ways in which cultural use of language focused on “inconvenience” in relation to their children with disabilities, often using it interchangeably with the word “problem” and prefixed by *ektu* (*a little*). Thus, the cultural construction of “interdependence” and support ensures that the family and community accommodate people with disabilities. These socio-cultural attitudes run parallel to medical categories of the Indian policy documents, which are exclusionary, while the colloquial Bengali terms refer to the problems both to describe the disability (“physical problem,” “mental problem”) and the issues they encounter at home and in the larger society.

Two decades after Rao’s research, we found that Bengali people make regular allusions to “normal” with an immediate caveat about the minimal difference of the disabled girls and women from other girls. The mother of Rupa³⁷, a 21-year-old girl with an intellectual disability, clearly talked of how her daughter was “*shwabhabik bachha na*” (not a normal child) but reiterated the different ways in which she had treated her daughter as

³⁷ All names of research participants have been anonymized.

“normal,” at par with other children.³⁸ The words normal and problem are used frequently by mothers and girls and women with disabilities unproblematically which is an indication of the level of colonization of their mental make-up. Rupa’s mother presents contradictory arguments by speaking of her daughter being “*thakurer moton*” (literal translation god-like but meaning passive like an idol, for whom much has to be done (Ghosh, 2016) while also highlighting that, unlike many other disabled girls, Rupa can pass as “normal” as her disability (down syndrome) is not as apparently visible. In comparison, Puja, who has cerebral palsy, has never been able to camouflage her disability and finds herself dismissed by her father and his family as “incompetent.” Puja’s mother narrated that she was forced to move out of her in-laws’ home and live at her natal place because of the lack of acceptance by her husband’s family. Class and impairment dimensions seem to affect ways in which acceptance is affected for girls and women with disabilities within families and communities.

In rural Bengal, we spoke to some women who are part of a disabled women’s collective, and it was interesting to find they used the term “*pratibandhi*” to refer to themselves using a political-legal coinage as an identity marker, but not the medico-legal terms. When asked about their childhood and the ways in which language around disability has changed, Amita stated that “*tokhon pratibandhi katha tai chilona*” (at that time there was no word for person with disability). People referred to persons with disability by their specific impairment and not necessarily in a demeaning manner. “*Tokhon boba* (mute), *kala* (deaf), *kana* (blind), *khoda* (lame) *esab katha byabohar hoto*” (then people used to talk in

³⁸ In Bengali language, “shwabhabik” means ordinary, regular, average, normal as well as natural. When mothers are using this word, the meaning they often refer to is “normal.” Source: Samsad Bengali-English Dictionary Online. <https://dsal.uchicago.edu/>

terms of physical and sensory conditions). Alia recalls when she was growing up, people used to call her “*kunji*” (person with a hunchback), using it more for description. Amita said, “when I used to go out of my house, people used to tease me by calling me *bamun* (dwarf) and gather around to watch me wherever I traveled.” Only when the women developed a disability consciousness through the collective formed some 20 years back, did they become aware of terms like “*pratibandhi*” which is generic, camouflages individual impairments, and creates a sense of solidarity crafted through a sense of discrimination (Ghosh 2022).

Pratibandhi appears to be embraced as more acceptable to people with disabilities as it brings to them entitlements like travel concessions, pensions and reserved seats in public transport. Within Indian languages, people with disabilities are commonly referred to as *viklang* or *apahij*, both words highlighting the bodily manifestation of impairments, while *mand budhi* refers to developmental disabilities. In all colonial and post-independence government reports the commonly used word was “handicapped,” thereby reinforcing the dependent status of disabled people. The media uses terms such as *langra/langri* (cripple), *andha/ andhi* (blind), *behra* (deaf), *pagal* (mentally insane) for referring to different impairments (Ghai, 2003). The present state has officially adopted the term *Divyangjan*, a term replete with religious connotations of divinity wherein people with disabilities are seen as being part of the divine. The word *Divyang* invests bodies with holiness to push for social acceptability of disabled people but actually reinforces the connotations of sin and punishment, and accommodation only within a charity/sympathy prism (Ghosh 2017). The state decision, however, did not seek or consider the opinions of disability activists about the coinage or its usage, which denies agency to an entire community on the process and language of naming. This term

dismisses the struggles faced by people with disabilities in everyday life and reasserts a negative social identity. In contrast to this, the word *pratibandhi*, the Bengali word currently being used to refer to people with disabilities, encompasses different disabilities; by asserting that barriers are not just physical, it moves beyond bodily connotations and pushes for an inclusive society.

Conclusion

According to Bhabha (1994), modernity can be understood through the continual contestation of the discourse in present times and re-inscribing “other” cultural traditions into narratives of modernity and thus transforming those narratives. This negotiation calls into question both the conditions with which modernity is typically associated and the agents that lay claim to it. In naming oneself, as Bhabha suggests, one moves from the periphery to the center, and in the process, transforms the understanding of “modernity” from and about which one speaks. In the case of disability, possibly one of the most marginalized and silenced groups of people in India, this claiming of identity and manipulation of discourse has been minimal from historical eras until the present day. The historical discourses of disability in India have always had parallel strands, where social ideologies about disabled people have coexisted with their everyday lived experiences in almost contradictory frames.

The tropes of disability in ancient and medieval India represented disabled people as incapable, weak and evil in mythological stories, religious texts and political canons, and envisaged partial and condition inclusion in everyday activities. Yet there are examples of people with disabilities playing useful roles in society as spies, singers and entertainers³⁹

³⁹ People with disabilities were employed as singers in royal courts, sometimes they were the ones who memorized the history of tribes and carried on the traditions to future generations, some learned skills and

which indicates inclusion in larger community-level processes (Miles, 1999, 2007). The colonial discourses of disability, expressed through the language and process of Census operations, however ignored much of these formulations and lived experiences, to bring about a transition from social inclusion, however partial, to ideas of perceived social exclusion, and a missionary zeal to reform. The colonial project of crafting the census category of infirmities allowed the colonial administration to push its project of modernizing the Indian masses. Over time, these colonial categories have come to dominate the existence of disabled people in India as the ideologies of disability became entrenched in social life and practices. The state in Independent India has done little to challenge the medicalized lens of the colonial discourses, remaining happy to promote charity and welfare for disabled people. Despite being a signatory to international treaties of human rights and enacting several rights-based legislations, the state in India knows disabled people through the discourse of dependence, clearly evident in the listing of particular categories of government jobs for particular groups of disabled people and the continuation of compulsory legal guardianship.

The discourses of disability across historical eras, thus have always maintained and projected negative ideas about disabled people and their abilities. Such discourses have always been couched in the language of power and abjection, where language has itself been used to categorize persons with disability, both at the level of the state and at local community levels. Bowers (1984) argued that language cannot be disassociated from the cultural context within which it occurs and the expectations about relationships between the users of the language within that context. This paper argues that, in the case of disability, the

became efficient craftspeople. Some were given jobs to make notes of secret documents in royal courts during Mughal times (Miles, 2007).

ideologies that led to formulation of official and legal categories have always been disconnected from the everyday lived experiences of disabled people. While ideologies and representation reflect the power dynamics of different historical periods in naming the other, the agency of persons with disabilities is evident from their lived experiences which point to their continued existence within communities. While colonial Census operations concretized the category of disability and bred certain kinds of exclusions, it must also be acknowledged that the pre-colonial naming of disability and the language used to represent disabled people was in sync with the colonial structuring. The colonial restructuring of the category was able to establish a cross-country uniformity of definitions, and yet the language representing the experiences of exclusion and inclusion remain rooted within communities and contexts. While medical discourses have powered much of the disability discourse in colonial and post-colonial India, the appropriation of such discourses of power by disabled people themselves has also gained traction over the last few decades of disability activism.

The tussle over naming, and claiming a name, along with the contours of usage of language, in the case of disability as structured by colonial and postcolonial discourses, continues until the present in India. Linton (1998) points out that language can convey passivity and reinforce stereotypes about disability. The present state in India uses political power to label persons with disabilities as *divyangjan*, which rallies the metaphor of divinity to compensate for bodily and mental impairments. The connection with the divine is often cited by state actors as investing power in disabled people, which will lead to changes in social attitudes, but the term itself reinforces the negative attitudes that construct disabled people as evil and monstrous in the religio-cultural ideologies. As the state seeks to

appropriate the ideological discourse of signifying disabled people in India, it erases the long struggles of disability activists who had advocated for the use of the neutral terminology, “persons with disability.” In contrast, at present the word *pratibandhi* that the disabled people in Bengal use to refer to themselves is a political coinage owned by disabled people in India. While postcolonial critical studies engage in problematizing the categories created by coloniality, it is interesting to note how the postcolonial state is crafting terminology that endorses religious ideologies and blends them with medical discourses, to negate the struggles that disabled people have been engaged in, for their socio-economic and political rights as well as for non-discrimination, respect, and dignity. The entire project of categorizing disability from a decolonial perspective therefore must prioritize the agency of disabled people to decide how they want to be named, in the light of their lived experiences within communities and in pursuance of citizenship in a post-modern globalized state.

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Inclusive Pedagogy: Rethinking Autistic Students' Behavior Using Motor Planning and Sensory Regulation

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Please note that the authors have intentionally used identity-first (i.e., autistic student) language as many self-advocates prefer terminology such as “autistic,” “autistic individual,” or “autistic student” because the person is not separated from the autism. With the aim of honoring the individual autistic experience and desire to use the terminology preferred by autistic self-advocates, this manuscript uses identity-first language. We advocate use of identity-first language when that is how the individual or group being mentioned prefers; in other words, always respect the preference of the person being discussed.

Abstract

Research suggests that sensory regulation and motor planning are differences for autistic students (Hilton et al., 2012; Moran et al., 2013; Paton et al., 2012), but so often the first approach to supporting in schools comes from an understanding rooted in behavior.

Grounded in a critical disability studies in education theoretical framework (Ferguson & Nusbaum, 2012; Goodley et al., 2019), this article centers the voices of autistic self-advocates to understand their perspectives related to how their sensory and motor needs have been misunderstood as behavior. Counter-narratives provide the foundation to illustrate critical reframing of behavior, and then the authors provide implications for educational practice for both pre- and in- service educators, with pedagogical strategies that account for sensory-motor perspective of understanding autism.

Keywords: autism, behavior, motor planning, self-regulation, self-advocates, pedagogical strategies

Inclusive Pedagogy: Rethinking Autistic Students' Behavior

Using Motor Planning and Sensory Regulation

As autism becomes more prevalent, and more and more autistic students are included in general education classrooms and settings, it is crucial that we continue to seek to understand and better support our autistic students. To illustrate the importance of this, we offer a couple of examples from our own experiences as educators; in these, re-thinking what we knew about a student and the student's experience changed the approach to supporting the student within inclusive educational settings.

For the first example, an autistic student attending his local public school was struggling with the afternoon bus routine, specifically in getting on the bus to go home. As we observed the scene, a bottleneck occurred at a bus as a line of students was growing behind one student and three adults. The student had one hand on the railing but was standing firmly on the pavement. He raised his left leg up to the stair multiple times, each time setting it back down. The student's support team offered candy to motivate and reward good behavior (getting on the bus), prompted the student to "do it quick," and recorded his behavior to gather data of what they viewed as "non-compliant" behavior. It took re-thinking what was happening for the student through a sensory-motor perspective to then change the approach. After making this shift, the team offered visuals and support in planning what steps were involved in physically stepping up onto the bus to resolve the issue for this student.

The second example features a third-grade student with labels of autism and fragile x syndrome who was new to the school and soon after arriving was given a three-day suspension for repeatedly stripping in school. This student was known for his outfits which

generally included coordinating bright color shirts, shoes and jeans. The team implemented several behavior interventions to no avail. Finally, during the suspension, a paraprofessional asked if something about the clothes themselves might be bothering him; the student bought a shirt that they now cannot wear it because the seams were so scratchy. Everyone else was skeptical, but after several behavioral interventions were unsuccessful, the team determined it was worth considering the clothing. They then changed approach, working with the student's parents to offer options for clothes in the morning: the student chose sweatpants, Velcro shoes, and t-shirts which were more sensory friendly and caused much less stress throughout the day, minimizing the need to strip. In each of these examples, it was crucial to understand autism and what was going on for the student through the sensory-motor perspective of autism to support the student in navigating their educational environment successfully.

The purpose of this article is to support pre- and in-service educators to understand the sensory-motor perspective of autism through centering the voices of autistic self-advocates. In the following sections, first guiding research on autism, motor planning, and sensory regulation will be explored. Next, the theoretical framework that guides this article, critical disability studies, will be discussed. Third, the voices of autistic self-advocates who have written about their sensory regulation or motor planning differences are examined. Finally, the implications for educational practice and pedagogical strategies for pre- and in-service educators are discussed.

Guiding Research

Within federal special education law, autism is:

a developmental disability significantly affecting verbal and nonverbal communication and social interaction...that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.

(IDEA, 2004 [§ 300.8 (c)(1)(i)])

Researchers have long argued that sensory and motor differences are critical to recognize (Bluestone, 2005; Dhossche, 2004; Donnellan et al., 2013; Endow, 2006) and the phrase “sensory and movement differences” used in this article intentionally accounts for the complex interaction between these two, as well as the associated motor planning, catatonia, sensory processing, and echolalia (Donnellan et al., 2013; Thelen & Smith, 1994). It is important to note the word “differences” is used to suggest that “unusual challenges and exceptional skills can exist side by side, in the same brain domains” (Amos, 2013, p. 140).

Motor impairments have been routinely documented in the literature as impacting autistic students (Boucher, 2003; Hilton et al., 2012; Liu, 2012; Ming et al., 2007), and even for desired “movements involving simple grasp and reach-to-grasp sequences,” motor difficulties interfere with hand coordination (David et al., 2012, p. 324). In the first example mentioned, motor-planning was at the core of the student struggling to get on the bus. Once this was considered, the student could be supported successfully. Research suggests that sensory processing has long been an associated difficulty for students with disabilities

(Jasmin et al., 2008; Moran et al., 2013; Paton et al., 2012; Tomchek & Dunn, 2007). As Robledo et al. (2012) suggest, we might see this “behavior as less a social inadequacy that fits our definition of autism than an individual’s best attempt to overcome a sensory problem that otherwise would interfere with [his] attempt to interact” (p. 68). In the second example mentioned, the student’s behavior of stripping was ultimately understood to be the student’s attempt at sensory relief from uncomfortable and unbearable clothes. Robledo et al. (2012) state, “Sensory and movement differences is [sic] a disruption in the organization and regulation of perception, action, posture, language, speech, thought, emotion, and/or memory” (p. 68).

Grounded in a critical disability studies theoretical framework, we center the perspectives of autistic individuals to give them power and agency; this all points to the importance of recognizing the motor planning and sensory complexities inherent in the experiences that autistic individuals share. According to advocate and scholar Linton (2005), disability studies “aims to expose the ways that disability has been made exceptional and to work to naturalize disabled people” (p. 518). Ferguson and Nusbaum (2012) describe disability studies as an interdisciplinary field that can be messy and complicated. They state the following about its core concepts: the study of disability must be (a) social, (b) foundational, (c) interdisciplinary, (d) participatory, and (e) values-based (pp. 72-75). Ware (2009) explains the importance of critical analysis in disability studies in education, stating “In the absence of such critical analysis educators will continue to deny the intrusive paternalism of the existing system, disbelieve that the system reinforces stereotypes of dependence and inferiority, dismiss the logic of the social construction of disability, and

dispute their own complicity in pathologizing disability” (p. 108). Critical disability studies recognizes “alliance to praxis” (Goodley et al., 2019, p. 976) and as such, in educational practice, it serves to provide a framework to understand disability, actively end institutionalized discrimination, and advance equity and justice for individuals with disabilities.

As a category, autism has been pathologized in schools and society. Our critical disability studies theoretical framework provides a lens through which to consider accommodations and equity for autistic students in schools. In alignment with such a lens, this article purposefully centers first-person perspectives, voices, and experiences of autistic individuals. As self-advocate Sabrina Guerra (2022) explains, “To be an ally means radically respecting a person and trusting their perspective on their lived experience.” By listening to self-advocates who describe motor, movement, and sensory differences, educators can begin to strengthen their reflexivity, critique the general framework of behavioral support in schools, and enact explicit analysis of their own pedagogical practices for supporting behavior. Inherent within this theoretical framework, critically conscious educators evaluate the existing structures of behavior management, the school-based behavior data collection methods and the over-reliance on behavior compliance. They also recognize sites of injustice and inequity as a result of classroom behavioral practices and reimagine more humanistic behavior supports for students with a range of needs that take into account the nuanced motor, movement, and sensory differences present. From this level of critical consciousness, a shift towards structural changes in how the actions of autistic students are understood,

framed, and responded to within our public schools can occur by inclusive-oriented critical educators.

Voices of Self-Advocates

Voices of autistic individuals have been left out of conversations of research-based practices, and how we understand autism and ultimately support autistic students. We are fortunate to live in a time that we can understand autism from first-person accounts of lived experiences (Biklen & Burke, 2006; Mukhopadhyay, 2000; Pena, 2019; Rajapatirana, 2015). In this section, the voices of self-advocates are centered. Criteria for selecting include: 1) publicly available written or record work; 2) self-identified as autistic; and, 3) expressing sensory and/or motor experiences navigating the world. In the larger body of literature, there is not a great deal of discussion on sensory and motor differences, the experiences of autistic students, and how this impacts their experience in schools; thus, these autistic individuals offer a unique perspective. As Sabrina Guerra (2022), who describes herself as a nonspeaking advocate for change, urges, “Listen with an open mind and generous heart to feedback from disabled voices.” Biklen (2005) argues the importance of literature that centers the perspective and experiences of autistic individuals:

In one central way, their accounts diverge dramatically from the prevailing clinical literature ... Their richness suggests the danger of privileging other forms of research about autism as more deserving of authority or as being in some way uncontested. Their forcefulness and consistency should signal clinical researchers to question every assumption brought to the topic of autism. (p. 281)

Behaviorism, and how it is used in school-based interventions, fails to give authority to autistic individuals. The centering of autistic voices has provided new understandings for actions and experiences traditionally seen only through the lens of behavior.

As Sue Rubin (2013), a college graduate and autistic advocate, states, “what was seen as non-compliance, was actually the inability of my body to follow the directions in my brain.” Here we see Sue naming her lived experiences as being misunderstood when her body presents challenges with motor planning. Sue further explained:

The awful ... movement disorder was canceling out my intelligence. I experience awful basic paralysis when I want to walk. If someone asks me to do something and I don't respond, they assume I didn't understand the request. Actually, I hear the request and can't move. I also lack the ability to modulate movement. I walk very slowly or run.

One common theme in discussions around autism is non-compliance, and Sue explains the connection with motor movements. To further illustrate this, Chandima, an advocate and co-president of the EASE Foundation says:

Helplessly I sit while Mom calls me to come. I know what I must do, but often I can't get up until she says, 'Stand up.' [The] knack of knowing where my body is does not come easy for me. Interestingly I do not know if I am sitting or standing. I am not aware of my body unless it is touching something ... Your hand on mine lets me know where my hand is. Jarring my legs by walking tells me I am alive (in Wallis, 2006).

Knowing where his body is in space is difficult for Chandima without touch, and complying to verbal questions requires direct phrasing. Educators often talk about autistic who do not quickly respond to directions, do not stop doing something when asked, and/or bump into objects, all of which they typically see through the lens of behavior. Here, Sue and Chandima push back on this prevalent narrative by explaining ways actions are not intentional non-compliance but instead represent the ways in which motor movement planning and body awareness do not occur as intended.

In the words of Jamie Burke, an autistic individual:

... more important, is the piece that motor planning ability does not exist and that I cannot plan movement. It does not mean that I do not want to initiate that movement. This of course, affects being able to speak, even though I can “see” all the language in my brain. Can you possibly attempt to comprehend the anger and frustration that I feel, or that students feel, because of this? I hear statements of others regarding “bad behavior,” and I try to elevate my soul to stay calm when others assumed I was unable to understand what they were saying, thinking I was not intelligent. ...The issue of Sensory Integration is a vast system of deregulation, where many of my difficulties reside. Can you imagine how crazily hard this is for us who have autism, when our systems are so incredibly mis-matched with what is expected and then with what actually happens? Each experience must be sorted out and interpreted almost every single time. Immense frustration, trouble staying calm, and negative emotions emerge.

(Burke, 2019)

Jamie's perspective has vast implications for educational practice. First, he explicitly names ways in which planning motor movements is challenging for him, including in connection to reliably and on demand producing verbal speech. Furthermore, Jamie calls out how frustrating it is for this motor-planning breakdown to be misread as behavior. Jamie also clearly highlights the ways in which sensory dysregulation is a component to the motor-planning challenges he experiences. In other words, sensory regulation supports his motor-planning processes. Opportunities for sensory regulation are not often prioritized in schools, which impacts students' abilities to plan motor movements and engage in required academic tasks.

Brianna Dickens, an advocate and scholar who identifies as autistic, discussed a motor support that created a sensory nightmare for her:

As a kid I received lots of OT services, because of motor planning and things I needed some support in learning how to make my body do what I wanted. But one of the OT tasks that I had every day was the Operation game. So that's that game with the guy on the table and it has the little bitty tongs, and you have to take the little bitty bones and put it in the correct hole. If you do not get it quite right in the hole, if the tongs hit at all or the piece doesn't fit right in, the game buzzes and some even make noise, so they scream at you or buzz at you, and it flashes... And so I was never good at the game, so all it did was buzz at me because I could never get the piece in the hole correctly. So I hated the game. At that point I had no reliable communication, so I threw a ton of temper tantrums and that didn't work, I still had to do the Operation game, so I came up with a brilliant plan to get out of the Operation game. So one day

I run to the classroom before the TA and I eat all of the Operation pieces. *And it worked.* I did not have to play the Operation game again, but people were not happy with me, and they saw it as a negative behavior, whereas I thought I was brilliant because I came up with a good plan to tell them I was not playing this anymore. (Dickens & Causton, 2019)

While the game of Operation was used by the adults supporting Brianna as an attempt to make fine motor practice fun, this motor planning exercise created sensory conditions that were so uncomfortable that she decided her best option was to make the pieces disappear, something that would typically be viewed as dangerous and as behavior by school team members.

Poignantly, Sabrina (2022) describes the ways her motoric and muscular movement were labeled as “maladaptive behavior” because of inconsistent responses to classroom demands:

I was constantly assigned negative motivations for my actions. Motorically, my body doesn't respond to my will. People have so many misconceptions about autistic people and non-speakers. I am able motorically to respond to a request sometimes ... Teachers think I'm not listening or not trying. ... My body and my mind do not act in unison. I'm compelled to empty containers of liquid. I don't mean to affect anyone. I wanted the windows closed and blinds up so I could look out for shooters. Teacher always told my paras I had to be kept quiet during drills or they'd all be in danger. I was terrified of being a reason my friends would be killed. Teachers called it maladaptive behavior.

Sabrina reveals a disconnect between body movement and mind interaction, and this being a “motorically” issue that gets framed or is “assigned negative motivations.” Revealing reflexivity, Sabrina is aware of the impact of her actions on others, reflected in her saying “I don’t mean to affect anyone” as well as her being afraid for her friends in an possible active shooter situation. Her powerful words have importance for educational practice: listening to her voice allows attribution of actions to motor or safety concerns and dismisses any inkling of non-compliance and “behavior.”

We offer perspectives from autistic individuals as counter-narratives to the behaviorism-driven lens that is often used to make sense of the actions of autistic students in our schools. More specifically, these narratives give agency to autistic individuals through an alternative viewpoint that offers a deeper understanding and explanation of the motor-planning and sensory differences that is often interpreted as behavior.

Discussion and Implications for Educators

As illustrated in the offered scenarios and supported by research, the self-advocate’s perspectives sensory and motor differences are central to how autistic individuals interact with and experience the world. Oftentimes, educational teams determine specific behaviors that they seek to collect data on and replace with other behaviors. When autistic students consistently demonstrate these so-called peculiar behaviors, these become justification for their removal. Instead, we advocate for teachers to understand, ask questions, and critically analyze these common behaviors. In the first example offered, we considered a student who was standing at the bus lifting his foot multiple times but not starting up the stairs. For this student, candy rewards and repeated reminders to “do it quick” were offered as supports, but

upon further consideration and observation, the team determined that the student was actually having a difficult time with the motor-movement of making the first large step up onto the bus. With the support of the occupational therapist and visual supports, he was quickly able to successfully make the first step and board the bus with ease. Without considering the motor-planning components of this moment, the team would have continued to offer supports not aligned with his actual needs. For the second student introduced, his team was making dangerous assumptions about his intent when he was removing his clothing in schools. Quickly known around the building as a “stripper,” which comes with specific sexual connotations, the misunderstanding of this student's actions had damaging impacts on how he was perceived as a member of his school community. His need was sensory comfort, and the response that he received was punishment and exclusion. This example highlights why it is essential for educators to consider the sensory experiences of students in their classrooms. In Table 1, based on the conversation within this paper that highlights voices of autistic students, examples of practice, and our own professional practice, pedagogical strategies that take into account the needs of sensory regulation and motor planning for autistic students are provided. First, these common behaviors are named with specific movement differences, as they often are labeled in schools. Then, a description of this rethinking process of what autistic students actually need, from a motor planning and sensory lens is shared. Robledo et al. (2012) state, “Sensory and movement differences is a disruption in the organization and regulation of perception, action, posture, language, speech, thought, emotion, and/or memory” (p. 68). Once these behaviors are analyzed from a sensory-motor perspective, then

specific school-based strategies to implement based on the specific motor planning or sensory need are provided.

Table 1

Sensory-Motor Pedagogical Strategies

Common “Behaviors”	Rethinking from a Motor Planning and Sensory Lens	Strategies to Implement Sensory-Motor Pedagogical Strategies
<p>Movement</p> <ul style="list-style-type: none"> · <i>Running</i> · <i>Repetitive or rhythmical movements</i> · <i>Walking, pacing around the classroom</i> · <i>Jumping</i> · <i>Bumping into objects</i> · <i>Hyperactive behaviors</i> 	<p>For many autistic students, movement provides proprioceptive input for their sensory system. It allows them to feel where their body is physically in space. The sensory input provides students information about their movements and body position. Students will engage in these movements in order to regulate their sensory system, which then often allows them to better process and plan motor movements being asked of them. By engaging in the movement students are regulating their sensory system and are better able to participate in classroom instruction and activities.</p>	<ul style="list-style-type: none"> ● Designated walking space ● Sensory options that provide proprioceptive input (trampoline, pushing/pulling objects, carrying heavy objects) ● Fidget bin with a variety of options ● Seat cushion and standing desk for sensory input and movement ● Break time for movement prior to academic tasks ● Physical Activity Choice Menu (jumping jacks, sit ups, bouncing on an exercise ball, workout strength bands, etc.) ● Method to signal to the teacher a need for sensory input ● Provide more opportunities to move in the classroom

<p>Non-Compliance</p> <ul style="list-style-type: none"> · <i>Not following classroom expectations or directions</i> · <i>Ignoring verbal questions or requests</i> · <i>Overreaction or Underreaction to demands and requests</i> · <i>Impaired social awareness</i> 	<p>After a teacher gives classroom direction, the student does not immediately follow it. Oftentimes, the autistic students are perceived as ignoring classroom expectations. From this perspective, what we are actually seeing is a student who (1) is able to understand what the teacher is asking but has not processed and planned the motor movement required, or (2) who is so sensory dysregulated, they are unable to complete the request.</p>	<ul style="list-style-type: none"> ● Provide directions in a different format (e.g., visual directions and pre-recorded audio directions) ● Provide a peer model to show an example of the motor movement ● Provide gestural cue to show action ● Provide a visual prompt that depicts the classroom expectation ● Use a combination of the cues above to allow the student to receive the direction information, make a motor plan, and follow the direction ● Provide wait time for the student to execute the motor plan ● Provide a “schedule within a schedule,” meaning both the daily schedule as well as the subset of tasks within each academic subject ● Minimize verbal input, provide visual sequential directions ● Monitor checklist for tasks ● Provide choice (e.g., materials, task order, seating options). When order is irrelevant, elicit student feedback.
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Stimming

- *Rocking*
- *Flapping*
- *Repetitive Movements*
- *“OCD” or “Anxiety” type movements*
- *Repeatedly touch an object*
- *Fixation on specific item(s)*
- *Using a preferred toy*

Many autistic students are positioned as engaging in stimming-type behaviors, such as rocking or flapping objects in their line of vision. From a sensory perspective, it is important to recognize that actions that fall into a traditional category of “stimming” are sometimes ways that students will seek to regulate their sensory systems. From a motor-planning perspective, these same actions might be a way for them to prepare their motor system for a task or action they are about to undertake. While often framed as a way for a student to “escape,” these very actions may in fact be helping them prepare to engage in what is being asked of them within the classroom.

- Timed opportunities across the day to engage in preferred stim activities
 - Sensory regulation opportunities at regular intervals offered proactively and in the classroom (e.g., deep pressure, weighted objects)
 - Planned time to engage in movements or routines
 - Written and visual directions minimize overload
 - Items that provide comfort should be available for their use, as these allow for self-regulation
 - Provide a way to advocate for a break as needed, that is respected when used (non-contingent)
 - Use anchor charts with strategies students can use when feeling anxious or need to calm their minds and/or bodies (e.g., deep breathing, listening to music, fidget objects, moving to a quiet area, walk break, meditation, and yoga movements)
-

Varying Abilities
(Speech and/or
Motor)

- *They could do it yesterday*
- *Do it Quick*
- *Echolalia*
- *Articulation*

Autistic individuals have different levels of being able to perform motor activities and oral motor movements, oftentimes impacted by how well regulated their sensory system is at any given moment. From a motor planning perspective, they hear and understand the information being asked, are in the processing information stage, and preparing for executing that motor movement or speech pattern. Recognize that articulation abilities vary, meaning that autistic students may need to intentionally plan the oral motor movement or the arm and finger actions required for typing.

- Provide wait time to allow autistic students to listen, process, plan the motor movement, then execute
- Listen for content shared, by speech or in writing, by an autistic student instead of focusing on the quickness of response (accuracy over speed)
- Recognize that all humans have good and not so good days, including your autistic students
- Have differentiated materials with varying levels of scaffolding and support
- Use multiple means of communication (e.g., communication board, typing, choices between preferences, PECs)

The “behavior” that autistic students have in the classroom is far more complex than movement, non-compliance, stimming, and varying abilities. Research suggests “that in autism this disruption of organization and regulation is amplified in terms of quantity, quality, intensity, and may affect everyday life” (Robledo et al., 2012, p. 68). For autistic individuals, it is differences in sensory, body feedback and awareness, and where the body is in space that can contribute to sensory-motor differences that often constrain their ability to act with socially constructed school norms.

Implications for Educators

Alternatively, these intentional actions provide essential information about motor and sensory needs and offer a signal indicating help is required. Instead of reading behavior as

being intentionally defiant, determine a better approach for supporting. As Donnellan et al. (2013) argue, "...observed behaviors may be artifacts of the difficulties a person may be having in organizing and regulating sensation and movement. Still others may be subtle signals of the desire for relationship or expressions of meaning" (p. 73). When coming from a sensory-motor difference perspective, the following are key implications for educators when supporting autistic students:

Humanistic Behavior Supports

Ensure that autistic students feel a sense of belonging, community, and connection with peers and teachers. Autistic students need to feel they are authentically valued, respected, and wanted in ways that are not reliant on being able to engage in normed ways. A humanistic perspective allows us to see the multitude of ways that students bring unique gifts to learning environments, and that their worth in the space is not dependent on doing and being in the ways that are traditionally valued such as sitting still and answering questions verbally. Develop relationships with autistic students (Amos, 2013; Causton et al., 2015). As Lovett (1996) states, "A positive approach invites people to enter into the same sort of relationship that most of us treasure: ongoing, with mutual affection and regard" (p. 137). Get to know their strengths, interests, communication styles, and learning preferences. Aim to use language, procedures, behavioral expectations, learning experiences, and materials that are least harmful for autistic students. This is most salient in listening to Sabrina (2022):

I ask everyone to appreciate I have a heart that aches, as yours would, when people make fun of me. You are needed as allies and soul defenders. [P]lease choose to respect me. Kindness is important, but respect is critical to acceptance and equality. I

encourage everyone to live authentically. I expect my movements and vocalizations will be accepted as simply a part of all that makes me who I am. (Guerra, 2022)

Most importantly, work *with* (not *on*) autistic students (Lovett, 1996), with the intention of positioning each as an expert, the authority of what it means to experience autism with sensory and motor differences.

Focus on Academics, Not Behavior

It is essential to forefront academics and access, not the behavior, of autistic students. Often educators think that behavior is a barrier to learning, but rich curricular access and inclusion increase engagement in learning and decreases challenging behavior. Ensure students are within the same physical environment and are involved in learning experiences with neurotypical peers. Modify academic tasks that invite autistic students to use their communication device to respond to prompts and interact with peers. Focus on adjusting these items, before focusing on “behavior.” Exclusion in the learning environment often is the root cause of an autistic student’s “behavior.”

Presuming Competence

Beginning with the assumption that autistic students are experts and the authority on their experience in the classroom, start with the mindset that autistic students are intelligent, that each has the ability and desire to learn, and can share information about their sensory and motor planning differences. As Sabrina reveals:

Respect is not something I have become familiar with so far in my lifetime. People have mistreated, abused, and harmed me. To them I was a substandard human; something to pit or fix. They treated me as if I had a disease, and I internalized that

fear and hatred. My mom fought for people to presume competence and treat me as an equal, but few did. ... Being non-speaking, many people assumed I was non-thinking and non-feeling... I've come to an austere revelation. So long as society equates worth with intellect, disabled lives are in peril. (Guerra, 2022, para 2-4)

As Biklen and Burke (2006) explain, “this is a situation that demands a kind of compact between teacher and student to choose the most optimistic stance possible, what we have called ‘presuming competence’, within which to effect inclusive education” (p. 172). Challenging behavior is often misread. Ask autistic students what their behavior is signaling. Dialogue about behavior with students is critical, and hearing from students themselves will give insight about environmental, sensory, motor planning, or relational items that can be adjusted.

Conclusion

The critical challenge to educators is to relook at “behavior” exhibited by autistic students to consider the motor planning and/or sensory regulation reasons. Research has shown the presence of complex sensory-motor needs for autistic individuals (Fournier et al., 2010; Jansiewicz et al., 2006; Whyatt & Craig, 2013), and this needs to be understood and examined as a possible framework for the rationale of behaviors. What is often framed as a challenging behavior to fix, replace, and remediate, in reality, is an issue of the motor planning components required to execute that action. Understanding the sequential motor movement process needed for certain requests, academic tasks, and school routines will help educators identify which portion causes an issue. Then support with the processing of that motor plan and executing the action can happen. We also need to move to a place in our

schools where we recognize sensory regulation as an essential component of teaching. While days are full of learning experiences that students are required to complete, the voices of self-advocates and the vignettes within this article demonstrate that sensory regulation must be valued. When students are dysregulated, this can impact their motor planning processes and their ability to engage.

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**The Right to Love and Be Loved:
Sexual Health Education for Students with Intellectual and
Developmental Disabilities**

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Abstract

Although there has been notable progress in educational inclusion for students with intellectual and developmental disabilities (I/DD), they generally receive inadequate sexual health education. This paper outlines the historical factors for this gap, current practices in sexual health education, and related outcomes for this group of students.

Keywords: sexual health education, intellectual and developmental disabilities, social connection

**The Right to Love and Be Loved:
Sexual Health Education for Students with Intellectual and
Developmental Disabilities**

People with disabilities and their families have experienced a long history of discrimination, mistreatment, and exploitation. The fight for social justice and civil rights for individuals with disabilities has resulted in legislation providing legal protections, especially with regards to education and employment (e.g., Americans with Disabilities Act [ADA], 1990; Individuals with Disabilities Education Act [IDEA], 2004; The Rehabilitation Act, 1973). These legislative acts have promoted significant positive changes in the way people with disabilities access public spaces, receive healthcare, and participate in education. However, there remain notable opportunities for improvement across a variety of life domains. This is especially true regarding sexual health education because people with disabilities often report diminished opportunities to engage in intimate relationships and increased risk for sexual abuse and assault.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) defines intellectual disability (ID) as a disorder that includes deficits in intellectual and adaptive functioning that have been observed since early childhood. Similarly, IDEA defines ID as “significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period” (IDEA, 2004). In both the DSM-5 and IDEA definitions, intellectual functioning encompasses mental abilities such as reasoning, problem solving,

planning, and abstract thinking. Conversely, adaptive functioning includes the skills needed for daily living such as communication, social skills, and self-care in home and community settings.

Developmental disabilities are a larger group of conditions typically identified in early childhood that persist throughout the lifespan; ID is one common form of developmental disability. Developmental disabilities often include impairments in physical, learning, language, or behavioral functioning. These impairments may adversely affect day-to-day functioning and require supportive services and intervention (Zablotsky et al., 2019). It is estimated that one in six children in the United States has been diagnosed with a developmental disability, and approximately 1.48% of male children and 0.90% of female children are diagnosed with an ID (McPartland et al., 2016; Zablotsky et al., 2017).

Due to the noted cognitive and adaptive functioning concerns experienced by people with intellectual and developmental disabilities (I/DD), they can encounter barriers to developing and maintaining intimate relationships, despite experiencing the same desire for intimacy and romance as their typically developing peers (Sala et al., 2019). Moreover, people with I/DD are too often presumed to be asexual or disinterested in meaningful interpersonal and sexual relationships, despite sexual expression being a significant part of human development and well-being (Treacy et al., 2018). As Ladau (2021) notes, individuals with disabilities are frequently viewed as “childlike, breakable, undesirable, damaged goods who are unfit to be sexually active or sexualized” (p. 134). In fact, individuals with I/DD frequently indicate a desire to establish meaningful interpersonal connections, while also confirming they have trouble finding romantic partners and maintaining intimate

relationships (Schaafsma et al., 2017).

Considering these challenges, the American Association on Intellectual and Developmental Disabilities (AAIDD) and the ARC released a joint position statement indicating that people with I/DD have “inherent sexual rights that must be affirmed, defended, and respected” (AAIDD, 2008). Similarly, Articles 23 and 25 of the Convention of the Rights of Persons with Disabilities (CRPD) outline the rights of people with disabilities to access information, education, and medical supports needed to facilitate their sexual and reproductive health (Perez-Curriel, et al, 2023). Moreover, Individuals with I/DD have the right to engage in safe, fulfilling interpersonal relationships (VanDyke, McBrien, & Sherbondy, 1995). In short, healthy sexuality and intimate relationships are a consideration in establishing satisfactory quality of life; conversely, experiences of social isolation and loneliness are consistently associated with diminished physical and emotional well-being (Pitonyak, 2003).

Disability Rights and Legislation

People with disabilities have a long history of being excluded from and ostracized in community settings. Changes with regards to the treatment and perceptions of people with disabilities have occurred primarily due to the activism of people with disabilities and their families. The Rehabilitation Act was passed in 1973, providing protection against discrimination in federal programs and services, as well as any program or service receiving federal funding. In 1990, the Americans with Disabilities Act (ADA) expanded discrimination protections for people with disabilities and clarified that they have the same rights and opportunities as others to participate in public life. These rights extend to

employment, school, transportation, and all public and private places.

Public Law 94-142 (P.L. 94-142) passed in 1975, guaranteeing a free and appropriate education to all children with a disability (U.S. Department of Education) Passage of P.L. 94-142 provided protection and support for children and adolescents with disabilities who had been excluded completely from the public education system. As outlined in the law, all schools receiving federal funding need to accommodate the needs of the students with disabilities, including providing appropriate instructional materials and supports. The Individuals with Disabilities Education Act (IDEA), originally passed in 1990 and reauthorized in 2004, is considered landmark legislation that ensured students with disabilities had the same rights as their peers without disabilities (IDEA, 2004). Of note, the commitment to provide students with disabilities access to a free and appropriate public education (FAPE) through special education services was reaffirmed by IDEA 2004. These services are developed to meet their individual needs with the goal of further education, employment, and independent living. Per IDEA 2004, the effectiveness of education interventions and supports must be assessed or evaluated. and that evidence-based practices must be used in teaching students with disabilities (SIECUS, 2014). Given these legislative provisions, implementation of a comprehensive sexual health education program to teach students with I/DD about sexuality and healthy relationships is not only supported by research, but one could argue is also mandated by federal law.

Unfortunately, most middle and high school students with I/DD do not receive adequate education regarding sexual health and intimate relationships. In fact, the sexuality of young people with I/DD it too often perceived as troublesome behavior that must be modified

or extinguished, instead of being viewed as typical expression of the human need for intimacy (Sala et al., 2019). Further, parents/guardians of youth and young adults with I/DD generally report they want to provide this education to their children but often avoid the topic due being unsure about what to talk about, when it is appropriate to talk about it, and how to modify information about relationships and sexuality so that their children will understand the concepts (Frank & Sandman, 2019).

Education about healthy relationships and sexuality is essential due to increased risks experienced by the I/DD population, including sexual assault, interpersonal violence, and victimization (Ward et al., 2013). For example, the United States Department of Justice reported that people with I/DD are sexually assaulted at a rate seven times that of people without disabilities (Inskeep, 2018). The U.S. Justice Department also disclosed that it estimated between 68% and 83% of women with I/DD have been sexually assaulted (Murphy & Elias, 2006). Further, researchers have consistently indicated that children with I/DD are at increased risk for sexual abuse as compared to typically developing peers. For example, Sullivan and Knutson (2000) reported that children with ID were four times more likely to be sexually abused than children without ID. Similarly, Skarbek et al. (2009) reported that children with disabilities are 3.4 times more likely to be sexually abused than children without disabilities. An increased risk for being victims of sexual violence also has been documented for adolescent girls with physical disabilities or persisting health problems (Treacy et al., 2018). Taken together, these data demonstrate that students with disabilities (including those with I/DD) are significantly more likely to experience sexual abuse or assault (Alriksson-Schmidt et al., 2010). Education regarding healthy relationships, biological

functions of their bodies, and sexuality is imperative for people with I/DD to understand and protect themselves (Treacy et al., 2018).

Social Connections and Social Support

Research also demonstrates that people with I/DD have smaller social networks that often consist of mostly family members and support staff. People with I/DD report social relationships and feelings of connectedness are missing from their lives, resulting in social isolation and loneliness (Emerson & McVilly, 2004; Knox & Hickson, 2001). Froese et al. (1999) reported that 81% of participants with ID in their study expressed a desire for more friendships and 65% reported wanting a chance to develop a “best friend” relationship. In terms of intimate relationships, Blum et al. (1991) indicated that over 70% of their study’s participants with developmental disabilities endorsed a hope to get married, although only 7% of respondents reported having the opportunity to maintain a consistent relationship with a close friend. In accordance with these findings, participants in a study completed by Robertson et al. (2001) stated their friendship networks consisted of approximately two people, excluding service providers. Similarly, Ward et al. (2013) found that participants had a social network consisting of approximately four people, and that number often included professionals who worked with participants. These studies reflect the critical need for people with I/DD to develop the skills to initiate and maintain close interpersonal relationships.

Social inclusion is a broad construct that may be more easily defined by what it is not: the exclusion of others based on specific characteristics such as race, gender, socioeconomic status, or disability. Inclusion of youth with I/DD requires removal of barriers and provision of supports to allow them to participate in all areas of life to their full capacity. Adolescents

with disabilities often experience challenges with social inclusion including difficulties making friends; limited opportunities to engage in leisure, play, and community activities; and diminished social interactions in the classroom setting (Frazee, 2003; Koller et al., 2018). Consistent with these findings, Pijl et al. (2008) reported that up to 25% of students with disabilities were rejected by their peers, did not have friends, and did not engage with a subgroup within their class as compared to only 8% of their peers without disabilities. Students with disabilities are at increased risk for social isolation and bullying, both of which result in a variety of poor outcomes (Koster, et al., 2010). Social isolation and bullying can lead to a diminished sense of school belonging, obstacles to participation in social activities, poor motivation, low self-concept, and difficulties in academic performance (Asher & Coie, 1990). While these concerns are relevant for any student experiencing peer rejection, students with I/DD appear to be particularly vulnerable.

Although they experience challenges around social inclusion, it also appears that adolescents with I/DD do identify peers in their class or school as being their friends. Matheson et al. (2007) found that being in the same class or school was an important defining characteristic of a friendship. This becomes problematic for students with disabilities as they leave K-12 education and experience loneliness associated with this transition period (Foley et al., 2012). Unfortunately, Snowdon (2012) reported limited integration and social supports were in place for adolescents with disabilities as they grow into adulthood. Services for this population generally focused on outcomes related to employment, postsecondary education, and community inclusion, but did not address other aspects important to quality of life such as friendships, dating, and intimate relationships (Carter et al. 2010; Haber et al. 2015).

Biggs and Carter (2016) found that parents of transition-age youth with I/DD reported lower ratings of their child's psychological well-being (e.g., feelings of positive emotions and satisfaction with life) and social support/peer relationships (e.g., quality of interaction and support between the child and peers) compared to typically developing peers. Among participants in Biggs and Carter's study, the lowest rated life domain was social support and peer relationships. Similarly, in a study conducted with young adults aged 17 to 20 years, participants with ID reported that their most significant worries included being bullied, making and keeping friends, losing a caregiver, and not being successful in life (e.g., passing driving tests). In comparison, their peers without disabilities reported that their most significant worries included getting a job, lack of extra money, failing, and making decisions that would affect their future (Forte et al., 2011). Implementation of effective interventions to support the development of interpersonal skills and relationships is critical not only for school-age children with I/DD, but for transition-age youth as well. Thus, as they transition through the lifespan, development of the skills necessary to form and maintain friendships and intimate relationships is imperative for the overall mental and physical health of people with I/DD.

Sexual Health Education in the United States

Sexual health education in the United States has evolved into two different approaches: abstinence-based sexual health education and comprehensive-based sexual health education. These two approaches affect how sexual health education looks in practice. For example, dependent upon the approach, the role and type of sexual health education in schools can vary with regards to how much time is devoted to various topics and the breadth

of content covered. Approaches to sexual health education generally are guided (and sometimes mandated) by federal and state funding. Specifically, if funding sources endorse abstinence-based approaches, then the enacted curriculum will be in line with this orientation.

The history of abstinence-based education can be traced to beliefs about the need to reform sexual sin in the United States and England in 1724 with the publication of *Onania*, a written work referencing the Bible and “the sin of wasting man’s seed” (Treacy et al., 2018, p. 67). This work has been attributed with influencing cultural views and laws prohibiting masturbation and oral sex and viewing sex as a sin against God to be performed only for procreation (Cornog & Perper, 1996). These beliefs influenced political campaigns, educational practices, and public health efforts during the 1800s. Social reformers (e.g., Sylvester Graham and John Kellogg) suggested sexual activity was immoral and separately authored anti-masturbation literature to be disseminated to the public during this time (Carter 2001; Cornog & Perper, 1996). Consistent with this theme, the National Education Association (NEA) passed a resolution supporting “moral education” in schools in 1892 (Treacy et al., 2018). Negative views of sexuality persisted well into the twentieth century and continue to play a part in culture, laws, politics, values, and norms in the United States.

Margaret Sanger, the founder of Planned Parenthood, also played a significant role in the early beginnings of comprehensive sexual education. Sanger, a nurse, opened the first birth control clinic in the United States in Brooklyn, New York in 1916. She published the first scientific journal about contraception, the *Birth Control Review*, and opened the Birth Control Clinical Research Bureau in Manhattan, the mission of which was to make contraception available to women and to collect data in order to improve the safety and

effectiveness of the contraceptive devices being provided (Treacy et al., 2018; Cornog & Perper, 1996; Planned Parenthood, 2014).

Following Sanger's work in the field of comprehensive sexual education and family planning, an abundance of sexual health information was published in the early 1900s, including research articles, books, and pamphlets. The early focus of sexual health education was deterrence of disease, as it was perceived that education about personal sanitation and hygiene in schools might assist in prevention of disease (Carter, 2001). Developments in the medicine and related fields, including confirmation of the first effective treatment of syphilis (i.e., discovery of penicillin) and identification of the hormones involved in the human reproductive system, further increased the push for sexual health education in schools (Treacy et al., 2018; Cassell & Wilson, 1989). Two organizations were developed and tasked with ongoing improvement and growth of comprehensive sex education in public schools and higher education institutions. In 1964 and 1967 respectively, the Sexuality Information and Education Council of the United States (SIECUS) and the American Association of Sex Educators, Counselors, and Therapists (AASECT) were formed (Seruya, Losher, & Ellis, 1972; Cornog & Perper, 1996; SIECUS, 2014).

The first funding initiatives for sexual health education occurred in the 1980s, starting with the Adolescent Family Life Act under Title XX of the Public Health Service Act (Advocates for Youth, 2014). This legislation provided funding to educate adolescents about the dangers of premarital sex. Education efforts also focused on promoting adoption subsequent to an unplanned pregnancy rather than abortion (Cassell & Wilson, 1989; SIECUS, 2014, 2016). In 1996, \$50 million in annual funding was allocated to abstinence-

based sexual health education programs through welfare reform policies and amendment to the Maternal and Child Health Block Grant (Advocates for Youth, 2014; Williams, 2006).

Currently, every state in the United States allocates funds for public schools to implement sexual health programs. However, this provision of funds has resulted in ongoing and combative discourse between parties endorsing abstinence-based education and those favoring more comprehensive sexual education (Treacy et al., 2018). A significant amount of research exists examining the effectiveness of both comprehensive sexual education and abstinence-based programs. For example, 56 studies evaluating the outcomes of abstinence-based sexual education and comprehensive sexual education were reviewed by Kirby (2008). Abstinence-based sexual education programs strongly encourage refraining from sexual behavior outside of marriage to avoid the risk of pregnancy and sexually transmitted diseases (STDs). While comprehensive sexual education emphasizes that abstinence is the safest choice, topics of discussion include methods of contraception such as condoms and birth control pills, sexual anatomy, pregnancy, risk of STDs, and places to seek sexual health care (e.g., Planned Parenthood). Multiple studies have reported abstinence-based programs do not delay participants from engaging in sex nor were there any positive effects on sexual behavior (Kirby, 2008; Stanger-Hall & Hall, 2011; Trenholm et al., 2007). Conversely, research indicated comprehensive sexual health education programs resulted in a significant increase in participants' use of condoms and contraception and delayed participants' initiation of sexual relations (Kirby, 2008; Trenholm et al., 2007). Furthermore, Kohler et al. (2008) demonstrated a 50% lower risk of teen pregnancy associated with comprehensive sexual education as compared to abstinence-based sexual education.

Santelli and Kantor (2008) made a strong argument that scientific evidence does not support abstinence-based sexual education to decrease unwanted outcomes of adolescents' sexual behavior and that the influence of politics and ideology have resulted in the undermining of best approaches to sexual education. There are significant ethical and human rights concerns about the provision of incomplete and inaccurate sexual health information. Government agencies and policymakers have an obligation to provide accurate information (and to prevent dissemination of inaccurate information) to the public. Despite this, abstinence-based programs in schools are restricted in the information they can provide to students (e.g., limited or no information about condoms and contraception), and are expected to promote scientifically questionable ideas such as potential links between early sexual behavior and mental health issues. Placing limits on the approved topics that can be discussed through these programs increases risks for students by withholding accurate information they need to protect their own health. Further, it presents an ethical dilemma for program facilitators, forcing them to refrain from sharing potentially lifesaving information or risk losing funding by violating policy requirements (Santelli & Kantor, 2008). In discussing the legislative mandate for abstinence-only programs, Treacy et al. (2018) stated:

The paradox here is that funding does not support the evidence-based practice. At a time in education when all instructional practices must be identified as an evidence-based practice, funding follows the less effective practice; therefore, denying both students with and without disabilities access to evidence-based sexual health education. (p.71)

Despite evidence indicating that comprehensive sexual health education results in

more positive outcomes than abstinence-based programs, most funding for sexual health education is provided to public schools for abstinence-only programs (Advocates for Youth, 2014; Kirby 2008; Kohler et al., 2008; Santelli & Kantor, 2008; SIECUS, 2014, 2016; Treacy et al., 2018; Trenholm et al., 2007). The National Conference of State Legislatures (2020) reported that as of March 2020, 29 states require public schools to teach sexual health education and 22 states dictate that if sexual health education is provided, it must be medically accurate. However, definitions of “medically accurate” vary significantly. Definitions are often vague and use terminology such as *age-appropriate*, *dissemination of factual information*, *respects community values*, *stress moral responsibility*, *technically accurate*, etc. Parent/guardian rights also come in to play in many instances, as 25 states require parent/guardian notification if sex education is provided, five states require parent/guardian consent for sex education to be provided, and 36 states allow parents/guardians to opt-out completely of sex education for their children. Shapiro and Brown (2018) found only 11 states included the concepts of healthy relationships, sexual assault, and consent in their state policies and education standards. This suggests that the majority of public school students in the United States are not receiving instruction through their schools’ sexual health education program regarding healthy and unhealthy relationships, dating and relationship violence, or negotiating consent.

Policies Regarding the Sexuality of Individuals with I/DD

Based on reported research, students with disabilities frequently have been excluded from education about sexual health throughout the twentieth century. Historically, many individuals with disabilities were placed in institutions where they did not receive instruction

in reading, writing, or mathematics, much less sexual health information (Barnard-Brak, Schmidt, Chestnut, Wei, & Richman, 2014; Cassell & Wilson, 1989; Murphy & Young, 2005; Preston, 2013). Eugenic beliefs and practices were a significant factor in American history and culture from the late 19th century until World War II. By the early 1900s, many American universities, scientists, and professionals promoted eugenic ideology and actively supported eugenics-inspired legislation. The American Eugenics Society and prominent eugenicists in the United States not only endorsed restriction of immigration to the United States for those viewed as inferior, but also advocated for the sterilization of American citizens considered to be “insane, retarded, and epileptic” (Bruinius, 2006, p. 7). In 1927, the U.S. Supreme Court ruled in favor of a statute for the “compulsory sterilization of the unfit for the protection and health of the state” (Bruinius, 2006, p. 7). This allowed for government and private agencies to sterilize people with disabilities (American Academic of Pediatrics, 1999). This ruling was reversed in 1942 when the U.S. Supreme Court declared procreation to be a human right. Despite this, 28 states still had sterilization laws two decades later. Twenty-six of those states included compulsory sterilization in order to prevent reproduction by people with disabilities (Stein & Dillenburger, 2016). Further, it should be noted that guardians of people with disabilities *can still* choose to have their child sterilized if they prove “good reason” (American Academy of Pediatrics, 1999). Stern (2005) reported that thousands of people continued to be sterilized through the late 1960s and into the mid-1970s as many academic and medical professionals continued to promote eugenics as a public health issue. Specifically, those with mental illness, physical or medical disabilities, or behaviors viewed as immoral (e.g., pregnancy out of wedlock) were seen as threats to

American society, and this ideology was promoted and accepted as it was supported by trusted medical and mental health professionals.

Political views and legislation at the federal and state levels have significant effect on policies and perceptions in both in school and community contexts. In many instances, funding is provided to promote only certain policies and to support implementation of only certain curricula. Hence, understanding the history of disability law is a critical piece in understanding perceptions of people with I/DD as competent, autonomous individuals. Disability law also has significant consequences for educational programming for people with I/DD, which includes access to educational resources and services.

Sexual Health Education and Individuals with Disabilities

Research suggests there is not a consistent, evidence-based sexual health education program currently being implemented in U.S. schools for any students regardless of disability status. Wolfe and Blanchett (2002) found that while there were sexual education curricula recommended for use with people with disabilities, materials were designed to be used with a broad range of individuals and were not specific to the needs of specific subgroups of participants (i.e., deaf students, students with I/DD, etc.). Sexual health education programs provided for students with disabilities often focus on the biological aspects of sexual health and behavior, while the emotional aspects of romantic relationships receive little, if any, attention (Knox & Hickson, 2001; Shakespeare et al., 1996). Given the previous discussion regarding the desire of people with disabilities to engage in intimate relationships, the lack of guidance regarding appropriate dating and romantic behaviors is concerning.

Further, McDaniels and Fleming (2016) reported that many of the sexual health

education programs recommended for implementation with people with I/DD were not comprehensive but focused on limited topics in isolation (e.g., sexual abuse or STD prevention). A critical piece missing from many of these educational materials was ecological validity, or rather the practical application of these skills in real-world contexts. While delivering sexual health education content and increasing knowledge of participants is critical, teaching participants how to successfully apply learned skills requires an additional level of implementation and skill on the part of educators/program facilitators (McDaniels & Fleming 2016).

The Community Advisory Group of the Sexual Health Equity for Individuals with Intellectual/Developmental Disabilities (SHEIDD) project conducted a review of seven curricula designed to address healthy relationships and sexuality education for people with I/DD (Kayser et al., 2018). Of these, five programs were specifically designed to target the school-age population and to be delivered in school or community settings while two of the programs were designed to be delivered to adults in community or agency settings. Several, though not all, of these programs were found to have strengths including affirming that people with disabilities are sexual beings and use of a variety of teaching strategies and materials. However, many of these programs were lacking in regards to including information about transgender and non-binary people, adaptations to account for participants' cultures and their influence on relationships and sexual health, information about contraception and STDs, and information about parenting rights and relationships. This review suggested that programs designed specifically for the I/DD population to teach sexual health and relationship education continue to be inadequate in several significant areas.

Conclusion

People with disabilities have a long history of discrimination, mistreatment, and exploitation. Moreover, people with disabilities, including school-age children and adolescents with I/DD, are often excluded from activities and supports that comprise a well-rounded, socially connected life. While many students with I/DD are enrolled in their neighborhood schools with their peers, true inclusion continues to be absent in too many cases. Students with disabilities, including those with I/DD, experience rejection, exclusion, isolation, and bullying at higher rates than their peers without disabilities. They also experience barriers to activities that their peers without disabilities freely access (e.g., participation in extracurricular programs and recreational activities). Social connectedness is a vital component of the human experience and has been linked to both physical and mental health. Yet lack of friendships and intimate relationships remain a primary concern reported by people with I/DD and their families. This becomes even more problematic once students with I/DD leave the school setting and transition into young adulthood, where the social support that was provided in the school setting is completely absent.

A key component to the achieving and maintaining quality of life is engagement in healthy intimate and romantic relationships. While the AAIDD and the ARC joint statement indicates people with I/DD have “inherent sexual rights that must be affirmed, defended, and respected” (American Association on Intellectual and Developmental Disabilities [AAIDD], 2008), most middle and high school students with I/DD do not receive adequate education regarding sexuality and healthy relationships. This exclusion could be due to people with I/DD being perceived of as asexual, as incapable of developing and maintaining romantic

relationships, or as uninterested in romantic relationships. However, in previous research conducted by Blum et al. (1991), people with disabilities have expressed they desire engagement in intimate relationships and think about marriage and having children just as many of their peers without disabilities do.

The type of sexual health education program delivered in schools is driven by competing ideologies: abstinence-based sexual health education and comprehensive-based sexual education. While overwhelming research indicates the positive outcomes of comprehensive-based sexual health education (e.g., safe-sex practices, delayed initiation of sex), abstinence-based education is the most common form of sexual education being taught in schools. The promotion of abstinence has deep roots in religious and moral beliefs, leading to significant political and financial support for implementation of these programs.

Furthermore, students with I/DD are often excluded from sexual health education altogether. When this education is provided, it tends to focus on the biological aspects of sexual health, while failing to address topics such as developing and maintaining intimate relationships, dating behavior, healthy versus unhealthy relationships, and negotiating consent. One could argue that, because IDEA dictates evidence-based practices must be utilized in teaching students with disabilities, implementation of a comprehensive sexual education program to teach sexual and relationship health to students with I/DD is both supported by research and mandated by federal law.

Based on a review of the literature, there is not a consistent, evidence-based sexual health education program being implemented in U.S. schools for students with and without disabilities. While there are sexual education curricula recommended for use with people

with disabilities, these materials are designed to be used with a broad range of individuals rather than specific subgroups of participants (i.e., deaf, I/DD, etc.) and focused on topics in isolation (e.g., sexual abuse or STD prevention). The aim of these programs is to increase the knowledge of participants, and while that is vitally important, a key component missing from these programs is providing opportunity for participants to successfully apply learned skills in real-world contexts. While these programs demonstrate distinct areas of strength (e.g., affirmation that people with disabilities are sexual beings and use of various instructional strategies and modalities), they often lack inclusion of information about transgender and non-binary people, adaptations to account for participants' cultures and their influence on relationships and sexual health, information about contraception and sexually transmitted diseases, and information about parenting rights and relationships (Kayser et al., 2018).

Overall, available educational materials designed to address sexual health and relationships with students with I/DD are severely lacking in many critical ways. Furthermore, implementation of effective sexual health education programs for students with I/DD is absent from most school settings. As outlined in the joint position statement by AAIDD and the ARC: "All people have the right within interpersonal relationships to develop friendships and emotional and sexual relationships where they can love and be loved" (AAIDD, 2008). Because healthy sexuality and intimate relationships strongly influence individuals' quality of life and well-being, policymakers and educators must work in earnest to provide quality programming and supports in this area. To that end, we propose the following action steps:

1. *Develop and implement sex-positive training for educators who work with*

students with I/DD. Goodley (2017) notes, “erotophobic attitudes and excessive repression suppress discussions about sex and pervade professional beliefs about disabled people.” For example, professionals in Colarossi et al. (2023a) reported discomfort talking about sexuality and the desire to learn how discuss sexual health with youth “in unbiased, fact-based, non-judgmental ways” (p. S154). As such, professional development efforts must address both professional knowledge and attitudes about sexuality.

2. *Promote creation and dissemination of sexual health education curricula address the specific needs of youth with I/DD*. Educators who were interviewed as part of Colarossi et al.’s (2023a) study endorsed the need for “accessible teaching tools, with videos and hands-on toolkits” (p. S158). In a separate study, interviews with youth with I/DD and their families identified a variety of instructional supports that should be integrated in sexual health education programs, including visual aids, hands-on learning activities, social stories, and case scenarios (Colarossi et al., 2023b). Program developers might utilize CAST’s Universal Design for Learning (UDL) Guidelines (CAST, 2018) to develop instructional materials that are maximally accessible for *all* students, including students with I/DD.
3. *Coordinated advocacy efforts from educators, families, and individuals with disabilities to impact state- and district-level policies regarding sexual health education*. In particular, IDEA mandates regarding research-based practices should be leveraged to advocate for comprehensive sexual health education for students with I/DD. Schools should be expected to implement programs that

address not only abstinence and human physiology but also include topics like dating, negotiating consent, and using contraception (Perez-Curiel et al., 2023).

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In the Forefront:

Public Housing Residents' Needs for Persons with Disabilities

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Abstract

Individuals living in public housing communities often experience access issues when it comes to advocating for community resources and services, especially services supporting people with disabilities (Anderson et al., 2021). Research has also pointed to the importance of stakeholder engagement in public housing communities (Mouratidis, 2020). Developing solutions with all stakeholders empowers individuals to help direct available resources towards new opportunities (Browne et al., 2017; Kennedy, 2018). Addressing the needs of diverse communities, including people with disabilities, needs to be in the forefront. There has been a paucity of disability research in a public housing environment. Furthermore, residents with disabilities may face even greater challenges acquiring services and advocating for their needs (Park, Cho, & Chen, 2019). This research employed a quantitative approach to understanding insights from community residents about their perceived needs. The research was conducted to understand the needs of residents with and without disabilities. For residents with disabilities, the programs that were ranked highest include: developing community projects, building age-focused programs, and addressing health related services. These findings offer suggestions for future programming, policies, and research.

Keywords: persons with disabilities, public housing, assessment, quantitative measures, advocacy, community empowerment, public policy

In the Forefront:**Public Housing Residents' Needs for Persons with Disabilities**

Encouraging public housing residents to participate in identifying their needs with the individuals who administer community-based programs and with their peers is important for enacting positive community changes affecting well-being (Browne et al., 2017; Kennedy, 2018). Participation in generating ideas for programming initiatives that community members want for themselves, their families, and their neighborhood is critical. In all settings, concerns about safety, personal health, food insecurity, and overall housing conditions are vital. These central issues are further amplified for public housing residents (Mouratidis, 2020).

Furthermore, residents with disabilities may face even greater obstacles acquiring services and advocating for their needs (Park et al., 2019).

According to Barrie et al. (2019), forming solutions with all stakeholders empowers a community to help direct available resources towards new opportunities and professional development. People with disabilities may face even greater obstacles acquiring services and advocating for themselves due to barriers leading to social isolation from others (Park et al., 2019). It has been found that residents feel a deep sense of belonging to their communities, rating social connections and relationships as a major benefit of living in an urban area (Ciorici & Dantzler, 2019). Building upon this concern for others lends itself to a strengths-based approach that may be used to inspire residents to participate in needs assessment research. In turn, residents can be heard, and stakeholders can support program development and advocacy efforts on the residents' behalf. This research explores the programmatic and resource-based needs of public housing residents and how these may differ for people with

and without disabilities.

Literature Review

Public housing residents, including those with disabilities, face systemic challenges when trying to voice their concerns and access necessary resources. While community centers are increasingly leveraging resident feedback to enhance their services, the distinct struggles of residents with disabilities often remain overlooked (Biederman et al., 2021). Anderson et al. (2021) demonstrated that residents deeply desired supportive relationships with community centers, emphasizing the need for regular programs that address all ages and service needs. To this point, a study by Adam and Donelson (2022) introduced reciprocity as a dimension of trust between generations, emphasizing its role in cooperative interactions and mutual benefits within health systems. Heyman et al. (2023) found that multigenerational programs are mutually beneficial for youths and older adults and can be a model for future programming. The aforementioned perspectives offer a framework for housing and community centers to deepen connections and responsiveness to their residents, especially those with disabilities.

Aspirations of residents are paramount for fostering an inclusive atmosphere. Hudson et al. (2020) explained that underrepresented youths, particularly those with disabilities, face a plethora of hurdles in transitioning into higher education. They emphasized the significance of participatory action research, which not only aids youths in navigating challenges but also actively involves them in shaping their community's future. This sentiment is mirrored by Zhong et al. (2020), who underscored the merits of intergenerational communities and

improved well-being across diverse age groups, including for people with disabilities.

Older adults and other groups in public housing are often affected by a range of health challenges. Addressing challenges as they relate to service delivery is also important (Brown et al., 2019). According to Finlay et al. (2021), some of these challenges can be met when residents with disabilities are engaged in community work and decision-making processes.

The desire for people with disabilities to share their concerns with the community provides a vehicle that galvanizes their voices to create change. In turn, people with disabilities who advocate for programs, services, and policy changes have reported personal benefits from their work, including positive self-perceptions, enhanced social networks, and a strong sense of belonging linked to their advocacy efforts (Fenn & Scior, 2019). Building inclusive community can foster relationships among generations and different population groups. Public housing and community centers can be a place where all groups can interact to improve quality of life (Generations United, 2020).

While the U.S. Department of Housing and Urban Development (HUD) offers assistance programs for residents who identify as persons with disabilities, oftentimes the services are not equipped to handle the enrolled individual's specific disability (Dawkins & Miller, 2017). Some suggestions that have helped foster engagement include performance arts training and creative endeavors that teach tangible skills (Monical et al., 2020). The power of self-advocacy is best found in an urban study where people with disabilities recorded images of the obstacles faced in achieving healthy lifestyles in their neighborhood (Weinstein et al., 2020).

Study Design

A cross-sectional study was used to capture public housing community residents' needs. This research received University Institution Review Board (IRB) approval. Quantitative methods of survey research were used to gain insights from residents about their perceived needs of the community.

A university research team actively engaged key resident members and leaders of a housing development project. Members of the university research team, staff from the participating community center, and members of the housing development residents' associations met to develop, review, and refine the instrument. The instrument was then pilot tested with center staff who live in the community to address comprehensibility and content. The survey was translated into Spanish and back-translated.

In an initial mailing and follow-up, the research team sent letters in both English and Spanish to 600 randomly selected residents inviting them to participate in the research. The mailing consisted of colored paper flyers with the dates and locations of the survey research listed, and participants were asked to bring the flyer to the survey locations. Of the 600 mailed flyers, a total of only 21 were returned as undeliverable. Eligibility criteria were being (1) individuals at least 18 years old and (2) public housing residents. Flyers were also posted in all 14 buildings with the dates and location for individuals to "walk-in" and opt to complete the survey. All 14 buildings had dates and hours available for residents to participate in the needs assessment.

An informed consent information sheet explaining the research was provided, and the researchers reinforced this information verbally to participants. The survey was set up in

Qualtrics and was provided in both English and Spanish. Residents were asked what language they preferred. The research team included four interviewers fluent in English and Spanish.

The research team administered the surveys in front of housing development buildings on different dates in spring 2019. To reach a cross section of residents, researchers were present in both afternoon and evening hours. Participants completed the survey on a tablet. Some asked the researchers to read out the questions, and responses were entered by researchers. A total of 303 residents participated. Three individuals were not included because they did not meet eligibility requirements. Participants were primarily walk-ins (86.3%), having been approached to participate on the day of the survey, whereas 41 or 13.7% of the participants had received a flyer in the mail about the survey.

Contextual Description of the Community

The community selected for study is a public housing development comprised of 1,259 units within 14 buildings. The community center is housed within the newest of the buildings (constructed in 1974). The community center serves a vibrant, resilient, and increasingly multicultural group of residents living in a large public housing project located within an affluent, highly gentrified, and expensive neighborhood. At the time of the survey, the community center was serving about 35% of the residents. The largest program provided social, health, cultural and case management services to older adults ages 62 and older. Specific services include an on-site nurse, fitness classes, workshops and classes in jewelry making and the arts, health management education, hot lunch served daily on weekdays for a voluntary contribution, case management and referrals as well as special events and trips. An early childhood center provides education and childcare year-round to 57 children ages 2 and

5 that is free or low cost. After school and summer day camp for children in grades kindergarten through 6 offers homework help and tutoring, art and fitness activities, trips, meals, and snacks. The center is open for teen services in the evenings during the school year and seven days a week during the summer. Through partnerships, the center also offers high school equivalency, English and Spanish adult language classes, weekly food pantries, and special events, including vaccination drives. The center is physically accessible to people with disabilities.

Thirteen of the buildings in the development were opened in 1948 and the center was established in 1956. In 1974, the newest of the buildings was constructed, at which time the center relocated. The center has a long history in the neighborhood with active members providing input and direction into the development of new programming. In 2015, the center merged with a larger organization that has been stabilizing operations, building community relationships and developing new programs. In this context, the center leadership reached out to the nearby university to assist with capturing community voices. These housing developments and their immediate community offer a unique look at low-income households with disabilities in the shadow of wealth and resources just outside of reach. Understanding the historical context can offer insights into the changing community and its implications for residents, including people with disabilities. In line with our Institutional Review Board (IRB) protocol to protect the privacy and identities of participants and locations, specific names and identifying details have been eliminated from this study. This ensures the confidentiality of the participants and the community while allowing the research's core themes and findings to be communicated effectively.

Measures

The self-administered questionnaire developed for this study included two sections: (1) demographic data and (2) needs assessment of programs and services at the public housing development.

Demographic Variables

Demographic information was collected by asking participants questions concerning age; race; gender; marital status; whether they lived alone; whether they had children under age 18; education, measured by highest level of education completed; employment status; rating of physical health; primary language; and whether they self-identified as a person with a disability or if there was a person in their household with a disability. An acknowledged limitation of this question is that some people may not self-identify due to stigma, or their understanding of “disability” may only refer to very severe disabilities.

Needs Assessment

The research team engaged key residents and leaders in the housing development to create the assessment. The assessment was organized around 11 areas: assistance, community, adult education, youth programs, children’s programs, employment, family support, health, social activities, community involvement, and age-focused programs. In each section, the respondent was asked to assess the extent to which community members believed there was need for the community focused on a particular area. The respondents used a four-point rating scale, from 0 meaning “not needed” to 3 being “very needed.” Each category contained between three and eight items to assess needs for a total of 55 items. Respondents

were given the option to complete the assessment in English or Spanish. Members of the research team were available to assist respondents in completing the survey. Four items in the assistance section asked respondents about the extent of the need for community members to receive help by accessing specific public assistance programs (i.e., SNAP, TANF, transportation, and a legal assistant program). Four items in the community section focused on physical and social aspects of the community, for example, the need for neighborhood cleanup and recreational opportunities. The five items that made up the youth programs section focused on respondents' perceived need for educational and recreational programs for primary and secondary school-age youth. The children's programs section has six items focused on academic, enrichment, and recreational programs for children and youth. One section consisted of six items asking respondents about the need for various adult education services. Four items are found in the age focus programs section to gather respondents' perceptions of the need for enrichment programs focused on different developmental stages. The three items in the employment section focused on the perceived need for job training and employment assistance. The four items in the family support section focused on services appropriate for parents and caregivers with small children. Six items in the health section focused on general health and fitness services. Eight items found in the social activities section focused on recreational services appropriate for all ages. Five items in the community involvement section focused on the need for opportunities to access community service activities.

Data Analysis Procedure

Data were transferred from Qualtrics into SPSS. First, univariate analysis was conducted to assess each variable with respect to frequency and appropriate central tendency. To understand differences by group, bivariate analysis was conducted, including t-tests and chi-square analysis. Comparisons of the different ranking of identified needs was examined.

Results

Demographics

Table 1 contains the study participants' descriptive information. Of the 300 survey participants, 286 responded to the question on whether they had a disability. Fourteen people chose not to answer this question and were not included in the analysis. Of those responding, 28.3% (n=81) stated that they had a disability and 71.7% said they did not (n=205). There were significant differences in the demographics of these two groups. Overall, people with a disability tended to be older than people without a disability and were more likely to be female. Individuals who identified as having a disability had lower levels of education and were less likely to be working. People with disabilities had indicated their perceived health was fair/poor, which differed for people without a disability.

Table 1*Demographics*

Characteristic	People without disabilities (n=205)	People with disabilities (n=81)	Test
Age (M)	39.22 (SD=17.88)	58.8 (SD=14.54)	t=9.59, p=.00
Gender (%)			
Male	42.4	27.2	X ² =5.75, p=.02
Female	57.6	72.8	
Race (%)			
African American, not Hispanic	58.3	52.1	X ² =1.04, p=.79
Hispanic, Latino	28.9	32.9	
White	4.9	6.8	
Other	7.8	8.2	
Marital Status (%)			
Single/never married	66.8	45.2	X ² =17.19, p=.00
Married/partnered	19.5	21.9	
Widowed	4.9	17.8	
Other	8.8	15.1	
Living situation (%)			
Live alone	26.5	35.8	X ² =2.68, p=.26
Live with someone	73.5	64.2	
Children Under 18 in household (%)			
Yes	40.5	23.5	X ² =7.34, p=.00
No	59.5	76.5	
Education (%)			
Less than high school	11.8	38.8	X ² =26.58, p=.00
High school diploma	37.9	26.3	
Some college, associate degree	36	25	
Bachelor's degree or higher	14.3	10	
Employment status			
Full time	41.7	2.5	X ² =59.94, p=.00
Part time	19.1	8.6	
Not employed	39.2	88.9	

Table 1*Demographics*

(continued)

Characteristic	People without disabilities (n=205)	People with disabilities (n=81)	Test
Rating of physical health (%)			
Excellent/very good	62.7	21.0	X ² =71.16, p=.00
Good	28.4	28.4	
Fair	7.8	35.8	
Poor	1.0	14.8	
Primary language spoken (%)			
English	89.3	75.3	X ² =9.12, p=.10
Spanish	8.8	21	
Other	2.0	3.7	
Does someone else in household have disability (%)			
Yes	13.2	48.8	X ² =40.93, p=.00
No	86.8	51.2	

Identified Needs

The top 10 items in terms of perceived need are presented for both residents with a disability and residents without a disability (Table 2). For respondents without a disability, the top items in terms of the highest average score, or highest perception of need, fell into various categories, although the most common were for employment programs, age-specific programs, particularly those for children and youth, and community programs. For respondents with a disability, the programs that were ranked highest in need were primarily community projects and health-related programs, along with some age-focused programs,

both for older adults and young adults. The most identified community projects were neighborhood cleanup projects and crime prevention, the highest ranked health programs were health education programs, mental health counseling services, and fitness classes for various age groups. The scores for these top-ranked items, which were between 2.0 and 3.0 for both groups, represented perceptions that these programs were somewhere between “needed” and “very needed.” For respondents without a disability, of the 55 items on the list, 45 had an average score of 2.0 or higher, signifying that it was “needed.” For respondents with a disability, however, just 29 of the 55 total items had an average score of 2.0 or higher. Programs and services that received the lowest scores for people without a disability were all with respect to assistance, such as help applying for social security, SSDI, WIC, TANF, SNAP, and assistance with food such as community food resources, pantry. Even though these items ranked the lowest among the 55 items, the scores still fell between “rarely needed” and “needed.” Moreover, the lower ratings for these items may be a reflection that needs of the residents have already been met in these areas. For example, at the time of the survey, the community center ran two food pantries used by residents (currently it is four), and about 300 older adults receive case management services through the center. Among the programs ranked as being of least need by people with a disability were youth programs, such as help applying to high school or middle school, as well as help applying for public assistance benefits, and some adult education language classes. However, these programs still ranked between “rarely needed” and “needed.”

Table 2 compares the top 10 needs of people with a disability and the top 10 needs of people without a disability. There were only two items that ranked in the top 10 for both groups:

programs for teens and young adults, and recreational opportunities. Other programs that ranked high among people with disabilities, such as programs for older adults and health programs, ranked lower among people without disabilities. In addition, programs that ranked high for people without a disability, such as children’s programs and employment programs, ranked lower for people with a disability. This indicates a difference in priorities for the two groups, which can be explained in part by the difference in their average age and health status.

Table 2

Comparison of Top 10 Needs

NEED	People with disabilities (Rank) ^b	People without disabilities (Rank) ^b	People with disabilities Mean (SD)	People without disabilities Mean (SD)
Community - Neighborhood cleanup projects	1	---	2.38 (.83)	2.26 (0.89)
Age-focused programs - Programs/activities for seniors (60+)	2	---	2.30 (.87)	2.18 (1.00)
Health education services	3	---	2.18 (.98)	2.17 (.97)
Health - Mental health counseling services	4	---	2.18(1.02)	2.21 (.98)
Health - Fitness classes, appropriate for different age groups	5	--	2.17 (.95)	2.24 (.92)
Community - Crime awareness or crime reduction	6	--	2.16 (.90)	2.00 (1.03)
^a Age focused programs - Programs/activities for teens/young adults (12-21)	7	2	2.16 (.97)	2.34 (.90)
Social activities – Low-cost space for special events	8	---	2.14 (.96)	2.25 (.88)
Family support - Classes on relationships, resolving conflicts	9	---	2.13 (1.00)	2.16 (1.04)

^a Community - Recreational opportunities	10	4	2.13 (.94)	2.31 (.82)
Employment - Job search assistance	---	1	2.08 (1.03)	2.34 (.91)
Employment - Help to improve job skills, training	---	3	2.05 (1.04)	2.33 (.92)
Adult education - Financial assistance to attend school	---	5	1.96 (1.12)	2.30 (.92)
Employment - Financial education/budgeting	---	6	2.12 (.96)	2.30 (.95)
Children’s programs - Arts and culture (dance, music, etc.)	---	7	1.96 (1.03)	2.29 (.91)
Children’s programs - Sports and physical activity	---	8	1.95 (1.03)	2.27 (.93)
Children’s programs – After-school programs	---	9	1.96 (1.12)	2.27 (.94)
Youth Programs - Recreational activities	---	10	2.01 (1.05)	2.27 (.89)

^aPrograms ranked among the top 10 needed programs for both people with disabilities and people without disabilities. The rankings beyond 10 are not displayed.

^bThe rank is based on the priority identified by residents. The rankings range from 1 to 55.

Discussion

Urban public housing has long been dominated by conversations centered around economic considerations and the availability of resources. Public housing residents are no stranger to such aspects that affect their daily lives. Our exploration into this urban context illustrates the intricate relationship between disability and public housing residents. The physical structures and environments participants live in is only one aspect. Persons with disabilities may face a range of issues. Identifying effective methods for ensuring connection with and tending to the additional needs (e.g., health needs) of individuals with disabilities (Valdez et al., 2021) becomes paramount to elevating the entire community.

Diverse demographics within public housing environments communicated their

aspirations and concerns. For instance, respondents without a disability highlighted employment programs and age-specific initiatives as their top needs. In contrast, people with disabilities prioritized community projects and health-related programs. This divergence in perceived need between the two groups underscores the challenges faced by decision-makers. Our study's findings shed light on the broader urban context in which disability needs to be viewed. While addressing immediate health concerns for disabled individuals is pivotal, the urban context adds another aspect regarding service delivery. The socioeconomic changes, for instance, place greater barriers to access for those with disabilities, exacerbating challenges (Mouratidis, 2020). Park et al. (2019) stressed that, as cities evolve, people with disabilities might find it even more difficult to acquire essential services and advocate for their needs. Thriving in diverse communities has challenges often faced by public housing residents, especially for residents with disabilities. To this point, Fainstein and Lubinsky (2020) emphasize the complexities of urban environments, underscoring the need for policies that address an environment for all residents.

Based on the findings relating to need, community centers may emerge as powerful change agents. Our results highlighted that at the time of the survey, the community center ran two food pantries used by residents, emphasizing the significance of such centers in addressing immediate needs. These centers have the potential to enhance experiences for residents with disabilities. The collaborative atmosphere within these centers fosters multigenerational interactions, which Generations United (2020) noted as pivotal in enhancing the quality of life across diverse populations.

In light of our findings, it is important to prioritize direct outreach to individuals with

disabilities and ensure their involvement in decision-making, including the insights from disability research on empowering persons with disabilities to promote a justice-based, holistic, and equitable approach (Barrie et al., 2019). In addition, grassroots community and feedback mechanisms ensure that the community voices of people with and without disabilities help shape urban strategies around housing, health, community resources, etc. (Browne et al., 2017; Kennedy, 2018). It is also paramount to address the socioeconomic disparities faced by public housing residents (Ciorici & Dantzler, 2019). Recognizing the importance of social determinants of health is critical in future planning.

In the context of public housing, disability justice and housing justice are inextricably linked (Christensen & Byrne, 2014). The intersection between disability rights and housing rights is central to the work of many community-based organizations that work with residents of public housing. Parker and Fisher (2010) suggest that in providing housing support to persons with disabilities, the following must be considered: human rights, quality of life, and independent living. A range of support services for residents of public housing by community organizations can help address these goals.

Conclusion

Our exploration provides further information on the complex dynamics of urban public housing. The voices of residents, particularly those with disabilities, challenge us to think beyond conventional paradigms for serving communities. Voices are not just a collection of needs and requests; they form a mosaic of experiences, aspirations, and challenges.

The responsibility lies with stakeholders such as community residents, urban planners,

policymakers, and leaders to transform these insights into tangible actions. Future research needs to prioritize continued resident collaboration. Only through sustained dialogue can we ensure that change focuses on being adaptive and responsive to the ever-evolving needs of public housing residents. The intersection of disability studies and the situation of public housing residents offers a new roadmap, one that champions inclusivity, community, and well-being.

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 **In the Forefront: Public Housing Residents' Needs for Persons with Disabilities** by G. Lawrence Farmer, Henry J. Davis, Janna C. Heyman, Susan Matloff-Nieves, Peggy L. Kelly, Smita Dewan, Nancy Wackstein, and Dalys Castro. <https://rdsjournal.org/index.php/journal/article/view/1277> is licensed under a [Creative Commons Attribution 4.0 International License](https://creativecommons.org/licenses/by/4.0/). Based on a work at <https://rdsjournal.org>

Love's in Sight: Japan's Graphic Narrative of BlindnessYoshiko Okuyama¹ and Osamu Kurikawa²¹ University of Hawai'i at Hilo² Ritsumeikan University**Author Note**

This article is dedicated to the late Professor Shinya Tateiwa and Dr. Mark Bookman, scholars affiliated with Ritsumeikan University's Graduate School, Institute of Ars Vivendi, in recognition of their profound contributions to disability studies. Despite their untimely departures, Shinya and Mark's invaluable work has significantly advanced our understanding of disability, inclusion, and human rights in Japan. Their legacies continue to guide scholars in the field. We also express gratitude to Cornell University's East Asia Program for providing Yoshiko Okuyama with the opportunity to present the brief history and potentials of Voice Comics, an emerging genre of audible manga, in April 2023.

Abstract

By utilizing its accessible format, Voice Comics, a sighted disability comics scholar and a blind scholar of disability studies examine *Love's in Sight*, a Japanese comic about a blind girl, and analyze how this comic can help increase disability awareness and remove the label of “otherness” from people with disabilities.

Keywords: blindness, manga (Japanese comics), Voice Comics

Love's in Sight: Japan's Graphic Narrative of Blindness

Disability is an internationally significant topic, transcending borders as it encompasses discrimination, poverty, and equity issues affecting individuals with disabilities and their families. According to the World Health Organization (WHO), 16% of the world's population, or 1.3 billion out of 7.8 billion people, is reported to have some form of disability. With the rising prevalence of disability, partly due to advancements in medical technology and increased longevity, WHO emphasizes that experiencing disability is an aspect of being human. Given this trajectory, nearly everyone is likely to experience disability at some point. Therefore, it is crucial for all of us to eliminate the "otherness" label attached to people with disabilities, both in reality and fiction.

This article examines *Love's in Sight* (original title, *Yankiikun to hakujō gāru*), a widely acclaimed comic that explores the romantic relationship between a blind girl and a sighted boy. One of this paper's authors, Uoyama, draws inspiration from personal experience, as her father shares the condition of low vision similar to that of the comic's heroine. By bypassing outdated narrative strategies, this story highlights blind individuals' everyday encounters with sighted people. We argue that comics like *Love's in Sight* can make a positive impact on disability awareness, helping remove the label of "otherness" from people with disabilities and normalize their lives.

Furthermore, while we commend the author's effort to portray the diverse aspects of visual disability, we also critique certain stereotyped or underdeveloped elements in its narrative about the blind community in Japan. The strength of this paper lies in the

collaboration between Yoshiko Okuyama, a sighted scholar, specializing in disability representation in Japanese comics (e.g., 2020; 2022), and Osamu Kurikawa, a blind scholar whose expertise focuses on the employment and inclusive education of Japanese people with disabilities, particularly those with visual impairments (1996; 2012; 2020).

In this paper, we first establish the theoretical framework for our comic analysis by examining problematic representations of disability in popular culture outlets, including manga, or Japanese comics.⁴⁰ For example, we highlight the supercrip trope, identified and criticized in Western disability studies, and extrapolate how this trope reinforces the image of disabled characters as the “Other.” Additionally, while briefly touching upon manga’s influence, we emphasize the importance of realistic representations of disability in this medium and argue for a realistic shift away from “extraordinary” portrayals to focus on the ordinary aspects of disabled lives. In the methodology section, we outline our approach to comic analysis, providing a brief description of the comic’s innovative and accessible format, Voice Comics, which facilitated our collaboration. In the analysis section, we delve into a detailed examination of *Love’s in Sight* from the perspectives of US and Japanese disability studies. The objective of our study is twofold: first, to demonstrate how *Love’s in Sight* provides an alternative perspective to the outdated narratives about disability like the supercrip trope; and second, to delineate the specific disability topics on which this manga has the potential to serve as an educational tool in helping to raise awareness of visual disability among sighted readers.

Theoretical Framework

Historically, disability has been misrepresented in various media. Research has found disabled characters are often underrepresented in media. When present, they are frequently shown only as background characters or defined solely by their disability. For instance, Schwartz et al. (2010) state disabled individuals are largely absent from mainstream media, while Moeller and Irwin (2012), in their analysis of graphic novels, point out the underrepresentation compared to real-world disability rates. Both cite the need for better representation of disabled characters.

Many books, including *Reframing Disability in Manga* (Okuyama, 2020), have analyzed the portrayal of disability in various popular culture outlets. They point out common stereotypical portrayals of disability in media, such as the “supercrip” who overcomes their disability through superhuman feats, as well as the negative portrayals of “the Other,” such as evil avenger villains motivated by their disability and object-of-pity figures who are helpless and in need of care. Negative representations in the media have been shown to adversely influence public attitudes towards disability (Shakespeare 1999; Ellis and Goggin 2015), as well as the self-image of people with disabilities (e.g., Nagai 1998; Zhang and Haller 2013).

In disability studies, the term *supercrip* is employed to describe a disabled superhero—a character hailed for their extraordinary physical abilities despite their disability. While the supercrip may appear to be a more positive characterization compared to depictions as either an evil avenger or pitiful figure, relying on portrayal. However, counteracting negative stereotypes solely with the superhero archetype is not only inadequate but can also be detrimental. First, casting the protagonist as a supercrip reinforces a sense of

otherness towards the character by unintentionally accentuating the character's disability rather than normalizing it, further contributing to societal perceptions of individuals with disabilities as inherently different. Second, the supercrip trope perpetuates an outdated narrative centered around "overcoming" disabilities through extraordinary feats, a common expectation in superhero stories. Films like *X-Man* and *Eternals*, while exploring themes of differences and diversity, portray characters with disabilities—visible or implied—as more powerful than able-bodied, non-superhero characters. This inadvertently places emphasis on the physical traits and strengths of characters, potentially leading viewers to judge their worth based on these criteria (Brylla, 2018). Moreover, the supercrip trope places a burden on individuals to navigate challenges themselves, deflecting attention from societal transformation needed in how they are treated. This approach detracts us from the imperative of fostering inclusivity and equal opportunities for people with disabilities. Finally, examining US comics, Alaniz (2014) posits that the supercrip portrayal obscures the lived reality of disabled people. Similarly, discussions on *X-Men* films by Hopkins (2009) and Ilea (2009) note that the trope often obscures authentic disability experiences, further distancing the representation from the actual challenges faced by individuals with disabilities.

Therefore, the supercrip trope, while initially appearing as a positive deviation from negative stereotypes, ultimately falls short in providing a nuanced and realistic portrayal of individuals with disabilities. Authentic representation in media is critical, especially because many people's first exposure to certain disabilities occurs through popular culture outlets such as film and comics when they lack opportunities for direct interaction, whether at school or work. For instance, Ellis and Goggin (2015) assert that, for those with minimal or no

firsthand experience with disabled people, media becomes a primary avenue through which they encounter disability. Similarly, Moeller and Irwin (2012) argue that popular media serves as the primary source of education about disability for many non-disabled individuals, especially in the absence of direct interpersonal contact with the disabled community. In this regard, the supercrip trope hampers the education of able-bodied students regarding the challenges faced by them. Therefore, we argue for media representations to transcend the supercrip trope and instead strive to provide authentic, realistic depictions of disabled individuals.

In the 1970s and 1980s Japan, the supercrip trope prevailed in the portrayal of characters with physical, mental, and intellectual differences in popular culture, oddly coexisting with discriminatory language in the media. Contemporary manga, like *Gangsta*, still tend to exaggerate the protagonist's considerable feats. As we emphasized in this paper, to foster public understanding of their lived experiences, there is a crucial need for comics that depict disabled characters in daily life (Corbella and Acevedo 2010; Okuyama, 2020). Furthermore, employing a narrative strategy where an ordinary person tackles challenging, if not humanly impossible, goals emphasize the journey of overcoming obstacles (Barasch 2001). This strategy introduces a disabled character as a tragic figure, highlighting their triumph "despite" the loss of sight. Paradoxically, in such narratives, disability is downplayed rather than embraced. Portraying disabled protagonists as the Other sustains their minority status, reinforcing isolation and segregation from mainstream society. Instead of being cast as different, disabled characters should be depicted like everyone else, advocating for their rights to wellness and happiness. Media portrayals of people with disabilities should not only

increase visibility but also emphasized our shared human humanity. Rather than glorifying imagined extraordinariness, the focus should be on embracing our ordinary selfhood.

Manga holds a significant and pervasive influence as a medium of entertainment in Japan and beyond. Contemporary representations of disability within manga are progressing positively; while a minority of manga still perpetuate inaccurate and stereotypical depictions, an increasing number of titles, such as *A Silent Voice*, feature characters with disabilities in prominent roles. The central concern now shifts from a lack of representation to the refined portrayal of these characters, as accurate representation is pivotal in fostering disability awareness and dismantling the “Other” label associated with this demographic.

The urgency, therefore, lies in cultivating a broader array of high-quality comic depictions of disability and recognizing their potential as catalysts for change that can promote acceptance and reshape social attitudes. A new wave of manga titles is emerging with the explicit goal of making a positive impact on disability awareness, seeking to function as agents of change in eliminating the pervasive stigma of “otherness” attached to people with disabilities. We contend that *Love’s in Sight* exemplifies such a transformative work based on the following reasons:

First, this particular manga avoids using the element of disability as a narrative prosthesis in the plot. Coined by Mitchell and Snyder (2000), the term “narrative prosthesis” refers to the intentional incorporation of disability into a story to drive the plot forward. In this narrative framework, disability is introduced as a defining aspect of the protagonist’s identity, ultimately becoming the central focus of the story and inadvertently amplifying the otherness of the character. Unlike manga from decades ago, *Love’s in Sight* does not employ

the heroine's visual disability in that manner, as confirmed by the author during an interview with *DI-AGENT* (2021).² Second, bypassing the supercrip trope, its narrative strives to normalize the lives of people with visual impairments. Third, the heroine of this manga not only possesses agency but also articulates her life philosophy clearly throughout the story, making her an unconventional central figure even by today's standards for comics featuring disabled main characters. The topic of agency in disabled heroines will be further elucidated in the analysis section of this paper. Fourth, this manga holds the potential for educational benefits for the sighted reader, as the majority of its episodes are highly relevant to real-life situations within the target community. Particularly, scenes that touch upon important social issues pertinent to that specific community. In other words, *Love's in Sight* frames blindness in the social model of disability,² illustrating how societal oppressions and obstacles impact the well-being of the heroine and the daily lives of other blind characters. To demonstrate this comic's potential educational benefits regarding visual disability, examples of relevant episodes will be described in the analysis section.

Methodology

The methodology begins by providing the criteria for selecting *Love's in Sight* for analysis as well as an overview of its plot. Subsequently, it examines our approach to comic analysis.

Selection of Manga

Figure 1

Cover page image: *Love's in Sight Volume 1*



This paper centers on the graphic novel, *Love's in Sight*, a *yon-koma* (four-panel) manga (Figure 1) published as an eight-volume series by KADOKAWA from June 2018 to February 2022. This manga gained immense popularity, leading to its adaptation into a Hulu drama series in 2021. Notably, the series included a narration broadcast (*kaisetsu hōsō*) for viewers with visual impairments. Despite its classification as a romcom tailored for teen and young adult readers, the comic provides a rich source of visual and narrative elements that warrant in-depth analysis. Our selection of this manga is grounded in several factors, including its critical acclaim in Japan, its contribution to the authentic portrayal of disability issues in the manga industry, and our belief of *Love's in Sight* as a valuable resource for teaching about visual disability, as mentioned earlier. An English-language translation was published by Viz Media in April in 2023.³

The protagonist, Yukiko Akaza, is an ordinary 17-year-old high school girl with low vision attending a school for the blind (*mōgakkō*).⁴ Her boyfriend is Morio Kurokawa, a sighted 18-year-old high school dropout. Their story unfolds when Morio falls head over heels with Yukiko on the very day they meet. Despite their differences, both face societal labeling as “the Other,” leading to similar challenges and prejudice. Notably, the original Japanese title, *Yankiikun to hakujō gāru*, designates Yukiko as the *hakujō gāru* (girl with a

white cane) and Morio as a “yankee” (a slang word for a male juvenile delinquent in Japanese). In the translated title, *Love’s in Sight*, the word “sight” carries a dual meaning, referencing Yukiko’s loss of sight and Morio’s love at first sight. The characters are artistically crafted with a comical dissonance in both appearance and demeanor. Morio’s rebellious exterior, characterized by small, fang-like teeth, multiple-pierced ears, and a long, deep scar beneath his left eye, sharply contrasts with Yukiko’s cute, doe-eyed, petite stature. Morio frequently adopts the behavior of an obedient dog with a wagging tail, whereas Yukiko radiates a more self-assertive demeanor, intensifying the artistic dynamic between the two.

Data Collection Methods and Types of Analysis

Another pivotal factor in choosing this manga is its accessibility for blind readers. Traditional printed comics pose challenges for readers with visual impairments like Kurikawa. Despite various innovative attempts, such as *shokuzu* (textile graphic conversion), to make manga accessible to the visually impaired (Mori 2018), the predominant format remains standard print or digital, primarily processed visually. However, a novel comic format, known as Voice Comic, or *voisu komikku* in Japanese, played a crucial role in facilitating our collaborative analysis of the manga. This format presents the manga with still images while audibly narrating not only the manga’s dialogs (i.e., text written in speech balloons) but also environmental sounds (onomatopoeic expressions written in the background) and the characters’ emotions and behaviors (other written expressions called *manpu*) in each panel. The narration in *Love’s in Sight* closely aligns with the style of *onsei-gaido* (audio description) provided for blind movie-goers or television viewers.⁵ In addition

to Voice Comic, *Love's in Sight* is available in other accessible formats such as the Daisey format (Braille version).

Our examination of *Love's in Sight* employed a comprehensive methodology that integrates textual, visual, semiotic, and content analyses. Textual analysis focuses on the written narrative, encompassing dialogues (print text within speech balloons), inner speech (print text in thought balloons or written directly in the background), and handwritten side notes, evaluating language use, literary techniques, and narrative structures employed by the author. Visual analysis involves a close inspection of graphic elements, such as panel layout, color, balloon shape, and artistic style on each manga page. Semiotic analysis enhances our understanding of the visual narrative by identifying and interpreting visual signs and symbols (e.g., *manpu*, *onyu*, *dosen*), considering their connotations and conveyed messages. Content analysis categorizes and quantifies specific aspects of the comic, including the frequency of metaphors, recurring themes, and character interactions. This systematic exploration allows for the identification of key patterns within the material and enabled us to understand how visual elements contribute to the storytelling process while collecting this data. In addition, our interdisciplinary approach incorporates insights from the scholarly backgrounds of both authors, ensuring a comprehensive examination of the comic's various elements.

A brief background of the population with disabilities in Japan should facilitate our following discussion of selected social issues that involve the blind community. Japanese government data categorizes disability in three groups: physical, intellectual, and mental disabilities. According to the 2021 disability whitepaper, 7.6% of the population has some form of disability. Specifically, 3.45% have physical disabilities, 0.87% have intellectual

disabilities, and 3.32% have mental disabilities. Breaking down the physically disabled group, a 2016 Ministry of Health, Labor and Welfare report reveals that 7.3% (312,000) are visually disabled, while the largest subgroup (45.0%) consists of individuals with mobility disabilities.⁶

Results of the Analysis

Overall Assessment of the Narrative: Perspective as a Blind Teacher

Love's in Sight opens with Yukiko confronting Morio, who casually stands on the tactile paving, blocking Yukiko's path. Outraged, Yukiko prods Morio in the buttocks with her white cane, yelling, "You're in the way!" Morio, attempting intimidation with menacing looks, soon realizes she cannot see him. Instead of mocking her disability, Morio narrates his "scary" appearance to her. Unintimidated, Yukiko reacts by stroking his cheeks, asking if he needs medicine for his "large" scar that he has exaggerated. Touched by her kindness, Morio takes a liking to her. To some readers, this boy-meet-girl start may seem farfetched. Yet, it is a common experience for blind people in Japan when sighted individuals obstruct Braille block users.

One of this paper's authors, Kurikawa, finds this opening hilarious and a testament to Morio's unbiased attitude toward Yukiko. Throughout their relationship, Morio never makes an issue of Yukiko's disability. He is aware of her low vision but does not use it to define her; instead, he tries to learn her way of seeing the world. Kurikawa wishes that Japan had more people like Morio. This paper's other author, Okuyama, initially sees the "punk" and "physical different" couple as a narrative device for dramatic effect. However, a blind person like Yukiko, Kurikawa recounts his experience as a high school teacher, during which

students dealing with their challenges often sought guidance from him instead of their sighted homeroom teachers. Initially, they would engage in conversation and offer frequent assistance. As trust developed, they began confiding in him, seeking advice on their concerns. Morio, in the manga, used to be ridiculed and ostracized by classmates because of his “illegitimate” family and eventually dropped out of high school. Yukiko says, “Morio needs someone who listens to him.” Kurikawa believes that troubled teens likely empathized with him, recognizing his marginalized position as the sole blind teacher in the school, and that this perception made him more approachable, akin to Morio’s perception on Yukiko. Both labeled as “the Other,” Yukiko and Morio are opposite sides of the same coin. Therefore, Kurikawa feels that this pairing is highly probable.

Challenging Ableist Stereotypes in Manga: Yukiko’s Empowering Agency

In manga, disabled female characters are often subjected to ableist stereotypes, portrayed as either powerless heroines or objects of pity (e.g., a blind woman in *To Terra*; a woman with mental illness in *Emma*; a deaf girl in *A Silent Voice*). However, Yukiko’s character defies these conventions: she is neither a pitiful, helpless figure nor disabled superhero. She is not portrayed as a “tragic” heroine “struggling” with her loss of sight. Instead, Yukiko is a young woman with strong agency, and Morio admires her as a senior in life, despite her being a year junior. This section delves into Yukiko’s agency to highlight the effective representation of her voice in *Love’s in Sight*.

Figure 2

Love's in Sight Volume 1, p. 53

Yukiko, the rough-spoken, spirited protagonist of this manga, consistently takes charge in the storyline. She initiates decisive moments, such as suggesting and planning their dates, showcasing her proactive and determined nature. Unlike the stereotypical portrayal seen in 1960s and 1970s manga, Yukiko rejects victimhood, co-creating a romantic journey with Morio. Her assertiveness, clear opinions, and strong-mindedness attract Morio, highlighting her agency in the narrative.

In this excerpt (Figure 2), Yukiko emerges as a resilient individual while navigating

her way through difficulties stemming from inclement weather and inadequately designed tactile paving. She confronts failures independently and adapts to unexpected situations. While Morio, akin to a protective knight, often intervenes to prevent Yukiko from accidental mishaps, his role is not to pity or perceive her as a weakling.

Their unique relationship is further illuminated through the use of role-specific language, or *yakuwarigo*. Visually contrasting, with Morio as an older, taller character with an intimidating appearance, and Yukiko as a younger, shorter figure resembling a “super cute” girl with big eyes typically depicted in the *moe* manga genre, their roles are completely reversed verbally. Yukiko addresses Morio by his last name, “Kurokawa,” adopting the tone of a senior addressing to a junior student, while Morio respectfully calls her “Yukiko-san.” Yukiko punctuates her speech with *zo*, a linguistic marker denoting authority, leadership, and manliness (Kinsui 2014:113-114), whereas Morio’s speech is marked with the *ssu*-ending, suggesting a subordinate position (127-128). This linguistic contrast cleverly subverts traditional gender role and age-based hierarchy.

A love story devoid of challenges may lack the intensity for compelling drama. In this narrative, the couple encounters occasional difficulties, resolving them through heart-felt conversations. However, these struggles serve as a dual purpose: not only do they contribute to the storyline, but they also underscore the social challenges faced by blind individuals, aligning with the social theory of disability. While manga stories featuring disabled heroines often adhere to the pure-love-tested-by-hardship formula, such a narrative tactic may reinforce the misconception that being close to a disabled individual inherently invites hardship. The couple’s romance unfolds through trial and error, stemming not solely from

Yukiko’s disability but mainly from the natural awkwardness and inexperience of a young couple. Though Yukiko’s low vision adds a layer of complexity, Morio’s struggles, such as feeling inadequate when describing artwork at a museum or a cave environment at a national park, stem from his sincere effort to understand Yukiko’s perspective. Despite initial clumsiness, these instances are woven into moments of intimacy, shaping a genuine love story.

Figure 3

Love’s in Sight Volume 2, p. 29



In this example (Figure 3), Yukiko reminds herself of how uncommon Morio is (first panel), free from the biased assumptions and negative stereotypes about visually impaired people typically held by sighted people, like his friend Hachiko (second panel). Despite feeling disheartened by society’s tendency to pigeonhole her as “disabled” rather than recognizing her as an individual human being (third panel), Yukiko resolves not to accept this label and advocate to be

judged based on her character, not her disability (fourth panel). This episode demonstrates Yukiko’s strong determination for equal treatment. Her insistence on autonomy, despite occasional frustrations and disappointments, renders her a human and relatable heroine. Moreover, she is unapologetically independent while open to seeking Morio’s help when necessary, carrying important implications for the broader world where interdependence

transcends disability.

A Myth Buster

Each person with a disability possesses a unique set of experiences. Therefore, it is important to recognize the diversity of these experiences beyond one individual blind person. Common misconceptions in Japan include assuming all visually disabled people are completely blind, expecting blind people to always wear dark sunglasses, associating white canes exclusively with those with complete blindness, and assuming all blind individuals proficiently read Braille (Shibata, 2015). However, *Love's in Sight* challenges these myths.

Figure 4

Love's in Sight Volume 3, p. 17



Love's in Sight visually articulates different types of blindness in several episodes. Illustrated in a sample image (Figure 4), Yukiko experiences central vision loss, and her hazy vision is akin to viewing the world through a film (top panel). In contrast, her

classmate Sora has peripheral vision loss, particularly on the left side (bottom panel). Aono, another classmate, deals with complete blindness, depicted with a black background.

This manga effectively portrays the diversity within the visual impaired population in Japan. Merely 10% experience total blindness, while the majority (80-90%) have low vision like Yukiko and Sora, and less than 10% have other types, such as color blindness (Japan

Federation of Visually Impaired 2016; MIC, 2009). Visual acuity, determining partial blindness (20/70 to 20/200) or legal blindness (above 20/200), varies within the low vision group, with each case differing in blind spots, blurriness, and night vision. Despite some remaining sight, skills in Braille reading vary widely. Therefore, not all students in a *mōgakkō* can use Braille, as illustrated in one episode when Yukiko's boss, a fast-food manager, presents a Braille menu to her and classmates, revealing that Aono can read it.

Yukiko and Aono are the only characters depicted using a white cane, whereas Sora, sensitive to sunlight, wears dark sunglasses. Yukiko and Sora, representing the majority with low vision, highlight additional diversity within this group. Yukiko perceives vivid colors and a frame with no details, whereas Sora's narrow vision, particularly on the left side, poses challenges, hindering her sight at distances of 20 or 30 feet. In one episode, Sora stumbles over a bicycle while jogging at night, a time she claims her vision is better. Through these and numerous other episodes, this manga dispels common myths about visually disabled people, in Japan, earning its status a myth buster.

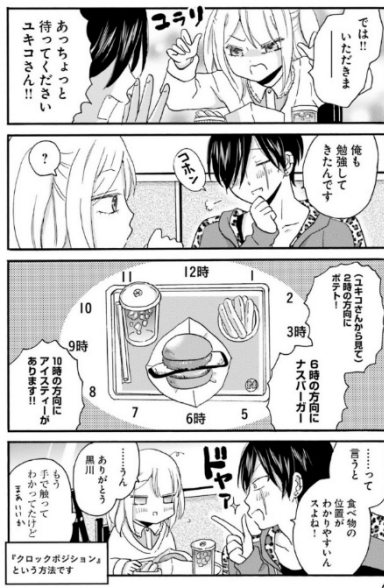
Normalizing Disabled Characters and Everydayness of Their Lives

Love's in Sight offers a refreshing departure from the common narrative prosthesis in depicting characters with disabilities. Furthermore, unlike traditional romcom manga that use the protagonist's disability as a challenge testing the couple's love, a trend prevalent since the 1990s (e.g., *Kimi no te ga sasayaiteiru*; *Pāfekuto wārudo*), *Love's in Sight* explores a different dynamic by focusing on Morio's internal struggles. This manga's story sheds light on Morio's self-doubt, wondering whether a jobless *yankee* like him is worthy of Yukiko's love. In doing so, it emphasizes his personal growth and efforts to make Yukiko's time with

him enjoyable, steering away from that conventional trope found in typical manga featuring disabled heroines.

Figure 5

Love's in Sight Volume 3, p. 6



In this episode (Figure 5), Morio proudly demonstrates his newfound knowledge of the clock position, a method used by sighted individuals to assist blind people during meals by indicating where each food item is placed on a clock face (e.g., “A cup of soup is at 3 o’clock”). While the actual techniques are more intricate, *Love's in Sight* presents this valuable information in a humorous style, avoiding a medical guidebook feel. For instance, Morio, reading off like a script, informs Yukiko

about the items on her plate. In response, she thanks him but thinks to herself, “I already knew where they were by touching them. Well, whatever.” Morio’s well-intentioned but awkward assistance serves as comical relief, contributing to the manga’s engaging storytelling.

Figure 6

Love's in Sight Volume 1, p. 199



Like the clock position episode, *Love's in Sight* features various scenes showcasing techniques for guiding the blind, often concluding with a humorous touch. For instance, in this episode (Figure 6), as Morio has Yukiko's body close to him, allowing her to hold his arm, he makes a playful comment about them walking "like a lovey-dovey couple." His remark leaves Yukiko blushing and switching her hold to his shoulder, momentarily trapping him due to their significant height difference. Even though a blind

person can walk independently on a familiar route, knowledge of walk-guide techniques, such as offering one's arm, elbow, or shoulder for guidance, become helpful when accompanying them. As these examples show, *Love's in Sight* weaves humor into Yukiko's routines, creating an entertaining and informative narrative that seamlessly alternates between comical and serious moments, capturing the essence of everyday teenage life.

Love's in Sight distinguishes itself by humorously and educationally showcasing a high schooler's ordinary activities, steering clear of the mundanity often associated with slice-of-life comics. Similar to the main characters of Saso Akira's *Hana ni toitamae* (2014-2015) and Sone Fumiko's *Itsukushimi no shiya* (2015), *Love's in Sight* portrays Yukiko as an everyday person without becoming entangled in trivial details. Kurikawa underscores the problem of relying solely on supercrip portrayals, like the protagonist of *Zatoichi*, to

represent blind people. Although he finds superhero movies quite entertaining, he believes that multiple representations are essential for depicting people with disabilities. To dismantle the “Other” label and foster inclusivity, Okuyama has also argued for more manga that focus on ordinary aspects of their lives, such as dating and shopping (2020; 2022). It is imperative for comics to illuminate the everyday life experiences of individuals with disabilities, opting out of the narrative prosthesis approach or supercrip trope.

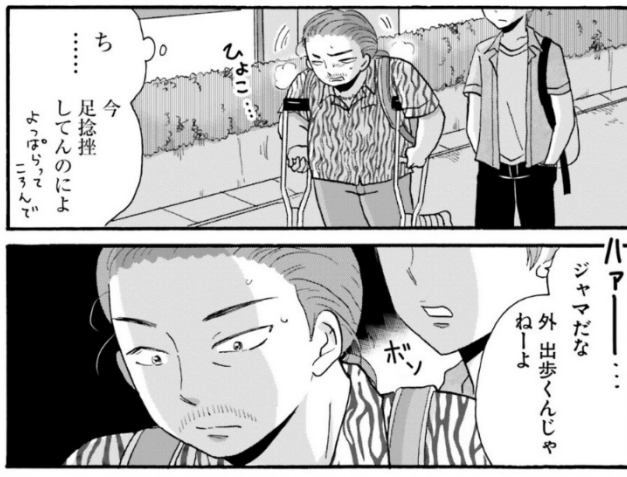
Figure 7

Love's in Sight Volume 6, p. 122



Moreover, *Love's in Sight* excels in conveying that disability is not just someone else's story but “our” story. In a poignant scene (Figure 7), Yukiko's classmate, Aono, stands on the Braille blocks, awaiting someone. When bumped into by a man who scolds him, “Don't just stand there! Pay attention!” Aono reveals that he is blind and asks about his white cane.

Disregarding Aono's question, the man insists, “Why don't the blind just stay home?” This assumption reflects the view that the street belongs exclusively to the sighted. Blind individuals often face such clashes in crowded public spaces, with hurrying passersby shouting, “Watch where you are going!” (Iijima and Hirose, 2022). Inclusive communities must recognize that the streets belong to everyone, blind or sighted.

Figure 8*Love's in Sight Volume 6, p. 202*

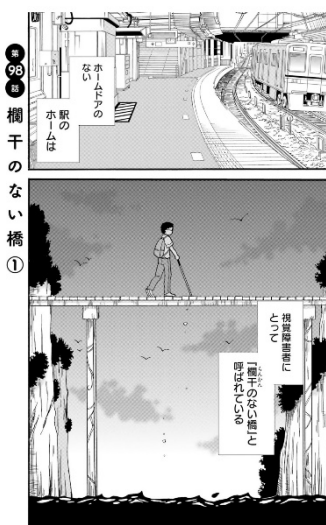
Ironically, in the same volume, the same man is depicted walking now using crutches. In this scene (Volume 6, p. 202), the man limps, overtaken by a younger able-bodied man who callously remarks, “Folks like you are in my way. Don’t hang out outside.” It

is a what-goes-around-comes-around moment, echoing the man’s earlier reaction to Aono.

This scene illustrates that anyone, like the nameless character, can find themselves marked as the “Other” at any given time.

Toward “Barrier-Free” Public Spaces

Japan’s advanced public transportation, while beneficial for sighted commuters, poses hazards for blind people. Ishimura (2019) points out that nearly half of visually impaired commuters face harmful incidents involving Braille blocks, accessible pedestrian signals, and platform screen doors. Nor do these devices fully meet the needs of the blind community in Japan. As Ishimura (2019) emphasizes, depending solely on a white cane or a guide dog alone is insufficient for safe navigation; the watchful eyes and support of fellow passengers are also necessary.

Figure 9*Love's in Sight Volume 7, p. 2*

Love's in Sight, Volume 7 depicts Aono's rescue by fellow passengers as he teeters on the train platform. This volume begins with the metaphor “*Rankan no nai hashi*” (a bridge without railing), illustrating the risk of a train platform without a “form door” (*hōmu doa* in Japanese), an automatic platform screen door ensuring safety, especially for the blind (Figure 9). While all platforms feature a tactile paving system for navigation, some sighted passengers thoughtlessly place

their belongings on the braille blocks, obstructing blind passengers. Despite the decline in falling cases due to form doors and other cautionary measures, approximately 2.2% of the 3,000 platform falling cases in 2019 involved visually impaired passengers,⁷ and 36% of them fell on the tracks⁸ (MLIT, or Ministry of Land, Infrastructure, Transport and Tourism 2021). This percentage is notably high, given that blind people constitute less than 0.3 % of Japan's population.

Figure 10*Love's in Sight Volume 7, p. 172*

Love's in Sight also presents data on train platform hazards for the blind. In this



episode (Figure 10), Morio, visibly alarmed (implied by the *manpu* signs of his sweat beads and pale shade), learns about grim statistics from the *mōgakko*'s teacher. He envisions Yukiko walking on

Braille blocks near the platform edge as the train station announcement blaring “The train is arriving shortly.”

Figure 11

Love's in Sight Volume 2, pp. 148-149



Experiencing social invisibility is a common aspect of having a disability, notably due to the accessibility challenges in Japan’s public transportation, as illustrated in a scene from Volume 2 (Figure 11) of *Love's in Sight*. Determined to visit Morio after weeks of silence,

Yukiko debates the challenges of taking the bus versus a more expensive yet easier cab ride (first to third panels on right and first panel on left). Her heart beats rapidly partly because she has been yearning to see him but largely because she anticipates the complication involving the bus ride (fourth panel on right). Momentarily, she even thinks of giving up on the idea as she stares at the clock (second panel on left). However, telling herself, “If I were a sighted person, I would jump on the bus by now,” she refuses to let her disability restrict her life and chooses the bus. Unfortunately, the episode takes on an unexpected turn: Yukiko boards the wrong bus and eventually takes a taxi home, discovering Morio eagerly waiting for her in her room. Concealing her failed attempt, Yukiko feels disheartened when Morio innocently remarks about the “easy and convenient” public bus system. These episodes underscore that, as shown, both the train and bus systems are not readily configured for all users.

The Old Notion of Blind Students

No manga is flawless, and *Love's in Sight*, while addressing disability with care, inadvertently reinforces stereotypes and leaves some aspects ambiguous. To enhance the narrative, we recommend the following improvements:

The manga artist Uoyama, drawing inspiration from her own father's low vision, interviews with blind people, and visits to *mōgakkō* and organizations for the blind (*DI-AGENT* 2021), approaches the subject with sensitivity, ensuring the fair treatment of the blind heroine and the sighted characters (*Sobikoto* 2019). However, despite these efforts, some aspects of *Love's in Sight* convey the author's “outsider” perspective on the blind community, as noted by Kurikawa. For example, the depiction of blind characters attending

the fictional *mōgakkō*, Nijimachi Public School for the Blind, mistakenly implies a commonality in educational choices for visual impaired children. This portrayal oversimplifies reality, as students with low vision, like Yukiko, are more commonly enrolled in regular high schools, aligning with Japan’s inclusive education movement, or *inkurūshibu kyōiku*. Although the narrative offers a brief backstory about Yukiko’s transfer from a regular school to this *mōgakkō* when her sight began to deteriorate, Kurikawa worries that this simplistic portrayal may mislead readers unfamiliar with the blind community.

Figure 12

Love’s in Sight Volume 2, p. 47



In this example (Figure 12), Yukiko’s monologue reflects her understanding of Sora’s resentment towards sighted people.⁹ Initially, she asserts, “Both Sora-chan and I know that there are more kind-hearted people out there than those who aren’t.” However, in the next three frames, Yukiko showcases incidents where sighted individuals unknowingly disregard people like her, behaving as if the blind are invisible and insignificant, albeit without malicious intent. This and other similar episodes position Yukiko

as a voice representing many white cane users.

Before Japan initiated its inclusive education campaign,¹⁰ the majority of visually impaired children were placed in *mōgakkō*. In 2011, 79.2% were in such institutions with only 20.8% mainstreamed, with 6.3% in regular classes, and 14.5% in special education classes (Mithout, 2017). However, since 2014, multiple legislative measures have been implemented in conjunction with the Rights of Persons with Disabilities (JASSO 2022), and educational segregation is no longer reinforced on children with visual disabilities who do not have other, compounding disabilities. The 2021 data from the Ministry of Education, Culture, Sports, Science and Technology (hereafter, MEXT) show that only 25% of blind students were in *mōgakkō*, while 74.3% were in regular schools (of which 65.7% in regular classes and 8.6% in special education classes).¹¹ By contrast, overall enrollment in special support schools is rising due to the rapid increases “in the categories of ‘developmental disorders,’ ‘health impairment or chronic disease/conditions,’ and ‘mental disorders’” (JASSO 2022: 11). Similarly, the 2022 White Paper on Persons with Disabilities reports on the installation of various structural accommodations (e.g., bathrooms and sidewalks for children in a wheelchair) in regular schools for a “barrier-free” public education, as well as a sharp increase of children with developmental disorders placed in special support schools (*Shōgaisha Hakusho*, 2022). Amid these changes, the declining number of visual impaired children and the push for inclusive education also challenge the survival of *mōgakkō* (Nakamura, 2019). While rare, schools like Tsukuba School for the Blind stand out, with large enrollments and selective admissions for applicants from all prefectures aspiring to pursue higher education. However, in Kurikawa’s hometown in Niigata, two special support

schools merged due to low enrollment in 2022. Therefore, Kurikawa believes placing the heroine of *Love's in Sight* in a regular high school and showing her encounters with sighted high schoolers would have been a more realistic setting, given current inclusive education trends in Japan.

Moreover, the absence of adult character with visual disabilities in *Love's in Sight* creates another unrealistic portrayal. The sole teacher shown, Ms. Kida, is sighted, leaving Yukiko and her classmates without a role model at Nijimachi Public School for the Blind. While unintentional, this reflects a reality in the Japanese educational system. In 2019, MEXT established a *shōgaisha katsuyaku sokushin* team to promote active participation by the disabled, outlining six plans. Plan Number 6 advocates for the inclusion of disabled teachers, covering mandatory activities and policies from teacher training to hiring practices to post-employment support services. Despite these efforts, the increase in hiring disabled teachers has been limited, crucial for achieving true inclusive education (Harada, 2021). Kurikawa believes that disabled teachers can serve as valuable role models for disabled students and foster a more direct understanding of disability among sighted students, teachers, and staff. Their presence is critically important to establish a more egalitarian relationship among the entire school community, breaking down the traditional dichotomy of educator/benefactor and learner/beneficiary (Harada, 2021).

Conclusion

In 2012, MEXT initiated “more inclusive education” (*inkurūshibu kyōiku*) to align with Japan’s broader goal of creating an “inclusive society” (*kyōsei shakai*) for active participation of disabled individuals. The 2017 establishment of a universal design committee

resulted in various inclusive policies, such as a booklet with sample activities connecting regular and special school students. Progress has been made, yet achieving a truly inclusive society necessitates not only inclusivity for disabled students but also a more supportive environment for disabled teachers (Harada, 2021). To cultivate a society where no one is marginalized as the Other, it is imperative to create comics that feature ordinary people with disabilities leading ordinary lives.

Despite the intense focus on Yukiko and Morio's romance, *Love's in Sight* does not obscure its portrayal of Yukiko's daily struggles with social barriers. Rather than treating her disability as a mere narrative device or dismissing as unimportant, the story highlights it as a key characteristic essential for Morio and other sighted characters to understand for equal coexistence. The inclusion of other blind characters like Sora and Aono also addresses important social issues within the blind community in Japan, revealing a broader context of disability.

While some manga continue to exaggerate their protagonists' extraordinary feats, works like *Love's in Sight* have begun to be published, enabling able-bodied readers to emotionally connect with the experiences of ordinary blind people and offering valuable insights for pedagogical applications. We argue that such comics can serve as heuristic material for readers across demographics, shedding light on the blind community and emphasizing the imperative for genuine inclusivity in Japanese society. As representation of disability in Japanese comics improves, caution is needed to avoid stereotypical descriptions of disabled people. Supporting for serious comic representations of disability and ensuring accurate portrayals of the lived experience of people with disabilities remain crucial. Lastly,

we advocate for the expansion of manga titles in audio formats like Voice Comics to foster inclusivity and accessibility in entertainment, aligning with the broader objective of building a more inclusive society.

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Footnotes

¹ Manga, denoting Japanese comics, is a medium comprising still, primarily monochrome visual images accompanied by written words.

² In the interview, Uoyama emphasized avoiding the use of Yukiko’s disability as a narrative device to make this story a “tear-jerker.”

³ In the 1970s, only a fraction of those engaged in disability studies in Japan endorsed the social model. However, spurred by significant political movements led by people with disabilities, the transition from the medical to the social model occurred in the 1980s.

⁴ Disclaimer: Our discussion of *Love’s in Sight* in this paper is not receiving benefits or favors from the publisher, Viz Media.

⁵ The official title of *mōgakkō* is now *shikaku shōgai tokubetsu shiengakkō*, reflecting the introduction of the special support schools system (*tokubetsu shiengakkō*) in 2007.

Compulsory education for the blind and the deaf predates that for children with mobility

disabilities or intellectual disabilities, and mandatory education for all children with disabilities was finally implemented in 1979 (Tateiwa, 2010).

⁶ Specializing in this format, the publisher KADOKAWA began converting widely popular manga titles like *One Piece*, around 2010. Okuyama speculates that the recent surge in fandom around voice actors and increased anime consumption during the pandemic has led to the conversion of more new titles into this format. However, not all manga titles are available in Voice Comics on KADOKAWA's website, and not all Voice Comics titles are narrated in the *onsei-gaido* style. For example, the romcom manga *Heika kokoro no koe ga dada more desu* (*His Majesty, Your Inner Voice is Audible to Me*) only features audio translations of dialogues.

⁷ Murata et. al (2021) reported the numbers, which are also available on the National Institute of Information and Communications Technology (NICT) website at <https://barrierfree.nict.go.jp/relate/statistics/population1.html>.

⁸ Ministry of Land, Infrastructure, Transport and Tourism's "Safety Report Concerning Train Transportation," November 2021, notes a decrease in falling incidents among the visually impaired in 2020, due to pandemic-related reduction in transportation usage. (国土交通省

「鉄軌道輸送の安全に関わる情報（令和2年度）」2021年10月

https://www.mlit.go.jp/tetudo/tetudo_fr7_000032.html.)

⁹ Ministry of Land, Infrastructure, Transport and Tourism's "Midterm Report: Safety Measures for Visually Impaired People Using the Train Platform," July 2021 (国土交通省

「新技術等を活用した駅ホームにおける視覚障害者の安全対策について～中間報告～」

¹⁰ In manga, characters' non-vocalized thoughts are written in boxy speech balloons, while their spoken words are framed in round speech balloons.

¹¹ In 2007, as part of educational renovation efforts, MEXT combined three types of schools specialized for students with particular disabilities – *mōgakkō* for the blind; *rōgakkō* for the deaf; and *yōgokkō* for children with other disabilities including mobile and intellectual disabilities – under one category of *tokubetushien gakkō* (lit. “special support schools”). This

¹² In 2012, MEXT initiated “more inclusive education” (*inkurūshibu kyōiku*) to align with Japan's broader goal of creating an “inclusive society” (*kyōsei shakai*) for active participation of disabled individuals. The 2017 establishment of a universal design committee resulted in various inclusive policies, such as a booklet with sample activities connecting regular and special school students. Progress has been made, yet achieving a truly inclusive society necessitates not only inclusivity for disabled students but also a more supportive environment for disabled teachers (Harada 2021).



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**Impairing the Vote:
The Effect of State Election Policy on Disabled Voter Turnout**

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Abstract

Prior disability research has failed to capture the nuanced nature of election turnout for individuals with disabilities. The current project investigates the impact of state electoral policies on the voting behavior of disabled individuals. Our findings suggest that individual electoral policies on their own do not significantly impact turnout.

Keywords: disability, voter turnout, state and local politics

Impairing the Vote:

The Effect of State Election Policy on Disabled Voter Turnout

The study of disability community has been the focus of political scientists for some time, and yet the field has several areas that require further inquiry. With the most recent national election cycle taking place within the context of the global COVID-19 pandemic, we saw those with and without disabilities overlap in their desires more clearly than ever before; the massive public health concerns born of the pandemic led to many states issuing far more convenience voting measures for their citizens than previously allowed (Tang, et al., 2021, pp. 1001-1007), which begs the question: if these voting measures are possible on such a large scale, why are they not more widely available in times without global public health crises? And, which of these measures can be expected to yield higher voter participation?

One area in which these questions might be answered concerns the state-level policies that impact voter turnout. The majority of prior research has been conducted using national election data to find patterns in behavior among disabled individuals, notably with regard to political engagement and efficacy. These studies have provided insight into the awareness and viability of the disabled community, but the scope of these studies addresses patterns of the past and has offered less insight into how to further enfranchise the constituency of

people with disabilities.

Avenues of Engagement

There are several forums within which citizens learn about and discuss political topics, which creates a social aspect of political engagement. People with disabilities are predisposed towards smaller social circles and a general exclusivity stemming from their individual impairments. People with disabilities often lack the social infrastructure to discuss politics openly, and therefore have less incentive to stay informed on current political discourse; furthermore, lack of social contact has been linked to the depression of the disability voter turnout (Trevisan, 2020, p. 2). That said, Powell and Johnson (2019, p. 402) found that the depression of engagement and awareness among disabled voters is largely bounded by the traditional modes of political engagement—ergo, voting in elections. Beyond being disenfranchised by various barriers from the voting process, the engagement of eligible voter with disabilities tends to stay on pace—and even outpace on occasion—that of those without disabilities. The alternative forms of engagement utilized by those with disabilities to stay informed and heard reflect freedom of time and space; that is, there are fewer constraints on time of completion or location of participation that tend to be the barriers faced by disabled voters.

As noted by Schur et al. (2017, pp. 1380-86) as well as much prior research, the voter turnout among those with disabilities is significantly lower than voter registration or other forms of political engagement. These other forms of engagement span traditional methods of participation as well as technological adaptations such as online forums and message boards. Trevisan (2020) found that online political participation—on social media and in various

interest groups—serves as a blessing and a curse for those reporting disabilities. On the one hand, platforms like YouTube allow for the disability community to produce informative content based on shared community interest in specific policy areas; on the other hand, the polarization of online information about current politics can result in significant mental and emotional distress (Trevisan, 2020, pp. 2-5). However, it appears that ease of access and the enhanced connectivity of internet-based engagement is preferable to those with disabilities. Johnson and Powell (2019, p. 264) suggest that this preference might drive a renewed interest on the part of politicians in courting those with disabilities.

Partisanship

The Americans with Disabilities Act (ADA) resulted from bipartisan support in Congress; today, many of the protections therein have been eroded individually rather than repealed wholesale (Rothstein, 2019, p. 272). As this erosion takes place, citizens with disabilities are left out of the discussion because they do not form a cohesive constituency. According to recent reports by the Pew Research Center, a factor that further compounds this cycle is the intersectionality that comes with the disability demographic. Prior studies tend to agree that disability is not a unifying political force and that people with disabilities operate in ways that would be predicted by their other demographic information. That is to say, people with disabilities trend in ways similar to those of the United States population as a whole (Igielnik, 2016). Per recent data from the U.S. Census Bureau, 12.7% of people living in the United States identify as living with some form of disability (2021). This means that one in every eight people in the United States is a member of this particular disenfranchised group. With such a substantial portion of the population being an identified member of this

group, politicians from both major parties are starting to take notice.

When conceptualized in a vacuum, the expectation is often that disabled voters skew Democrat because of that party's support for social support programs, such as universal mail-in voting, that would benefit a constituency of people with disabilities. Online engagement targeted at disabled populations has been embraced by many candidates, particularly Democrats, in an attempt to mobilize that untapped voter market (Trevisan, 2019, p. 1593). Online outreach of this kind, however, has been largely ineffective. Most of these attempts and the literature that recounts them focuses on supply—i.e., what the policy makers are willing to give rather than on the demand of the disabled, which would be what they actually seek from lawmakers. It is in this misperception of disability and the resultant needs that many measures to address lower voter turnout have failed.

Advocacy & Understanding

Popular support has been on the rise for many measures that would enfranchise the electorate. Support for reform has been strong and rising from 2008 through 2016, with a growing majority of respondents to the Survey on the Performance of American Elections (SPAEE) seeking convenience reforms (Bowler & Donovan, 2018, pp. 976-977). As Trevisan (2019, p. 1596) states, “people with disabilities are a group that is relevant to candidates from any party. Despite a widespread belief that people with disabilities vote Democrat, political ideology, and party identification trends among Americans with disabilities are similar to those for nondisabled Americans.” Partisanship among people with disabilities is something that has been lagging in research, possibly due to the popular assumption that disability communities lean Democrat (Gastil, 2000, p. 589). This is in line with research suggesting

individuals with disabilities are notably hard to pin to one party ideology (Powell and Johnson, 2019, p. 403). While disability is a factor that impacts daily life for those living with it, the diverse set of causes and effects for disabilities overall make it hard to unify disabled voters as a single voting bloc. Spagnuolo and Shanouda (2017) mention this diversity of disability by calling attention to the “major divisions within disability communities and organizations...[to] include people with chronic illnesses, disabled immigrants and refugees, people labeled with an intellectual disability, disabled people with invisible impairments, Mad people, racialized disabled people, and institutionalized people, among others.” While disability has been shown to lack a unified identity and political goal, some advocacy movements still argue for the administration of unilateral fixes to disability issues (Spagnuolo & Shanouda, 2017); this singular approach then poses yet another problem for disabled voices: it paints a diverse group as homogenous. In the face of this, self-advocacy among those with disabilities is on the rise. This comes hand-in-hand with new conceptualizations of disability community dynamics and culture.

Models for social understanding, i.e., widely accepted beliefs about capability or incapability, underpin nearly every aspect of daily life for those with and without disabilities. However, the former tend to be the subject of generalization more often than not. The current model often conflates disability with inability. In reference to these connotations, Spagnuolo and Shanouda (2017, p. 705) state “[current policies] make issues of access an individual rather than social problem; inaccessibility comes to signify an individual’s inability to participate, rather than the effects of faulty social arrangements.” According to Morgan (2021), the current models of understanding disabled persons view them in the individual

context while models proposed to improve the status quo view them in a sociopolitical context. The difference is that the former takes a disabled person to be operating at a disadvantage in a non-biased system of denotations whereas the latter insists that a disabled person operates in a functionally different manner within a system of connotations (pp. 1406-8). In the current system of understanding disability, issues are arising from all the traditional barriers to access, and yet the options for addressing these inconveniences for disabled voters are widespread. Absentee voters who are overseas or are serving in the military are offered significant time concessions to allow for their ballots to be cast and counted. Online tools and requests are allowed for multiple options, but in most states disability is not an accepted reason for those concessions (Belt, 2016, pp. 1506-9).

Remedies

Efforts for reforming the election process in the United States may be rising due to popular demand, but the support for that movement is heavily influenced by partisanship. Voter ID laws are a prime example, with partisanship heavily influencing how the status quo is perceived. In this case, it can be seen that convenience is supported by Democrats and resisted by Republicans. However, disabled voters tend to find ways to vote that are not impacted by voter ID in the same way (Bowler & Donovan, 2018, p. 973). Much of this support or lack thereof comes from voters and political actors on behalf of disabled people rather than from amongst that community. This, too, becomes an issue of whose voice is being heard on the issues facing individuals with disabilities. Bagenstos (2020, p. 1341) says it is integral to the enhanced understanding of disability among the populace that voters with disability participate in state and local elections because it is through cooperation toward

shared goals that the alienating stigma and policies can begin to break down.

This then leads to the question of how to address the barriers that create the disability voting gap. In some prior studies, convenience voting reforms intent upon reducing the costs for disabled voters to participate are found to have low to no positive effects on turnout. Thus, consideration of supply and demand for disabled voters is raised once more (Miller & Powell, 2015, pp. 47-48). The issue that arises from these middling positive effects again comes back to where these “fixes” came from. However, the literature leans more towards soft support for such convenience reforms. According to Tang et al., voting by mail is a viable path for people with disabilities to increase rates of democratic participation (2021, pp. 1005-7). Absentee voting is available in all 50 states, though restrictions and guidelines governing that practice vary widely throughout these jurisdictions (National Conference of State Legislatures, 2020). In an election year that found the United States in the grips of a global pandemic, absentee voting became increasingly considered a necessity. According to Miller and Powell, mail-in ballots make up a sizable portion of disabled voting across physical impairments and pan-disability types (deaf, blind, mental impairment, etc.) and the results show that the likelihood of voting decreases with disability, and likelihood of voting by mail increases with disability (2015, p. 42).

The extension of absentee and mail-in ballot options to a larger portion of the population, particularly those who find physical barriers to voting access in standard polling places, is a recommended course of action, per a joint report from the American Civil Liberties Union and the National Disability Rights Network (2020, pp. 4-5). These methods of voting were extended in several states during the 2020 election because of public health

concerns about the COVID-19. In those states, there was a marked increase in disability voter turnout (Tang et al., 2021, pp.1001-7; Schur & Kruse, 2021, pp. 9-11). This closing of the disability gap, albeit achieved in a time of crisis, is further proof for many that the disability gap is not a function of individual disinterest but rather of institutional obstacles. People with disabilities are not an untapped minority group that could only be engaged by one political party. It is a diverse group of voters numbering in the millions who could be incorporated into the democratic process (Schur & Adya, 2012, p. 836).

Compounding Factors

The disability turnout gap is a function of many interlaced factors. Beyond state-level policies in voting administration, disparities in education are among these indicators of turnout by people with disabilities. While education has improved for those with disabilities over the last two decades, research shows the inordinate influence of education on the disability turnout gap—nearly 40%—at the national level (Schur & Adya, 2012, pp. 836-7). Of further concern are the current allowances for mental health aides for those who fall into the mental disability category. Many instances of voting assistance, which would otherwise be election fraud, have been cited by critics as arguments against further expansion of election accessibility (Hoerner, 2015, pp. 117-8). However, Schur and Kruse point out that significantly fewer voters with disabilities reported needing or using allowed assistance in their chosen method of voting for the 2020 elections (2021b, p. 9). This decrease in election assistance use does not mean that those with disabilities has been fully incorporated. As Ward et al. (2009, p. 81) illustrate, people with disabilities are not a monolith, and some portions of this broad demographic are further incorporated and engaged than others. Schur and Adya

(2012, p. 837) concluded that the political inequality of those with disabilities does not arise from disability but rather from the inequalities baked into economic and social structures that pose barriers to people with disabilities. That is to say, institutional obstacles create conditions for lack of engagement.

Hoerner references the Elections Assistance Commission in discussion of voter education, relaying the emphasis that commission places on informing the mentally disabled about elections in ways that are accessible to them (2015, p. 124). This approach is echoed in the research done on the pathic and social models for disability by Reynolds and Kiuppis (2018, pp. 564-5), who found that the differing language and concepts used in referring to those with disabilities ought to be evaluated on their effectiveness for the subdivision they were meant to address rather than by application to the broad and diverse category of disability on the whole. There is in this finding a call for more depth and diverse consideration among researchers of disability, perhaps even specializations in specific subcategories that could be better expected to have a unified vision of desired assistance. Trevisan (2019, p. 1602) agrees with this in his discussion of online engagement, stating that the differing degrees and functions of disability require different measures to address their specific barriers to entry. The diversity of disability is so vast in scope and externalization that taking this group as a whole for considerations of amelioration may be the flaw holding back full incorporation of voters with disabilities. It should also be noted, as Powell and Johnson point out (2019, p. 406), that surveys of disabled individuals often do not penetrate institutions in which those with the most socially stigmatized disability characteristics are housed. Furthermore, it must be taken into consideration that the gravity of elections and the

potential obstacles to participation have a real effect on psychological state (Johnson & Powell, 2020, p. 266). Excessively negative experiences with the voting process run the risk of deepening the divide in voter turnout. However, in the 2020 election, voters with disabilities were more likely than those without disabilities to report a positive experience with election officials (Schur & Kruse, 2021b, p. 11).

Current Project

Across the wide array of prior research, several key similarities have arisen. Bagenstos (2020, p. 1340) outlines the increase in perceived efficacy among disabled voters as the scale of elections moves from national to state levels. Following from this increased efficacy is the assumption of greater participation. Using policy data from The National Conference of State Legislatures (NCSL), we seek to take state-level election policies into consideration with hopes of finding out which measures help and which hinder political incorporation of disabled individuals. The level of healthcare coverage in individual states is another marker of institutionalization that should be considered in the context of disability turnout. Using healthcare data from the Centers for Disease Control (CDC), we analyze the possible relationship between state-level healthcare coverage and voter turnout. Finally, education has been used as a predictor for voter turnout among the broader population, as well as those with disabilities. For this reason, we examine the connection between education levels and voter turnout in individual states, using data from concomitant data from the CDC. These variables are investigated as predictors of 2020 turnout data for voters with and without disabilities compiled by Schur and Kruse (2021a, pp. 9-10).

Hypotheses

This project considered how a variety of state-level policies affected voter turnout.

Specifically, we investigated the relationships between turnout, both among those with and without disabilities, and election regulations related to same-day registration, early voting, mail-in/absentee voting, and voter identification policies.

H1: The accessibility of mail-in and absentee ballots has a significant impact on participatory behavior for all types of individuals. Here, we expected to observe a positive relationship between convenience voting measures and turnout among those with disabilities. In contrast, we expected more restrictive voter identification laws should result in depressed turnout for disabled individuals.

H2: Because voting in person sometimes presents significant difficulties for people with disabilities, same-day registration and early voting policies were expected to have a muted—or even non-significant—effect on disabled turnout. In addition to these convenience measures, we also considered the impact of two other state-level factors—education and healthcare coverage—to ascertain how those play into the voter turnout.

H3: A healthy democratic system requires an electorate healthy enough to participate in it. Therefore, we expected that states with greater healthcare coverage would also see increased levels of voter turnout, both with regard to those with and without disabilities.

H4: Although educational attainment is commonly used as a predictor of voter participation, research shows typically lower levels of education among those with disabilities. As such, we expected to observe that lower state-level education rates correlated with lower turnout among those with and without disabilities.

Data and Methodology

Our analyses used data from the National Conference of State Legislatures (NCSL) and the Centers for Disease Control (CDC). Independent variables included those state-level election policies previously discussed (e.g., same-day registration, early voting, mail-in/absentee voting, and the restrictiveness of voter identification policies). See Appendix B for details on how each variable was coded. Dependent variables in this analysis included voter turnout among disabled and non-disabled populations in 2020. These numbers represented the raw percent of voters either reporting or not reporting a disability (Appendix A). State demographics, such as percent of the population aged 65+, percent with a high school diploma, percent with healthcare coverage, percent White, and partisanship of the governor (1= Democrat, 0= Republican), served as control variables within our multivariate analyses. To investigate Hypotheses 3 and 4, our later models treat healthcare coverage and educational attainment as predictor variables rather than controls.

Results

In a recent analysis, Schur and Kruse (2021a) outline the changes to the gap in voter turnout rates between the disabled and non-disabled populations for the national elections in 2016 and 2020. According to their data (Appendix A), the overall voter gap between those with and without disabilities did decrease by about 0.8% across that term. The key for the data representation shows a range of gap change between -12.5% and +11.5%; therefore, significant decreases and increases to the gaps exist across the various states. Due to the vast differences across states, the national average hovers at nearly zero. This represents the current problem with studying disability as a variable in the election process: national data tend to wash out or negate actual changes. Using state-level data will allow for greater depth

of analysis, which should help determine which factors offer the greatest potential for closing the gap even further. From these data at the state level, comparisons and correlations will be made for several state-level election policies as well as the aforementioned factors such as healthcare and education. Furthermore, when considering voter turnout rates for those with disabilities, it becomes necessary to compare those rates with the voter turnout among those without disabilities. Historically, this comparison does present a noticeable gap in participation with disabled voters showing up at lower rates.

Mail-in Ballots and Voter Identification

In 2020, the bulk of states allowed for no excuse absentee ballot access (Figure 1), whereas only five states automatically mailed voters absentee ballots. As noted in H1, the expectation was that accessibility of mail-in and absentee voting would result in higher turnout, while more restrictive voter identification laws were expected to result in depressed turnout for the individuals reporting a disability. The results offer several observations about how these convenience measures affect voter participation. Critically, states with automatic ballots—as opposed to those requiring excuses and request—are more likely to see greater disabled turnout ($p = 0.023$). The same is true for non-disabled individuals ($p = 0.078$) but with marginally significant effects. Putting this into context, several states send out absentee/mail-in ballots to every registered voter, regardless of whether they are requested; this circumnavigates the physical obstructions of polling places and the cognitive obstructions of finding out mail-in voting regulations (which are often hard to locate and harder to understand). Both physical and cognitive obstructions are regularly cited by persons with disabilities as reasons for not participating in elections.

Additionally, we observed that voter ID laws have no effect on turnout among those without disabilities ($p= 0.107$) but do affect turnout among those with disabilities ($p= 0.055$). Therefore, more lenient voter identification laws directly relate to greater disabled turnout. This result follows the same tendency as the one mentioned: fewer administrative hoops to jump through is directly related to higher participation among individuals with disabilities. This tends to make sense for voter engagement in general, but worthy of note here is the fact that such gains in turnout were not felt by those not reporting a disability to any significant degree.

Table 1: Effect of Mail-in Access and Voter ID Leniency on Voter Turnout

Predictors	Bivariate Models		Multivariate Models	
	Disability	No Disability	Disability	No Disability
Mail-in/Absentee Access	0.023*	0.078	0.107	0.308
Voter ID Leniency	0.055	0.107	0.996	0.543

Note: Analyses reflect unstandardized beta coefficients from four separate regression models. The dependent variable in each model is 2020 voter turnout percentages by individuals with and without disabilities. Full models control for the following state-level demographics: % aged 65+, % high school graduate, % healthcare coverage, % white, and governor’s partisan affiliation. * $p < 0.05$, ** $p < 0.01$

However, consideration of a group that blurs traditional lines like the disability community requires controls for demographic factors such as race, education, partisanship of state governments, age, and healthcare coverage. When these factors were considered, there was no significant relationship found between either mail-in/absentee voting access ($p= 0.107$) or voter identification laws ($p= 0.996$) with the participation of disabled voters in the 2020 elections. Similarly, those without a disability showed no significant connection

between turnout and mail-in/absentee voting ($p= 0.308$) or voter identification laws ($p= 0.543$). The null hypothesis cannot be rejected in this case; thus, we do not find meaningful support for either tenet of Hypothesis 1 in our analysis of the current data. The voter gap between individual with and without disabilities is therefore not explained by either of these state-level factors.

Same Day Registration and Early Voting

As noted in H2, we expected same-day registration and early voting to have less—if any—correlation to increased voter turnout due to the continued presence of physical and cognitive obstacles for people with varied disability externalities. To begin with analysis of early voting, the data would indicate no differential effect on turnout between the populations with and without disabilities ($p= 0.740$ and $p= 0.600$, respectively). As predicted then, early voting shows a significantly smaller degree of influence over voter turnout. Considering same day registration allowances, this option boosts turnout among those without a disability ($p= 0.032$) but has only marginal ($p= 0.082$) effects for disabled voters. Thus, same day registration shows itself as a minimal factor in determining the participation of disabled voters. In context, this follows the same inclination as the factors considered in H1: the continuity of barriers to entry from traditional to convenience voting options tends to prevent uptake of voting by those means. Essentially, same day registration still requires that disabled voters deal with the long lines and other accessibility issues of polling places, while early voting only differs from traditional voting in its time of access. Neither of these measures enables disabled voters to meaningfully surpass the traditional barriers they face.

Table 2: Effect of Same day Registration and Early Voting on Voter Turnout

Predictors	Bivariate Models		Full Models	
	Disability	No Disability	Disability	No Disability
Same Day Registration	0.082	0.032*	0.497	0.131
Early Voting	0.600	0.740	0.634	0.105

Note: Analyses reflect unstandardized beta coefficients from four separate regression models. The dependent variable in each model is 2020 voter turnout percentages by individuals with and without disabilities. Full models control for the following state-level demographics: % aged 65+, % high school graduate, % healthcare coverage, % white, and governor's partisan affiliation. * $p < 0.05$, ** $p < 0.01$

When adjusted for the same demographic factors, the current project found that early voting remains without support as a factor for predicting turnout for either population—disability ($p = 0.634$) and no disability ($p = 0.105$). As for same day registration, a similar pattern came up in the analyses. Same day registration showed no connection to turnout among those with ($p = 0.497$) or without a disability ($p = 0.131$), when models took demographics into account. As assumed by H2, neither factor carries significant weight in predicting the engagement of disabled individuals. Furthermore, neither factor seems to impact the turnout of those without disabilities either. Thus, neither consideration offers a determination for the source of the voter turnout gap in 2020.

Education and Healthcare Coverage

As noted in H3 and H4, the expectation of the current project was that an increased level of access to different forms of disability inclusion—like education and healthcare—within individual states would result in higher turnout rates among those with disabilities. Initial models do display a positive connection between state-level healthcare coverage and disabled voter turnout ($p = 0.013$). The indicators for higher education are less robust,

showing that education on its own does not predict for higher disability turnout ($p= 0.097$). Thus, healthcare appears to be a much more valuable indicator of disability inclusion than education. Where education and healthcare are concerned, both were taken to be indicators for the inclusivity of a state toward its disabled population; considering the direct connection between disability as a recognized status and medical diagnoses, it makes greater sense that healthcare would be the stronger signifier of disability inclusion than education (a field in which addresses for disabilities are still being developed at the earliest stages).

Table 3: Effect of Healthcare Coverage and Educational Attainment on Turnout

Predictors	Bivariate Models		Full Models	
	Disability	No Disability	Disability	No Disability
Healthcare	0.097	0.362*	0.142	0.173
Education	0.013*	-0.343	0.151	0.064

Note: Analyses reflect unstandardized beta coefficients from four separate regression models. The dependent variable in each model is 2020 voter turnout percentages by individuals with and without disabilities. Full models control for the following state-level demographics: % aged 65+, % high school graduate (only for healthcare model), % healthcare coverage (only for education model), % white, and governor’s partisan affiliation. * $p < 0.05$, ** $p < 0.01$

However, full models adjusted for demographics and state controls paint a less deterministic picture. Where disabled individuals are concerned, there does not appear to be any significant relationship between turnout and either hypothetical inclusion metric, healthcare coverage ($p=0.142$) or education level ($p= 0.151$). For those without a disability, there is one notable difference: education level ($p= 0.064$) appears to possess at least marginal connection to turnout, whereas healthcare coverage ($p= 0.173$) appears to have no significant bearing on turnout. States with greater turnout among disabled individuals also

tend to have a greater proportion of the population with high school education levels (Figure 2). Notable outliers within this sample are Washington, D.C., with 80% disabled turnout and only 50% high school education rates, as well as Arkansas, with only 48% disabled turnout despite 70% high school education rates. In context, this makes some sense as we often take education to be a signifier of voting likelihood. Yet, disabled individuals appear to miss out on this guarantee of greater engagement. The notable throughline for the full models was the significant effect on turnout for both populations by membership to the 65+ age bracket: disabled ($p= 0.005$) and no disability ($p= 0.004$) turnout were both inversely related to the portion of the electorate comprised of that age demographic. This appears contrary to the conventional political wisdom that elderly people vote at higher rates than do younger people.

Conclusion

Taken as a whole, our results seem to offer more questions than answers in reference to state-level policy effects on voter turnout. The hypotheses presented at the origin of the current project appear to fail in their attempts to discern causes for the discussed voter participation gap. The variables studied in all hypotheses—mail-in access, voter ID laws, same-day registration, early voting, healthcare coverage, and educational attainment—did not present significant results in regression models. The null hypotheses, therefore, cannot be rejected in any of the considered cases; thus, we do not find meaningful support for any hypothesis in our analysis of the current data. The voter gap between those with and without disabilities is therefore not explained by these state-level factors alone.

Future research in this regard should consider the potential coexistence of historically influential factors such as income brackets, perceived political efficacy, non-voting forms of

political engagement, and partisanship of voters. The leading sources of this type of data would include American National Election Study (ANES) and Cooperative Congressional Election Study (CCES) surveys; the current limitations of those sources are scopes of questions asked, which do not tend to focus heavily on disability as a voter demographic category. Similarly, the limitations of the current project result from the areas of focus and the level of analyses. Considering the impacts of state-level policies and factors resulted in the necessary exclusion of individual level factors like those mentioned. There is exciting potential for future marriage of these two levels of disability study, pending the expansion of disability-focused data collection on a national scale.

The current study did account for the partisan alignment of state governments leveraged against the causality of each independent variable; however, this version of partisan consideration is limited to too broad a category. As mentioned, consideration of individual partisanship alongside the state-level factors considered here might provide a better picture of how those factors relate to individual political behavior. Furthermore, consideration must be made for the unique nature of the 2020 election amidst a global pandemic that shut down much of the country during the election; decreased mobility of the public during enforced quarantines coupled with significant accommodations being made in the mail-in/absentee voting space across many states stand to impact the operant validity of those data. Future consideration of convenience voting measures such as those taken by the current project might be more successful in focusing on a specific policy and analyzing historic connection between that policy and election participation.

Overall, the current project presents the community of disability studies—and

the larger political science community—with direction for future scholarship. State-level considerations are a category that has gone underrepresented in political science scholarship, likely because individual-level data is much more accessible on the national scale.

Extrapolation of state-level factors from available datasets creates the opportunity for further study of how institutions and their realms of sovereignty impact individual behavior. The value added by the results of the current project is the recognition that those institutional factors are not sole causes for heretofore unexplained phenomena. No single state-level policy meaningfully determines disabled turnout, just as prior scholarship has found that no single individual-level factor determines such engagement. Yet as the population of voters with disabilities continues to grow, we believe scholarly research will likewise expand its scope to more fully understand the dynamics of this valuable portion of the electorate.

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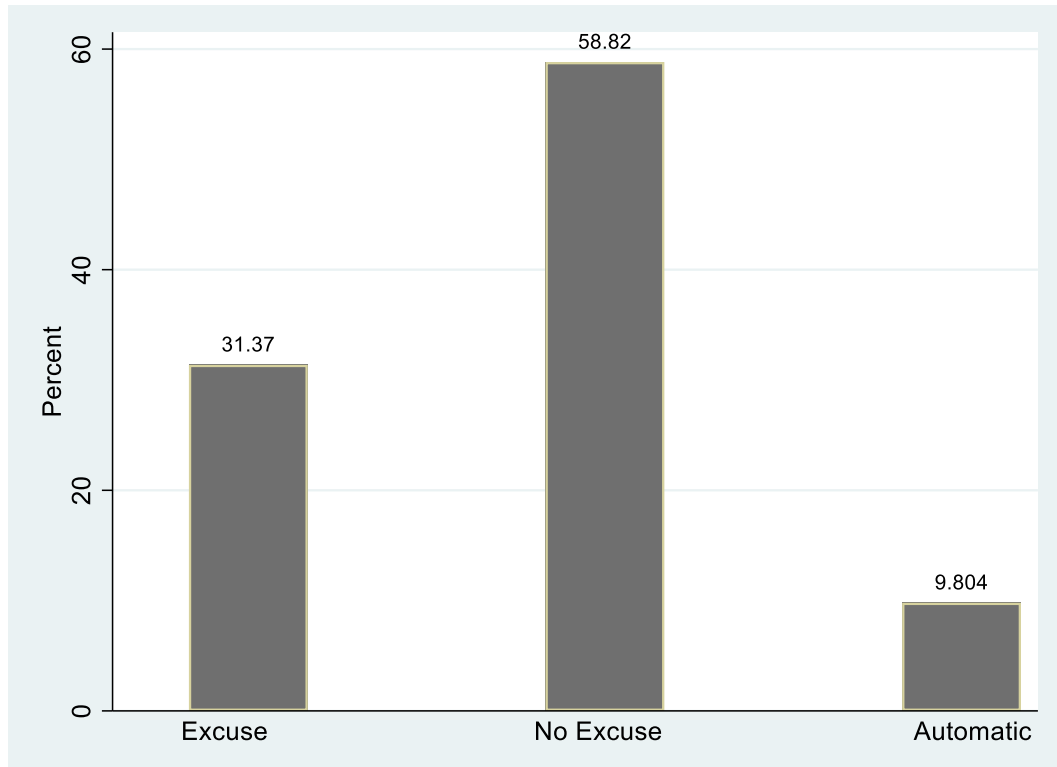
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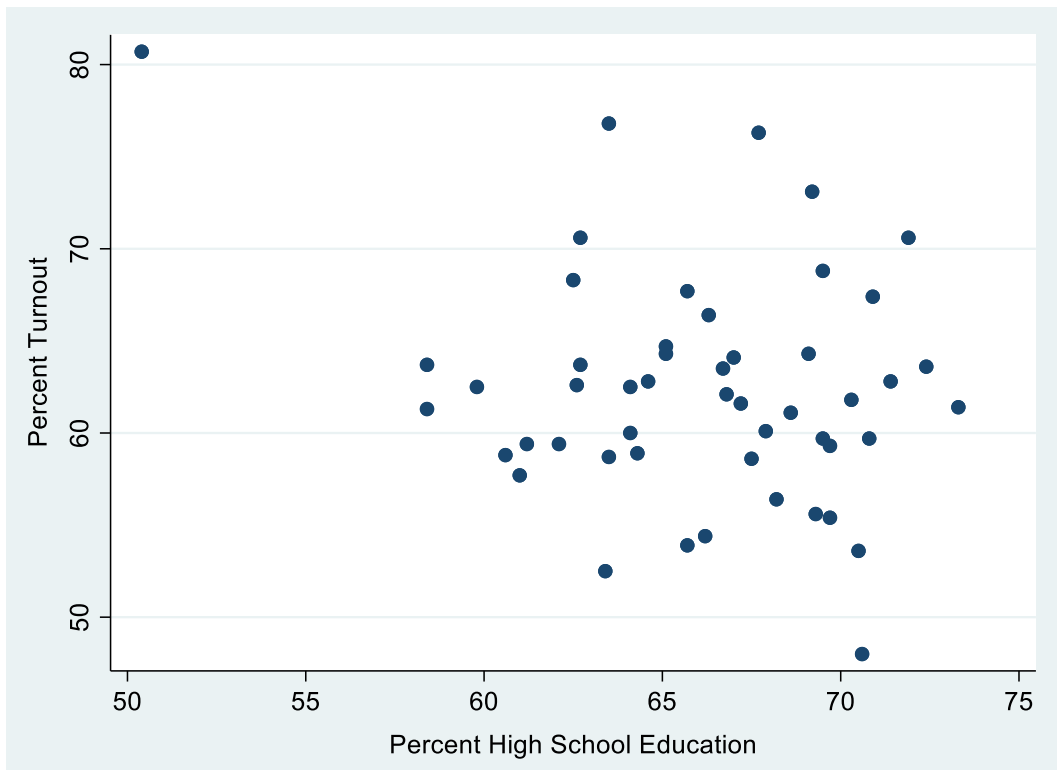
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Figure 1*Mail In Ballot Access Across States*

Note: In 2020 the bulk of states allowed for no excuse absentee ballot access, whereas only five states automatically mailed voters absentee ballots.

Figure 2

Relationship Between Education and Disability Turnout in 2020



Note: States with greater turnout among disabled individuals also tend to have a greater proportion of the population with high school education levels.

Appendix A

Full Data Set for Voter Turnout and Participation Changes

Voter Turnout by State, Disability Status, and Year

State	DT2016	DT2020	DT Change	WT2016	WT2020	WT Change	2016 Gap	2020 Gap	Gap Change
Alabama	47.4	52.5	5.1	59.4	61.8	2.4	12.0	9.3	-2.7
Alaska	60.1	55.6	-4.5	61.5	64.9	3.4	1.4	9.3	7.9
Arizona	66.2	76.8	10.6	59.6	71.3	11.7	-6.6	-5.5	1.1
Arkansas	51.2	48.0	-3.2	60.1	55.1	-5.0	8.9	7.1	-1.8
California	52.3	58.8	6.5	58.6	65.9	7.3	6.3	7.1	0.8
Colorado	69.0	66.4	-2.6	69.5	67.7	-1.8	0.5	1.3	0.8
Connecticut	65.0	63.7	-1.3	63.8	67.0	3.2	-1.2	3.3	4.5
Delaware	53.0	58.6	5.6	63.5	68.9	5.4	10.5	10.3	-0.2
Florida	58.9	61.6	2.7	59.5	62.2	2.7	0.6	0.6	0.0
Georgia	57.8	62.8	5.0	60.6	66.4	5.8	2.8	3.6	0.8
Hawaii	54.1	61.1	7.0	46.3	64.8	18.5	-7.8	3.7	11.5
Idaho	65.1	59.7	-5.4	61.6	65.8	4.2	-3.5	6.1	9.6
Illinois	65.8	64.3	-1.5	63.5	68.9	5.4	-2.3	4.6	6.9
Indiana	49.4	59.3	9.9	59.7	61.2	1.5	10.3	1.9	-8.4
Iowa	56.1	67.4	11.3	64.7	70.9	6.2	8.6	3.5	-5.1
Kansas	53.0	58.7	5.7	62.9	66.8	3.9	9.9	8.1	-1.8
Kentucky	42.5	64.1	21.6	60.2	69.5	9.3	17.7	5.4	-12.3
Louisiana	48.2	57.7	9.5	64.0	62.6	-1.4	15.8	4.9	-10.9
Maine	68.2	68.8	0.6	73.5	71.9	-1.6	5.3	3.1	-2.2
Maryland	60.4	59.4	-1.0	66.4	75.1	8.7	6.0	15.7	9.7
Massachusetts	59.6	63.7	4.1	67.6	66.7	-0.9	8.0	3.0	-5.0
Michigan	63.7	60.1	-3.6	64.4	68.0	3.6	0.7	7.9	7.2
Minnesota	58.7	76.3	17.6	69.9	78.0	8.1	11.2	1.7	-9.5
Mississippi	63.2	62.6	-0.6	68.6	71.8	3.2	5.4	9.2	3.8
Missouri	55.9	62.1	6.2	66.2	67.7	1.5	10.3	5.6	-4.7
Montana	67.0	70.6	3.6	65.7	73.9	8.2	-1.3	3.3	4.6
Nebraska	70.4	62.8	-7.6	66.2	65.5	-0.7	-4.2	2.7	6.9

Texas	51.5	59.4	7.9	55.9	64.5	8.6	4.4	5.1	0.7
Utah	63.3	56.4	-6.9	62.6	64.4	1.8	-0.7	8.0	8.7
Vermont	57.6	67.7	10.1	63.2	68.5	5.3	5.6	0.8	-4.8
Virginia	57.4	68.3	10.9	69.5	71.9	2.4	12.1	3.6	-8.5
Washington	62.5	63.5	1.0	66.8	72.9	6.1	4.3	9.4	5.1
Washington, D.C.	60.0	80.7	20.7	76.1	84.3	8.2	16.1	3.6	-12.5
West Virginia	45.9	53.6	7.7	52.0	56.6	4.6	6.1	3.0	-3.1
Wisconsin	63.9	63.6	-0.3	71.6	75.0	3.4	7.7	11.4	3.7
Wyoming	54.5	61.4	6.9	66.1	66.2	0.1	11.6	4.8	-6.8
National Average	57.3	62.6	5.3	63.3	67.8	4.5	6.0	5.2	-0.8

Source: Schur & Kruse, 2021a; **DT—Disability Turnout, WT—Without Disability Turnout

Appendix B

Coding of Independent Variables

Mail In Access

Coding: 1=excuse required, 2=no excuse required, 3=automatic mailed ballots to all voters

Same Day Registration

Coding: 1=no same day registration, 2= same day registration only during early voting, 3=same day registration even on Election Day

Early Voting

Coding: 1=no early voting, 2=in-person absentee*, 3=Early voting allowed, 4=in-person or mail-in early voting

**Considered more restrictive because it requires extra steps for access, both in-person absentee voting and early voting take place at physical polling place*

Voter ID Laws

Coding: 1=strict photo ID; 2=strict non-photo ID*; 3=photo ID requested; 4=ID requested, photo not required; 5=No document required to vote

**proof of address and/or residency required, but not specific to photo ID*



Impairing the Vote: The Effect of State Election Policy on Disabled Voter Turnout by April A. Johnson and Wyatt Dunlap

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**Bridging the Communication Chasm Between
Deaf Patients and Masked Medical Professionals**

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Abstract

The coronavirus pandemic drastically changed communication for individuals who are deaf and hard-of-hearing in the healthcare setting. Patients' need for quality healthcare was impacted when masks obliterated the usual facial expressions and lipreading methods, creating a vast gap in essential communication between patients and healthcare professionals. This article explores the impact of the pandemic on communication and the search for new innovative and creative solutions to bridge the chasm.

Keywords: awareness, communication, deafness, healthcare, inclusivity, medicine

Bridging the Communication Chasm Between Deaf Patients and Masked Medical Professionals

The coronavirus pandemic seems to have deepened the chasm in communication between masked healthcare professionals and individuals who are deaf or hard of hearing. In their attempts to curb its spread, medical professionals failed to take into account the profound impact of masks and alternative communication methods to ensure optimal healthcare for individuals who are deaf or hard-of-hearing. In this extended personal reflection, I share from my experience as a profoundly deaf individual, the impact of the pandemic on optimal access to healthcare and subsequent lack of equitable communication in a mandated masked environment.

Historically, masks have long been used to minimize spread of infection. Ancient Iranian medical practices created masks made of cloth soaked in vinegar, onion, and garlic to prevent spread of disease (Taghizadieh et al., 2021). During the Bombay fever, scarves and veils were worn in India. Cotton masks were recommended in the US during the late 1800s; wealthy women in Paris wore lace veils in the early 1900s. Today's N95 surgical masks focus on minimizing the transmission of infectious diseases, especially respiratory infections (Loeb et al., 2009). Even though many of these historical articles center around patient physical well-being, none focus on the impact of masks on patient' emotional and mental well-being or optimal access to communication.

Fast forward to present, growing research continues to expand on the negative impact of the pandemic on patient-masked medical professional communication. In one of those studies, Chodosh et al. (2020) stress that "communication between patient and

clinician is the heart of medical care” (p. 1). Carstairs (2020) attests that masks “impede communication for frail elders and the hearing impaired” (p. 4). The pandemic has, since its onset, changed drastically the interactive, in-person communication as we once knew it. No longer do those of us who are deaf or hard of hearing have consistent access to the facial cues and lip movements essential to daily communication. Masks severely challenge those of us who depend heavily on our vision as compensation for our inability to hear (Gutierrez-Sigut et al., 2022).

Personal Reflection

Although I have lived with my deafness from birth, stepping into an unprecedented masked world quickly made communication quite daunting. In a matter of seconds after the mask mandate became a reality, I was plunged into a world of bewildering and terrifying isolation with no access to my usual communication of lip-reading and facial expressions. Throughout most of my life, I could be surrounded by a sea of people yet feel completely alone. Not just for people like me who are deaf and oral, masks worsen the communication barriers for patients from other marginalized groups. Some examples are elderly patients, patients who are hard-of-hearing or late-deafened, and even medical professionals with their own hearing loss. I have not even touched the vast realm of other disabilities where providing medical care behind masked faces could be at least just as overwhelming.

My journey started when I was turned away from an orthopedic medical office. The receptionist informed me quite bluntly that the doctor would not wear a clear mask or write things down. At my regular physician’s office, the office staff kept talking to me behind their masks, despite the innumerable times I asked them to write on paper. While checking

in at a local lab for bloodwork, the lab clerk kept talking behind his mask no matter how many times I explained that my deafness prevented me from understanding him and my requesting that he please write things down. At the pharmacy, I was shooed from one person to another, four people in total, while trying to pick up some medications for my child. Despite a thick clear plastic wall and a good six-foot distance between all four pharmacy technicians and me, no one wanted to help. After one hour of waiting on the side and watching the long line behind me get served, I finally left and returned in the afternoon when the supervisor was available. The supervisor lowered her mask behind the safety of the thick plastic barrier and the 6-foot distance, allowing me to see her face. At my son's medical appointments, doctors and nurses would tell him to interpret. Not only was their request unfair to him as he was the patient and a minor, but clearly it was not his responsibility to be my interpreter. Most recently this year, I had my sensorineural deafness re-evaluated and tested by an ENT. Despite this physician's daily exposure to deaf patients, he and his medical staff would not wear a clear mask; the receptionist refused to write anything down on paper for me. The physician himself finally relented to writing 1-2 word responses for every question I had. Under such debilitating circumstances, I did not receive the optimal care or an accurate audiological evaluation. In all these cases during the pandemic, I quickly became an object of unkind and impatient stares from these medical professionals; my deafness seemed to create an extreme inconvenience given the masked mandate and my inability to see lips so essential for my communication needs. Since the onslaught of the pandemic, every day became an experience fraught with constant communication challenges whenever I hesitantly ventured beyond the safe,

sheltered sanctuary of my parents' home. I soon came to dread even stepping out, knowing the battles and hurdles that awaited me no matter where I went.

As a result, my own personal encounters have spurred me to turn my negative experiences into an opportunity for positive reflection with the purpose of creating awareness and solutions. We now exist in a time when everyone has had to rapidly and drastically discard old, taken-for-granted ways of thinking and doing and, instead, create new ways of interacting and communicating. For many of us heavily dependent on visual cues, such an action now requires thinking outside the box and creating innovative solutions to ensure the highest level of continued medical care for patients regardless of condition, disability, and circumstance. How can these patients get the much-needed care if physicians and other healthcare professionals are not willing to accommodate them? Filing a complaint with the American Medical Association (AMA) or even the Americans with Disabilities Act (ADA) may bring temporary attention, but will not create effective, long-lasting reprieve or solutions. People who are deaf and hard-of-hearing can turn the experience of the pandemic into an opportunity to don creative hats and devise solutions that will bring inclusivity, equity, and advocacy, with the ultimate goal of providing further education, communication choices, and more inclusive awareness that masks severely exacerbated.

Quality of Communication and Healthcare Access

Well before the onset of the pandemic and the unprecedented mask mandate, the overall quality of communication between patients with hearing loss and medical professionals was already being explored; general research consensus appears to indicate

that communication was already strained between healthcare personnel and patients who are deaf or hard of hearing (Iezzoni et al., 2004). In another study, patients with hearing loss reported significantly lower ratings of patient-physician communication and less quality of healthcare than patients with without hearing loss (Mick et al., 2014). The study concluded that patients with hearing loss “may have had greater difficulty understanding or engaging in discussions with their physicians” (Mick et al., 2014, p. 2). Hospital settings may not be providing necessary and effective communication strategies with patients who are deaf or hard of hearing (Bluestein et al., 2020).

Furthermore, Pratt (2018) attests that patients with profound hearing loss, prelingual hearing loss, adventitious hearing loss, and signing individuals in the Deaf community are often “reluctant to access healthcare due to potential communication breakdowns and the rapid pace of medical delivery” of information (p. 2). She further points out that medical professionals might be unaware of the communication discrepancies due to poor understanding of patients’ nonverbal communicative needs or patients not understanding the medical information being relayed. Deaf patients who sign tend to need interpreters; their ability to communicate may also be impacted by lack of (or the quality of) interpreting and captioning services (King, 2020). If the patient communicates primarily through American Sign Language and if English is not the patient’s first language, then their ability to access and understand written health information may be compromised (Meador & Zazove, 2005). Finding skilled and certified interpreters who can accurately translate medical terminology may be difficult despite the Americans with Disabilities Act requiring such provision from medical offices (Pratt, 2018). Deaf patients may also not want signing

family members or friends to assist, preferring to maintain confidentiality.

With the hasty closure of nearly all in-person contact with medical personnel during the pandemic, patients who are deaf or hard of hearing experienced exacerbated challenges in accessing healthcare and communicating effectively with their physicians. Patients who use oral skills also experienced challenges, since the lips and facial expressions, on which they heavily depend, were obliterated by the mask mandate. Martin (2020) shares that face masks are known to “adversely impact” aspects of communication, which “created unique challenges for the hearing-impaired community who may be put at a greater communication disadvantage” than those with typical hearing (p. 1). In an online presentation for the 2021 Pacific Rim International Conference for Disabilities and Diversity, many attendees shared that they simply avoided seeing their physician due to coronavirus safety mandates, invasive masks, and lack of access to proper communication channels (Sundaram presentation, February 2021). Pandi et al. (2011) further state that hearing loss contributes to greater barriers to health care with long-term negative consequences. The study deduces that adults with hearing loss tend to “experience difficulties and delays in accessing health care as compared to those who are not hard-of-hearing” (p. 5).

Goldin et al. (2020) critically point out the impact of medical masks on speech reception and that the “cornerstone of patient safety and quality healthcare is effective communication” (p. 8). The authors stress that such “effective communication” allows the patient to fully participate in his/her healthcare; the communication must occur appropriately based on age, understanding, and communication abilities; and that the medical professional needs to provide clear, complete, and accurate information to the

patient. How does the physician then ensure high levels of healthcare quality and communication access if the physician's face is obstructed by a facial mask and in the presence of a patient who cannot hear?

Not only do masks obstruct visual cues for patients dependent on lipreading, but the masks also prevent the acoustics of the physician's voice from traveling clearly through the filters of the mask to patients with usable residual hearing. According to data gathered in this study, speech quality severely deteriorated, given that the masks worn by physicians obstructed transmission of high frequencies critical for speech comprehension with patients using hearing aids, cochlear implants or other acoustic technology. Blustein et al. (2020) clearly stress the urgent need to address this communication chasm with the fitting title of their paper, "Time to Take Hearing Loss Seriously." They further stress that most hospitals and medical care settings still do not routinely employ practices to ensure clinician-patient communication, especially for those with hearing loss.

Even more critically, physicians and other healthcare professionals who have their own hearing loss understand only too well the challenges patients who are deaf or hard of hearing face. These physicians struggle to ensure that they continue to provide the highest level of patient care. How can they if they cannot communicate with the patient, if they cannot attend rounds, if they can no longer lip-read other masked physicians? Grote and Izagaren (2020), both deaf physicians, share their struggles and the lack of available transparent masks for use in healthcare settings. Crume (2020), a deaf pediatric resident, shares her loneliness, isolation, and tensions from having "no idea what was going on" (p. 1). The General Medical Council in the United Kingdom states that "communication 'in a

way patients can understand' is vital for informed consent, patient care, and safety" (p. 1). However, how do facial masks meet that goal when "60-70% of communication is based on non-verbal cues from lip patterns and facial expressions?" (p. 1). Grote and Izagaren (2020) further emphasize that the negative impact of masks on patients and professionals who are deaf or hard of hearing has been substantial, increasing the risk of isolation and detrimental mental health consequences.

Based on my own personal experiences and evolving research, solutions are being created to address the communication barrier between masked medical professionals and patients who are deaf or hard-of-hearing. Many agencies and organizations, particularly those that focus on individuals who are deaf or hard-of-hearing, offer detailed and very helpful resources. For example, the Hearing Loss Association of America shares a guide on strategies and tools for communicating with medical professionals during the pandemic (HLAA, 2020). Other associations, such as the National Association for the Deaf (NAD, 2020), Alexander Graham Bell Association (AGBell), Greater Los Angeles Agency on Deafness (GLAD), local and state chapters for deafness or hearing loss, DeafBlind organizations, etc., all have valuable resources as well.

Ask patients for a preferred mode of communication

Chodosh et al. (2020) stress the importance of awareness in understanding the differing needs of deaf and hard-of-hearing patients. Rather than making assumptions about a patient's level of comprehension and communication abilities, masked doctors can start by simply asking the patient for their preferred mode of communication (Fuller & Howell, 2020). Patients also have the responsibility of notifying the office in advance of

their communication preferences and requesting additional time for the appointment if needed. For example, a deaf patient may request an oral interpreter or a signing interpreter; the extra time to relay information back and forth may necessitate a 40-minute appointment instead of a regular 15-20 minute consultation. More time should be allocated for appointments with any other conditions, such as elderly patients needing more time, health literacy, education limits, socioeconomic factors, drug impairments, cultural issues, cognitive functioning, and any mental health disorders (Dr. R. Koshy, email communication, March 18, 2021). Dr. Koshy (2021) further stresses the importance of having more time with the patient and “asking clarifying questions” to ensure clarity and comprehension of communication between physician and patient, especially if the patient or the physician has a hearing loss.

Other patients with hearing loss may wish for simple solutions, such as the physician speaking more clearly or slowly, not talking while washing hands or pacing the room, maintaining eye contact, checking in with the patient if they have any questions, or providing visual documentation if the patient requests it. Most hearing people are used to talking to each other without looking at each other; for deaf patients, that lack of eye contact simply does not work. Raising one’s voice tends to be counterproductive and may only increase the anxiety and stress of the patient and compromise the effectiveness of communication. Physicians can further reduce breakdowns and miscommunication by reducing environmental distractions, reviewing patient notes prior to the appointment, knowing the reason for the patient’s visit and the current treatment plan, and checking in advance past methods of

communication. They can review critical health information, such as asking clarifying questions or explaining medical terminology, with the patient to prevent potential miscommunication (Iezzoni, O'Day, Killeen, & Harker, 2004).

Clear Masks

Many options for clear masks and facial shields now exist on the internet and in most stores. However, the clear masks are still being perfected. Ashley Lawrence, a student at a midwestern university, studying deaf and hard-of-hearing education, was one of the forerunners of the clear mask. This enterprising student wished for deaf people to have continued access to lip reading and facial cues while adhering to the guidelines set by the Center for Disease Control and Prevention (Coyne, 2020). With clear masks, the plastic tends to fog or gather moisture, as well as attracting unwanted reflection from overhead lights. Since the light is not able to filter through the plastic barrier, its reflection bounces off the surface of the mask. These unintended factors make visual cues for communication through lip-reading very difficult. Many do not yet have FDA approval.

The “Communicator Surgical Facemasks with a Clear Window” appears to be one of the better clear masks available currently. FDA-approved, these masks are single-use and disposable and can be worn in medical and other health settings with sufficient protection. More details and prices can be found on the website: [The Communicator™ Surgical Face Masks with Clear Window \(Level 1\)](#). The “Transparent Face Mask,” also FDA-compatible, has adjustable straps, and offers a large clear facial shield. However, fogging, condensation, and light reflection issues exist. More information can be found at this website: [ClearMask - The Fully](#)

[Transparent Mask](#). The Bendshape Mask is also another option available at <https://bendshapemask.com/>. Many creative, enterprising individuals have created their own clear masks, which will only continue to improve with time. Some websites where these masks can be found include Etsy, Pinterest, Amazon, etc. Medical professionals can also create their own clear, non-reflective, condensation-free medical masks, FDA-approved, to enhance communication with their patients who are deaf or hard of hearing.

Telehealth (virtual consultation)

When all medical appointments were closed to in-person visits, unless for emergencies, patients soon had the option for telecommunication through online platforms, such as Zoom, Skype, Google Meet, Microsoft Teams, and Facetime. Some of these platforms have automatic captions. Live captions are also another option through captioning providers. Behind the safety of a virtual screen, patients and healthcare professionals could discard their masks and remain safe. However, online platforms have their limitations. Poor internet connection made access to facial cues, lip-reading, and other visual cues tricky. At times, the person's mouth and face would freeze into comical expressions, or essential signs from interpreters or the patient would abruptly halt in mid-air, cutting off critical communication access. Acoustics for patients who are hard of hearing could become distorted or muffled. Furthermore, physicians could not physically examine a patient; subsequently, they had to rely on patients' description of their symptoms and read past medical notes. Many patients were either not familiar with online platforms or wary of discussing their personal health issues via a relay operator or an interpreter. In addition,

many patients did not have access to technology or lived in rural communities where the internet access was spotty, scarce or non-existent.

Written and Electronic Communication

With the 2000 HIPAA Privacy Rule, the 2009 HITECH Act, and the 2021 Cures Act, the U.S. Department of Health and Human Services Office for Civil Rights and the Office of the National Coordinator for Health Information Technology have provided patients with the opportunity to access their medical records. The most recent CURES Act, passed on April 5, 2021, provides the opportunity to improve communication, to provide post-discharge follow up, to access medical information critical for one's health, and, most of all, to strengthen patient-medical professional relationships (Morgan & Moriarty, 2016). According to Dr. Koshy (2021), if patients have access to their healthcare information, it "decreases the chance that information won't be seen or heard." Patients have always had that right to request written copies; they now have electronic access as well through safe and secure portals. More medical offices are creating these portals, although many others remain reluctant to flow with changing times. Patients, especially those who are deaf or hard of hearing, can also be proactive in accessing their records to help maximize their communications with masked healthcare professionals.

Voice-to-text applications

Numerous speech-to-text applications have been created. Otter Ai is one example of

speech-to-text translation developed in California. The software provides captions for live speakers and generates transcription of the voice into written text (www.otter.ai). Other applications are readily available, such as Google Assistant, Deepgram, Dragon Anywhere, Transcribe, Speechnotes, Notes, Speech Texter, and iTranslate Converse. Some of these dictation applications are free while others have a trial period or require subscriptions. Providing captions in person and through online platforms continues to be an evolving process.

Voice-to-sign and text-to-sign applications

In addition to voice-to-text applications, applications for translating voice and text into American Sign Language and other sign languages also exist. Hand Talk and Mimix3D are among some versions found on smartphones. Apple has its version, ASL Translator. Python, recently developed by organizations in India, converts speech to Indian Sign Language. The authors hope to improve the software by incorporating facial expressions along with the signs (Harkude et al., 2020).

Voice Enhancement Technology

For patients who are hard of hearing or who benefit from acoustic technology, voice enhancement technologies can help the doctor's voice travel better through mask filters. Some examples are Alango, BeHear ACCESS, BeHear NOW, or Williams Sound Pocket Talker. Smartphones and Apple phones have their own enhancement applications, such as Jacoti Listen App (Goldin et al., 2020). All these technologies can help the listener optimize any residual hearing used for listening and communicating. Other organizations, such as Diglo (formerly Harris Communications), Hearing Loss of America, National

Association for the Deaf, AARP, and ADCO Hearing Products all offer resources for clientele who are deaf or hard-of-hearing.

Translation

LanguageLine interpreting provides translation for at least 360 languages including sign language. Video, telephone, and in-person interpretation are offered depending on the client's needs. An on-demand phone and video services allow a client or an office, such as the doctor's office, to pre-schedule an interpreter for a certain time and location. Accounts vary such as pay-as-you-go or contracted ones. The Americans with Disabilities Act mandates that medical settings provide an interpreter based on the patient's needs. Other tools involve communication boards, voice to text relay services, signing relay services, and mobile apps (McGee, Moran, & Zazove, 2020).

Writing on Paper

This eternal time-tested method remains one of the oldest ways of communication through writing on paper, yellow pads, whiteboards, etc., if clear and visual-verbal communication is not possible. However, there may be some patients who may not be able to read written English. For those who know American Sign Language, this visual language does not follow the English syntax and grammatical structure (Holcomb, 2013). Other sign languages, including British Sign Language, may also not be similar to the written structure of their country's respective language(s). Grote and Izagaren (2020) indicate that if British Sign Language is a person's first language, then written notes may not always be the most effective.

The authors recommend trying clear signs, pictures, and other resources such as Cardmedic-digital communication flashcards. Other options are texting applications, such as through NOTES, WhatsApp, Messaging, etc., on iPhones and smartphones. Even more critical, how many physicians can accurately write word-for-word a spoken conversation? During my recent encounter with my ENT over an audiological evaluation, his abrupt, cursory 1-2 word written responses did not even begin to create any communication channel to ensure I was getting proper audiological care. How many interpreters can transmit medical jargon accurately to a patient heavily dependent on third party communication? At best, writing is better than no solution at all, but difficult to convey a full, true and accurate depiction of a verbal medical exchange between doctor and patient, crucial for the patient's optimal health.

Training for medical professionals and medical schools

Medical professionals and medical students could benefit from enhanced exposure to cultural and linguistic training for all healthcare professionals who work with patients who are from the Deaf community, and other minority groups. According to Pratt, (2018), "lack of awareness of their hearing loss and limited access and treatment options can further interfere with getting appropriate services" (p. 432). For example, learning American Sign Language as a second language to be able to communicate with deaf patients who sign, would be one option for medical professionals to consider. An American Sign Language Medical Dictionary exists which both signing patients and medical professionals can have on hand for medical office or hospital visits. For deaf patients who do not sign, who may be hard-of-hearing or late-deafened, who speak, lip-read, and depend on facial cues, medical

professionals can explore alternative communication strategies for those patients by asking them for their preferred choice of communication. However, it is also the patient's responsibility to check with their medical professional ahead of time to ensure their communication needs are met and honored.

Pratt (2018) further indicates that deaf people have different social and communication criteria that naturally differ from those of hearing people. Most people who are deaf or hard of hearing may come across as different, simply because they are desperately trying to communicate their needs but are not being "heard." Many hearing people themselves can also be perceived in similar ways in how they come across to their patients or other people. Hearing physicians and other medical professionals may also contribute to the communication breakdown since they may lack that necessary understanding or tolerance of the differing communication styles of patients who are deaf, hard-of-hearing, late-deafened, or identify with the Deaf community (Mick, Foley, & Lin, 2014). It is all a matter of the perspective from where the person is coming. Fuller and Howell (2020) suggest multiple tools medical professionals can add to their communication repertoire to re-instill trust and repair the patient-clinician relationship.

Most hearing people seem to take for granted their ability to communicate. They can easily chat with each other without any eye contact. For a person who cannot hear or who depends heavily on visual communication, not establishing eye contact is considered a huge deterrent to effective communication, mask or no mask. Hearing professionals tend to talk over a person who is deaf or hard-of-hearing by talking, instead, to any hearing person that might have accompanied the person with the hearing loss. Deaf people are used to touching

each other to get their attention; touching a hearing medical professional to get his/her attention may be natural to a person who is deaf or hard-of-hearing, but the hearing professional may not view it that way. With users of American Sign Language, facial expression is critical in understanding the meaning of signs. One sign can have multiple meanings, just like English words. However, the person who is deaf or hard-of-hearing may rely heavily on facial expressions and context to make sense of the signs. American Sign Language does not follow English grammatical structure, making reading and writing comprehension difficult for people whose first language may not be English. Imagine how much worse the entire communication process has become for the patient who is deaf or hard-of-hearing dealing with a masked face obliterating all access to lip-reading and facial cues (Goldin et al., 2020).

Recommendations for Further Research

Given that masks will remain in our lives for a long time to come, increased proactivism on both the part of patients who are deaf or hard-of-hearing and medical professionals is needed to bridge the communication chasm. Fuller and Howell (2020) stress that “communication is at the core of the patient-physician relationship (p. 1). Conducting further research on divergent communication methods within populations who are deaf or hard-of-hearing would be a starting foundation on which to expand communication options. Iezzoni et al. (2004) share six themes in their research: conflicting views between physicians and patients about being deaf or hard of hearing, differing perceptions of what defines effective communication (lip-reading, writing notes, sign language interpretation, etc.), medication safety and other risks from inadequate communication, communication problems during

physical examinations and procedures, difficulties in interacting with office staff (in office, waiting room, etc.), and problematic telephone communication.

To gather more accurate and comprehensive data of the communication between patients who are deaf or hard-of-hearing and masked medical professionals, further research should include these six themes. In-person interviews can be facilitated with physicians and patients on how masks impact communication and subsequently quality of healthcare for patients. Interviews can be facilitated in the patient's preferred mode of communication (Iezzoni et al., 2004). Mick et al. (2014) mention using the Consumer Assessment of Healthcare Providers and Systems (CAHPS) to rate patient-physician communication. Possibly, this research tool could be used to assess communication between patients who are deaf or hard-of-hearing and masked medical professionals during the pandemic. A pre-post test study could be done assessing communication and quality of healthcare before solutions are implemented and then testing the efficacy of the solutions afterward. Research could also include the differing communication abilities of patients with hearing loss or who are deaf across borders of other health conditions and medications, age, language, ethnicity, socio-economic status, and geographic location to broaden understanding of factors that create those gaps (Ries, 1994).

Exposing medical professionals to Deaf culture, communication styles of patients who are deaf or hard-of-hearing, as well as providing viable communication options would greatly improve communication access and increase optimal quality of health care. Late-deafened patients and a longer-living geriatric population come with their own degree of hearing loss.

Their perspectives are valuable. Hearing physicians and other medical professionals can also learn from their own medical colleagues who are deaf or hard of hearing. As Crume (2020) pointed out, her colleagues were highly receptive to implementing changes to improving communication and increasing her access to information. However, Crume (2020) was proactive in implementing those much needed accommodations. Having more physicians who are deaf or hard of hearing would be a valuable asset to the healthcare community. Other health professionals (such as counselors, audiologists or nurses) who are also deaf or hard of hearing could make a huge contribution among the healthcare community in ensuring equitable communication and access.

Additionally, curriculum in medical schools on diversity, inclusion, and advocacy should be assessed. Courses could involve awareness and education on alternative communication tools such as taking sign language courses. Are medical students receiving the necessary training to be able to communicate in alternative ways with patients who are deaf and hard of hearing? What about medical residencies or internships with the Deaf community? Medical schools and organizations that offer continuing medical education could have guest speakers who are deaf or hard of hearing speak to the audience about effective communication strategies. Are physicians also getting such education and awareness through continuing medical education credits? Pratt (2018) mentions the importance of professional training, counseling, community outreach, and multidisciplinary activities to help remove barriers between patients with hearing loss and healthcare professionals.

Conclusion

Even to this day, my journey continues to focus on educating healthcare

professionals on equitable communication to ensure optimal healthcare for their patients. I also seek to empower patients who are deaf or hard-of-hearing to learn their options and self-advocate. Healthcare settings are, for the most part, receptive and willing to improvise. The medical office that canceled my orthopedic appointment was startled when I still showed up and insisted on speaking with the doctor in person. Once the doctor saw me and realized my deafness was not so intimidating, he became quite open to the solutions I had brought: Notes app on my iPhone, a box of transparent face masks, and an old-fashioned pad of paper. By realizing he could communicate through the microphone on the Notes app, he was able to then use the voice-to-text feature without having to lower his mask.

Another doctor was quite willing to accommodate me by standing at the entrance of the room and lowering her mask while I sat at the furthest corner at the opposite end of the room and lip-read her. However, not everyone can lip-read tiny lips from such a far distance. Another doctor accepted the box of packaged clear transparent face masks I had brought and passed them out to her staff at the office for future use. She also was not aware of the Notes option until I demonstrated how to use the app. My son's medical doctor switched to video telecommunication through Zoom. The doctor did not need to wear a mask; I was able to lipread the conversation, and my son got the critical care he needed. The doctor also connected me with an electronic portal where I could easily access medical notes and communicate with him and the nurses. I was so grateful for the efforts made on our behalf.

Most physicians and other medical professionals tend to have the patient's highest well-being in mind; the communication breakdowns can be addressed if both

the masked physician and the patient are willing to work together and create solutions to bridge the communication chasm. Maru et al. (2021) summarized communication beautifully: “Communication is more than just spoken language.” The authors add, “good communication techniques and awareness encourages inclusivity which can address the isolation and marginalization of people with hearing loss,” with the goal of rebuilding patient satisfaction, trust, and optimal communication (p. 1). McKee et al. (2020) remind us that patients who are deaf and hard-of-hearing already faced communication struggles pre-COVID; this is all the more reason to not forget that “effective clinician-patient communication” continues to serve as the cornerstone for optimal patient care and satisfaction (p. 4).

Our journey in this masked world-for those of us who are deaf, hard of hearing, or other disabilities-continues every day, everywhere. The communication chasm exists not just within the medical setting, but also in one’s own home when a masked plumber comes by to fix a leak, in the coffee shop trying to order a hot beverage with a masked employee, in the post office being shooed away by a masked postal clerk who refuses to write things down, or in the grocery store searching for a seasonal item but not being able to ask masked faces for help.

Ample opportunity exists in such times of adversity. We can use these experiences to pave the way for change, to address and acknowledge the unique communication abilities of people who are deaf or hard of hearing, and for physicians to continue to provide the highest level of safe and ethical medical care. Like anyone else, patients who are deaf or hard of hearing (or have other disabilities) deserve to be treated with

compassion, dignity, and, ultimately, feel that they were heard and listened to regarding their medical needs. All we ask for is some understanding, compassion, and decency as we, the deaf and hard-of-hearing, navigate added adversity in uncharted masked waters. As Dr. Gutierrez-Sigut (2022) shares, “We are so thankful deaf and hard of hearing shared their experiences and we hope we can make their voices seen and heard” (p. 2).

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Bridging the Communication Chasm Between Deaf Patients and Masked Medical Professionals by Renuka Sundaram
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**U.S. Postsecondary Students with Disabilities:
Where Do They Enroll and Document Their Disability?**

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Abstract

To date, no quantitative studies have explored what types of institutions of higher education enroll college students who document a disability (SWDs) over extended periods of time. This study leverages five years of institutionally reported (IPEDS) data related to the enrollment patterns of SWDs. This data suggests urban, public, and bachelor's-level institutions have enrolled more students with documented disabilities than other institution types over time. Additionally, we find that enrollment of SWDs in U.S. higher education has steadily increased since 2013. Implications for research and practice are addressed.

Keywords: disability studies, IDEA, IDEIA, higher education, postsecondary education, United States

U.S. College Students with Disabilities:

Where Do They Enroll and Document Their Disability?

Decades of research has suggested students with disabilities (SWDs) have been a consistently minoritized student population in U.S. higher education, evidenced by much lower enrollment rates in higher education compared to students without disabilities (Adams & Proctor, 2010; Plotner & Marshall, 2015; Renn & Reason, 2013; Postsecondary National Policy Institute, 2023; Stanley, 2000; Yssel et al., 2016). To close these access gaps between SWDs and non-SWDs, researchers have advocated for secondary school counselors and other stakeholders (community members, parents, etc.) to provide college counseling for SWDs (Adams & Proctor, 2010; Brinckerhoff et al., 1992), in addition to institutions of higher education providing SWDs with pre-college experiences to inspire SWDs to pursue higher education and inform them of their opportunities (Renn & Reason, 2013; Skinner & Lindstrom, 2003). Yet, despite advocacy for SWDs supported by empirical research, SWDs have continued to lag behind non-SWDs regarding enrollment in higher education. This access gap has been further exacerbated by the negative impact the pandemic had on SWD enrollment in higher education (Postsecondary National Policy Institute, 2023).

Yet long before empirical research identified these access gaps, U.S. legislation has

attempted to open the door to higher education for greater numbers of SWDs through institutional policy reforms. In 1973, U.S. Congress passed the Rehabilitation Act of 1973 containing Section 504 (Rehabilitation Act of 1973). Section 504 allows postsecondary institutions to “require students who are requesting services on the basis of a disability to submit documentation that verifies the nature and extent of the disability” (Madaus & Shaw, 2006, p. 13). However, no regulations have provided guidance regarding what type of documentation is acceptable or required, and how institutions of higher education have conducted the disability verification and documentation process varies tremendously and may be simpler or more difficult depending on where a student enrolls (Madaus & Shaw, 2006).

Shortly after passing the Rehabilitation Act in 1973, Congress passed the Education for All Handicapped Children Act in 1975—known later as the Individuals with Disabilities Education Act (IDEA, enacted in 1997) and even later as the Individuals with Disabilities Education Improvement Act (IDEIA, enacted in 2004)—which guarantees access to a free, appropriate, public education (FAPE) in the least restrictive environment to every child with a disability. Extending to higher education, IDEA requires U.S. institutions of higher education provide reasonable accommodations for students with documented disabilities. Yet, as the processes that SWDs must follow to document their disability at their institution varies (Madaus & Shaw, 2006), accommodations services also vary greatly by institution and are often slow to adapt to an ever-changing student population (Bursick et al., 1989; Madaus, 2011; Plotner & Marshall, 2015; Skinner & Lindstrom, 2003; Stanley, 2000).

As a result, despite legislative intervention, researchers have identified three structural issues facing SWDs pursuing higher education:

1. Enrollment has been difficult (Renn & Reason, 2013; Postsecondary National Policy Institute, 2023; Yssel et al., 2016).
2. After enrollment, navigating the process to have one's disability documented at their institution of higher education has been difficult (Brinckerhoff et al., 1992; Cawthon & Cole, 2010; Madaus & Shaw, 2006).
3. Once one's disability has been documented, accommodation quality may vary by institution and be inadequate for a SWD to be successful in higher education (Bursick et al., 1989; Madaus, 2011; Plotner & Marshall, 2015; Skinner & Lindstrom, 2003; Stanley, 2000).

As a result, a large body of research has examined how secondary school students with disabilities can best transition to higher education (Adams & Proctor, 2010; Brinckerhoff et al., 1992; Getzel & Thoma, 2008; Plotner & Marshall, 2015). Because many support services provided in the K-12 school system are not carried into higher education settings, students with disabilities who successfully access and thrive in U.S. higher education have needed to be effective self-advocates, meaning these students must advocate for their rights and educational needs (Getzel & Thoma, 2008; Mamiseishvili & Koch, 2012). This has led school choice researchers to suggest that students with disabilities—in concert with their parents or support network—explore institutions of higher education in depth and learn how certain institutions support students with disabilities on their campus (McGuire & Shaw, 1987; Skinner & Lindstrom, 2003; Renn & Reason, 2013) before deciding where to enroll.

Although work related to the self-determination of college students with disabilities is

important, disability-related research in higher education has predominantly analyzed this phenomenon through qualitative measures, finding that SWDs often struggle to complete college admissions processes to gain enrollment and then struggle to navigate the process to document their disability on campus (Adams & Proctor, 2010; Kimball et al., 2016; Mamiseishvili & Koch, 2012; Quick et al., 2011; Plotner & Marshall, 2015; Paul, 2000). Understanding this work, it seems critical to understand what types of institutions successfully enroll students with disabilities who successfully navigate the process of documenting their disability. Without this information, students with disabilities, researchers, policymakers, and other interested stakeholders lack insight into which types of institutions may better facilitate SWDs' transition to U.S. higher education through enrollment and disability documentation processes.

However, Fichten et al.'s (2003) study "Canadian Postsecondary Students with Disabilities: Where Are They?" leveraged institutional characteristics to explore where college students with disabilities enrolled—in this case, in a Canadian context. Employing survey and quantitative methods, Fichten et al. (2003) suggested 8% of Canadian institutions reported enrolling zero SWDs, 2% of students had their disability registered with their institution, and junior colleges had a higher percentage of students register their disability with their institution than four-year universities (Fichten et al., 2003). Additionally, Québécois institutions enrolled a smaller proportion of SWDs than did other provinces (Fichten et al., 2003). Here, Fichten et al.'s (2003) quantitative research revealed that—in a Canadian context—institutional differences did exist when considering where SWDs enrolled and where these students successfully navigated the disability documentation process,

informing the college choice of prospective students and their support networks.

Regarding similar studies in a U.S. context, the National Center for Education Statistics and the U.S. Department of Education sporadically publishes a report detailing where students with disabilities enroll in U.S. higher education, how many students disclose their disability and receive accommodations and services, and how many students with disabilities earn a postsecondary credential (U.S. Department of Education, 2000, 2017). The last report in 2017 provided a breakdown of which types of students were most likely to document their disability and a broad overview of where SWDs have their disability documented. It found that public less-than-2-year institutions (16.2% of undergraduates documenting a disability) and for-profit 4-year institutions (16.0%) enrolled the highest percentage of college students having their disability documented (U.S. Department of Education, 2017, p. 30.). Beyond this brief report and Fichten et al.'s (2013) Canadian study, no quantitative studies have leveraged institutional characteristics to predict enrollment of college students who have had their disability documented by their institution. A quantitative analysis in U.S. contexts could explore potential relationships between institutional enrollment processes, institutional disability documentation processes, and whether certain institutions are more adept at enrolling SWDs and facilitating the disability documentation process.

As a result, this study seeks to make a unique contribution to the literature and leverage institutional characteristics over time—such as urbanicity, sector, type, and institutional spending—as they predict the enrollment of students with documented disabilities to answer the question Canadian researchers have previously answered (Fichten et

al., 2013): Where are they?

This study's research questions are as follows:

R1: In recent years (2013-2017), which institutional characteristics are predictive of enrollment of college students with documented disabilities?

R2: Of institutions whose students with disabilities population is higher than 3%, which institutional characteristics predict an increase in enrollment of students with documented disabilities?

By answering these questions, educational researchers, policymakers, and students with disabilities will better understand which U.S. institutions of higher education enroll the greatest percentages of students with documented disabilities, informing disability policies aimed at increasing access to and support in higher education for this minoritized student population. Moreover, this study will expand the wealth of research focused on students' self-advocacy by understanding which institutional characteristics may or may not facilitate a living and learning environment in which students may be better self-advocates, and thus, successful in accessing U.S. higher education.

Literature Review

Educational research has produced a voluminous amount of work related to students with disabilities and their transition from secondary to postsecondary education, in addition to how these students are supported once they arrive on campus (Haber et al., 2016; Kochhar-Bryant et al., 2009; Madaus, 2011; Paul, 2000). An extensive review of this literature does not substantially support the aims of this study. Instead, this brief review will focus first on the scant research focused on institutional predictors of enrollment of students with

disabilities, as well as how these students transition from secondary to postsecondary education. Then, the review will briefly focus on the few studies which have identified institutional characteristics that may be supportive of students with disabilities.

Where Are They? What We Do Know

The National Center for College Students with Disabilities (NCCSD) routinely publishes reports that gather information from a variety of secondary and postsecondary databases to inform the community regarding both student access to and success at institutions of higher education. In the NCCSD's most recent report providing an overview of postsecondary enrollment patterns of students with disabilities, Avellone and Scott (2017) argued that, despite there being 11 different databases including information relevant to SWDs, there are "significant gaps in the breadth and usability of current datasets that include information on college students with disabilities," (p. 3). This includes that these databases often rely on student surveys and institutional self-reporting, which may be incomplete or flawed. Of these databases, Avellone and Scott (2017) reasoned that many, including the Beginning Postsecondary Longitudinal Study (BPS) and the National Survey of Student Engagement (NSSE), do not publish on data related to students with disabilities due to potential privacy concerns, and these organizations require students to complete a survey, which may marginalize students with disabilities who are unable to access or take a survey without assistance. For example, the most recent BPS report in 2011 titled "Trends in Attainment Among Student Populations at Increased Risk of Noncompletion" did not mention students with disabilities once (U.S. Department of Education, 2011, p. 1). This is even though the research community has long known that the SWD population is perhaps at

the highest risk of noncompletion of any population in higher education. From here, Avellone and Scott (2017) concluded that much more work should be done to learn more about where students with disabilities enroll in U.S. higher education and earn their degrees, as extant databases are insufficient to inform support of this population.

The most recent national-level report of students with disabilities enrollment in U.S. institutions of higher education was the 2017 U.S. Department of Education's "Characteristics and Outcomes of Undergraduates with Disabilities." Therein, the U.S. Department of Education (2017) synthesized data from multiple sources (e.g., the High School Longitudinal Study of 2009, the 2012/14 Beginning Postsecondary Students Longitudinal Study). Via survey, the study explained that nearly 12% of undergraduates reported having a disability in 2011-2012, and that only 13.8% of high school students who received special education services in 2009 expected to earn a bachelor's degree in the future. In addition, of high school students who received special education services in 2009, administrative data suggested that 37.4% had not enrolled in any level of postsecondary education by 2013. If students with disabilities did pursue higher education, public less-than-two-year institutions (16.2% of undergraduates documenting a disability) and for-profit four-year institutions (16.0%) enrolled the highest percentage of college students having their disability documented (U.S. Department of Education, 2017, p. 30.). Beyond this reporting of institutional percentage share of enrollment of students with disabilities, the U.S. Department of Education (2017) did not report on any other data besides self-reported student-level characteristics (e.g., race, sex, age, immigrant status, and veteran status) and broad student disability types (e.g., cognitive, ambulatory) that were not tied to any institutional

characteristics.

Similarly, Fichten et al.'s (2003) study examined the enrollment of students with disabilities in Canadian postsecondary institutions. Their results also suggested students with disabilities are a minoritized population in higher education—albeit a Canadian context—as 8% of postsecondary institutions reported enrolling zero students with disabilities in 2000. In addition, only 2% of the overall postsecondary population of Canadian students with disabilities were registered to receive disability-related services (Fichten et al., 2003). Parallel to U.S. contexts, Fichten et al. (2013) also found that Canadian junior and/or community colleges enrolled a higher percentage of students with documented disabilities than Canadian universities, akin to 2017 U.S. data suggesting that U.S. public and private non-profit two-year institutions enrolled a higher percentage of students with documented disabilities than U.S. universities (U.S. Department of Education, 2017). Importantly, Fichten et al.'s (2003) study suggested that the geography of Canadian institutions may play a role in the enrollment of students with disabilities, as the researchers found Québécois institutions enrolled a smaller proportion of students with disabilities than did other provinces in Canada, even though the population of people with disabilities was not significantly lower in Québec than other provinces. However, Fichten et al. (2013) did not elaborate on why Québécois institutions may have been more successful in enrolling SWDs and facilitating their disability documentation process.

Ultimately, both the U.S. Department of Education's (2017) report and the Fichten et al. (2003) study did not consider other institutional characteristics that may or may not predict the enrollment of students with documented disabilities. Although it is useful to

understand that 29.9% of students with disabilities who received special education services in 2009 enrolled in either public or private nonprofit two-year institutions (U.S. Department of Education, 2017), these descriptive statistics do not strongly inform policy or practice. It is important to expand upon this work and learn how institutional characteristics may influence the enrollment of students with disabilities, such as geographic location, Carnegie classification (a U.S. higher education measurement of institutional research intensity), sector, type, and institutional expenses on student services, academic support, and instructional support.

Barriers Faced by Students Transitioning to Higher Education

Students with disabilities often face barriers when transitioning from secondary school to higher education, including barriers related to disability type, knowledge of higher education, difficulty in documenting one's disability, and institutional support. Since the passage of IDEA in 1997 and its updates in the form of IDEIA in 2004, researchers have written about how students with disabilities transition from secondary to higher education, especially given that many Section 504 protections no longer apply in higher education settings, such as functional and formative assessments and creation of individualized education plans (IEPs) to ensure students are meeting benchmarks and accommodations are provided by instructors (Madaus & Shaw, 2006). According to the most recent survey of the National Longitudinal Transition Study (NLTS) in 2009, college students with documented disabilities most commonly have a hearing (73%) or visual impairment (67%), while far fewer have autism (39%) or multiple disabilities (28%), suggesting that students with certain disability types may face fewer barriers when accessing higher education and documenting

their disability. Additionally, students with disabilities from higher-income homes tend to attend higher education in larger numbers, a finding supported by subsequent research (Cheatham & Elliott, 2013), while both race and gender were not significantly different between nondisabled students and students with disabilities who attend institutions of higher education. However, at the time of this study, the NLTS is already over a decade old and draws upon a small survey of students with disabilities and not the entire population of students with disabilities in U.S. higher education.

Given the persistent hurdles facing students with disabilities as they pursue postsecondary education, researchers have argued that disability services offices at institutions of higher education are often not equipped with the knowledge base or the resources necessary to support students with disabilities as they explore institutions and research services to inform their college choice (Cawthon & Cole, 2010; Kochhar-Bryant et al., 2009). In addition, researchers have pointed to weak data systems and communication networks between secondary and postsecondary schools, including how secondary schools communicate IEPs with institutions of higher education to help postsecondary staff understand how students with disabilities were supported at the secondary level (Kochhar-Bryant et al., 2009; Sitlington, 2003).

Of these major hurdles faced by SWDs during their transition from secondary to postsecondary education, researchers have found that recent and accurate documentation of one's disability can be cumbersome and costly for SWDs and their families. For example, according to the National Longitudinal Transition Study in 2009, students with disabilities were more likely to pursue higher education as they got older, as 65% of 25-year-olds took at

least one postsecondary course, whereas only 58% of 21-year-olds took at least one postsecondary course (Institute of Education Sciences, 2009). Madaus and Shaw (2006) argued that, as students with disabilities leave the K-12 system and their disability documentation becomes outdated, institutions of higher education may require updated documentation and accommodations information, while also asking to review copies of a student's (potentially outdated) IEP while they were still a K-12 student. In these situations, many SWDs and their support networks—especially those from low-income backgrounds—may struggle to procure updated, accurate disability documentation information, possibly restricting a student from navigating the institutional process of documenting their disability.

Recently, in 2019, Scott (2019) from the NCCSD conducted focus groups with 46 students with disabilities currently enrolled in institutions of higher education to learn more about their transition to postsecondary education and any barriers to access that they experienced. Students consistently reported that communicating with campus disability resource offices was difficult, as students claimed that accommodations were inadequate, and professionals working at the offices did not provide students with necessary information for navigating office procedures and resources for skill development. Moreover, students also claimed that class instructors were not informed of campus policies and were often unresponsive to student needs, even if that student correctly documented their disability and requested reasonable accommodations through the disability services office. Finally, students also asserted that accessing higher education was difficult due to gaps in online information about resources and services, as well as campuses being situated in areas that were physically difficult for students to access and navigate without substantial support given poor building

accessibility and a lack of accessible transportation.

Given this scant prior work (Madaus & Shaw, 2006; Scott, 2019), researchers have pointed to the IDEIA update in 2004 and its focus on transition documentation as a possible pathway for more secondary schools and K-12 systems to better support students with disabilities transition to higher education. Madaus and Shaw (2006) explain that a Summary of Performance or SOP would require K-12 school systems to “provide the child with a summary of the child's academic achievement and functional performance, which shall include recommendations on how to assist the child in meeting the child’s postsecondary goals” (p. 14). Given this new requirement levied by IDEIA, Madaus and Shaw (2006) reason:

A well-developed SOP will comment on what modifications and accommodations are actually used and how effective these have been in helping the student to be successful at the secondary level. It will likely be a substantial improvement over current IEPs and perhaps offer professionals working with students with disabilities meaningful and relevant data for planning interventions. (p. 14)

In a review of IDEIA’s new documentation of transition planning which extended IDEA’s notion of secondary student transitions to adult life, Sitlington and Clark (2007) reason that a SWD’s SOP should detail a SWD’s academic progress, skills and abilities, levels of connection and communication with one’s community, socioemotional background, and other information relevant to informing a student’s transition to postsecondary education. An extension and elaboration of a SWD’s IEP, a SOP could serve two purposes: 1) as a guiding document for both SWDs to be their best self-advocate when exploring institutions of

higher education and support services, and 2) an institution of higher education's guiding framework for supporting a SWD and attempting to mirror a SWD's secondary support services in their new higher education setting.

Since IDEIA's mandate of a SOP and augmented transition planning, several SWDs and their families have sued K-12 school systems, alleging violations of IDEIA and improper transition planning. Prince et al. (2013) reviewed 11 such court decisions and argued that although transition planning goals were often vague and necessary public agencies were not invited to the SWD's transition planning meetings, many K-12 school districts did not violate IDEIA because they "supplied the family with substantial information and assistance" (p. 287). Moreover, additional case law has suggested that K-12 districts will not be liable for additional transition services as long as "the IEP or transition plan [SOP] provides for a free appropriate public education" (p. 287). For example, Prince et al. (2013) briefed *Sherri High et al. v. Exeter Township School District*, a case where a SWD sued their school district for failing to facilitate postsecondary and adult transition services, including ACT and SAT testing, course placement evaluations, and job application practice sessions. In the case, the court ruled in favor of the district, reasoning that the district did provide the resources and did not violate IDEIA: The district did not facilitate the services, including making ACT or SAT appointments and providing private tutoring services, which do not fall under the purview of IDEIA.

Ultimately, Prince et al. (2013) argued that SOPs should contain "results-oriented, measurable, and appropriate postsecondary goals" (p. 289) that may or may not include plans for pursuing higher education or providing higher education planning services, such as course

placement testing, ACT and SAT preparation, or evaluations of a college or university's disability services, including the institution's process for documenting a student's disability. From here, even with enhanced higher education planning mandated by IDEIA in the form of a SOP and more robust transition planning, students with disabilities must still be self-advocates and follow up on the resources provided by the SOP and their K-12 school district, as IDEIA case law has largely dictated that K-12 districts can provide the information, but SWDs must act on the resources and facilitate their own higher education transition on their own.

Evaluating Institutional Support for Students with Disabilities

Prior to important legislation meant to support students with disabilities pursuit of U.S. higher education (e.g., the Americans with Disabilities Act and IDEIA), disability in higher education research addressed how important the higher education exploration process is for these students and their families (Bursick et al., 1989; McGuire & Shaw, 1987; Wiseman et al., 1988).

McGuire and Shaw (1987) explored the higher education decision-making strategies of students with disabilities and their parents, finding that both students and parents should consider the specific disability of the student and then attempt to locate institutions that provide specific supports for that disability. Of institutional characteristics that students with disabilities and parents should consider, McGuire and Shaw (1987) asserted that an institution's criteria for determining a disability and the overall admissions processes should be evaluated. In addition, students and parents should assess an institution's disability programming, including how many full-time staff are employed, how many hours per week

the institution funds disability support services, whether peer mentoring groups are present and active, and how many students with disabilities persist and earn their degree (McGuire & Shaw, 1987).

To better understand the level of institutional support provided to students with disabilities, Bursick et al. (1989) surveyed a national sample of college students with disabilities across several two- and four-year institutions (n=197) and learned only 33% of institutions provided counselors trained in disability services and only half provided remedial instruction to develop social skills. Regarding institutional characteristics which predicted disability services, Bursick et al. (1989) found students with disabilities reported that smaller schools were more likely to facilitate individualized group tutoring for all students ($p < 0.01$) and remedial mathematics instruction for all students ($p < 0.01$) than larger institutions. Finally, the researchers learned two-year institutions were more likely to review individualized education plans (IEPs) for their students than four-year institutions ($p < 0.001$), while two-year institutions were also more likely to provide broad remediation services than four-year institutions ($p < 0.01$).

Wiseman et al. (1988) also surveyed currently enrolled students with disabilities in U.S. institutions (n=100 students) and learned that social and emotional involvement with peers, in tandem with institutional support, may not be enough to overcome a lack of sense of belonging on campus. After measuring the students' relationships between peers and their campus and the level of institutional support, Wiseman et al. (1988) argued "if the disabled student feels alienated from campus, these factors [institutional supports] will not be sufficient to ensure the student's retention in the university" (p. 266). However, Wiseman et

al.'s (1988) study did not address the factors related to SWDs and their enrollment patterns, instead focusing on institutional and social predictors of academic success.

After the passage of the Americans with Disabilities Act (ADA), the amendments to Section 504 of the Rehabilitation Act, and the passage of the Individuals with Disabilities in Education Act, the number of students with disabilities in U.S. higher education has increased, but this population is still considerably underrepresented (U.S. Department of Education, 2017). However, rigorous quantitative work has not been performed to explore institutional characteristics as they predict the enrollment of students with documented disabilities. Prior research has provided evidence that an institution's physical location (Fichten et al., 2003), sector (public or private) (Bursick et al., 1989; U.S. Department of Education, 2017), and level of institutional support (Madaus & Shaw, 2006; Mamiseishvili & Koch, 2012; McGuire & Shaw, 1987; Plotner & Marshall, 2015; Wiseman et al., 1988) may all contribute to the enrollment of students with disabilities and their success in higher education. As a result, this study considers longitudinal institutional data alongside U.S. higher education enrollment trends of students with documented disabilities to answer a simple but informative question: Where are they?

Methods

The following sections will detail how data was collected, how quantitative methods were determined, and how the research team addressed limitations.

Data

The research team employed the Integrated Postsecondary Education Data System ([IPEDS], National Center for Education Statistics, 2019) to explore where students with

documented disabilities enrolled in U.S. institutions of higher education. IPEDS provides annual, comprehensive, standardized data on U.S. colleges and universities through annual institution-level surveys that collect information related to institutional enrollment, graduation rates, student financial aid, and many more characteristics which allow for comparison between institutions in different sectors (public, private, two-year, four-year, etc.). A limitation to be addressed later, IPEDS only includes percentages of SWD at the 3% threshold. This means that institutions that enroll less than 3% SWD do not report individual percentages, and institutions who enroll 3% or more SWD population report their percentage without reporting specific enrollment numbers or the types of disabilities that students have reported.

As a result, the research team collected IPEDS data from a total of 6,165 institutions of higher education across five years—descriptive statistics of this population can be found in Table 1. Institutional characteristics included sector (e.g. public or private), Carnegie classification, geographic location (e.g., rural, urban), four-year and less-than-four-year programs, student services expenses (aggregated), academic support expenses (aggregated), and instructional expenses (aggregated), student-faculty ratio, and average institutional grant aid (non-government aid). These variables were included in the data collection process, as extant research has supported that these institutional characteristics may influence the enrollment of SWDs at institutions of higher education (Bursick et al., 1989; Fichten et al., 2003; Mamiseishvili & Koch, 2012; McGuire & Shaw, 1987; Plotner & Marshall, 2015; U.S. Department of Education, 2017; Wiseman et al., 1988).

Analytic Strategy

Given the limitations of how SWDs data is reported by institutions and collected by the National Center for Education Statistics (2019), this study employed a random effects probit model with reporting of robust standard errors. Given the binary reporting structure of the data (institutions with 3% or less SWDs versus more than 3% SWDs), the data justified the use of a random effects probit model (Gibbons & Hedeker, 1994; Wooldridge, 2009). A random effects probit model is appropriate for longitudinal data predicting a binary outcome including both time varying (e.g., academic support expenses) and time invariant characteristics (e.g., institutional sector).

The random effects probit model formula employed in this study can be found below, where:

$$Y_{it} = B_0 + B_1X_{it} + B_2Z_{it} + \alpha_i + \tau_t + \varepsilon_{it} \quad (1)$$

The outcome variable of interest— Y_{it} —represents an institution i 's first-time undergraduate students with disabilities enrollment in a given year (t). X_{it} represents institution i 's time-varying characteristics (such as student services expenses per FTE). Z_{it} represents institution i 's time invariant characteristics (such as geographic location) in the equation 1. Institutional-level fixed effects (α_i) considers differences in observable and unobservable characteristics across institutions. τ_t represents time dummy variables, which control for observed and unobserved events that may affect students with disabilities enrollment over the time (such as the law, or technological change). ε_{it} is the robust standard error term.

Limitations

The primary limitation of this study—and all disability-related studies in higher

education—is the way in which SWDs data is reported by institutions and collected by the National Center for Education Statistics (2019) and/or the federal government. Because specific enrollment numbers (instead of percentages of overall enrollment) and disability types (e.g., autism, deafness) are not made available by the institutions themselves or data reporting entities, quantitative, higher education-focused disability studies must employ a blunt instrument to articulate a highly contextualized, nuanced student population and their institutional environment(s). To date, it is unclear why NCES—and their IPEDS database—does not provide more robust information or request more robust SWD-related information from institutions of higher education, suggesting further research could explore why the NCES operates the way it does and limits the robustness of the information they collect related to SWD.

As a result, this study—and others employing quantitative measures—do not adequately explain how students with a wide range of disabilities may or may not access a diverse, wide range of institutions, each with institution-specific nuances and subtleties. Decades of research has given SWDs an amplified voice in higher education settings, but institutional characteristics must be considered to provide a more holistic, comprehensive understanding of how institutions support SWDs. From here, disability studies researchers and policymakers must continue to advocate for SWDs and encourage institutions of higher education to provide anonymous, detailed SWDs data in order to analyze extant policies and advocate for more inclusive, supportive policies to facilitate SWD access to higher education.

Results

Descriptive statistics of 2017 institutional-level data can be found in Table 1 below.

Data from 2013, 2014, 2015, and 2016 can be found in the Appendix.

Table 1

Institutions enrolling more than 3% students with disabilities and institutions enrolling 3% or less than 3% students with disabilities, by Carnegie classification, location, sector, and type in 2017 (n=6,153)

	Institutions enrolling more than 3% students with disabilities		Institutions enrolling 3% or less than 3% students with disabilities	
	N	% of Institution Type	N	% of Institution Type
Carnegie Classification				
Baccalaureate	327	49.2%	338	50.8%
Master's	324	49.8%	327	50.2%
Doctoral	40	49.4%	41	50.6%
High Research Activity	58	61.1%	37	38.9%
Very High Research Activity	62	57.9%	45	42.1%
Other*	541	11.9%	4,013	88.1%
Location				
Urban	609	21.0%	2,290	79.0%
Suburban	381	20.4%	1,487	79.6%
Town/rural	362	26.1%	1,024	73.9%
Sector				
Public	661	34.2%	1,270	65.8%
Private non-profit	629	39.8%	952	60.2%
Private for-profit	62	2.3%	2,579	97.7%
Type				
Four-year	971	38.6%	1,543	61.4%
Less-than-four-year	381	10.5%	3,258	89.5%
Total	1,352	22.0%	4,801	78.0%
Student Services Expenses	\$3,690	-	\$1,969	-
Academic Support Expenses	\$2,806	-	\$1,623	-
Instructional Expenses	\$10,590	-	\$6,541	-
Average Institutional Grant				
	\$11,281	-	\$4,152	-
Student-to-Faculty Ratio				
	14.93	-	14.91	-

*Notes: Other includes associate’s institutions, special focus higher education institutions (trade schools, barber colleges, rabbinical institutions, etc.), and Carnegie unclassified institutions; All expenses figures were calculated per enrolled student.

Across all institutional characteristics, most U.S. institutions of higher education (78.0%) do not enroll greater than a 3% SWDs population, with institutions in urban settings, public institutions, and four-year institutions being more likely to enroll a greater than 3% SWDs population in 2017. In addition, institutions enrolling greater than 3% SWDs spent more per enrolled student on average in student services, academic support, instructional expenses, and average institutional grant aid. Student-faculty ratio between 3% and non-3% institutions was similar in 2017.

A random effects probit model predicting enrollment of students with disabilities in U.S. institutions of higher education (N=6,165) can be found in Table 2 below:

Table 2

Random effects probit models predicting whether institutions enroll more than 3% students with disabilities

Variables	Model 1	Model 2	Model 3
Carnegie (reference = Bachelor's)			
Master's	-0.351 (0.195)	-0.323 (0.183)	-0.333 (0.183)
Doctoral	-0.423 (0.408)	-0.456 (0.389)	-0.612 (0.400)
High Research Activity	-0.014 (0.415)	-0.198 (0.389)	-0.507 (0.381)
Very High Research Activity	-0.364 (0.374)	-0.845* (0.355)	-1.412*** (0.349)
Other	-2.228*** (0.177)	-2.101*** (0.172)	-1.425*** (0.187)
Location (reference=Urban)			
Suburban	0.230	0.235	0.250

	(0.131)	(0.124)	(0.134)
Town/rural	-0.429***	-0.428***	-0.410*
	(0.125)	(0.121)	(0.130)
Sector (reference=Public)			
Private non-profit	-0.650***	-0.702***	-0.704***
	(0.124)	(0.120)	(0.148)
Private for-profit	-3.404***	-3.110***	-3.056***
	(0.372)	(0.233)	(0.199)
Four-year (reference=Less-than)	0.184	0.077	0.016
	(0.140)	(0.131)	(0.149)
Student services expenses (logged)		0.040	-0.055
		(0.024)	(0.028)
Academic support expenses (logged)		0.025	0.097***
		(0.021)	(0.026)
Instructional expenses (logged)		0.500***	0.820***
		(0.071)	(0.098)
Student-faculty ratio			0.021*
			(0.008)
Average institutional grant (logged)			0.357***
			(0.056)
Year (reference=2013)			
2014	0.155***	0.113*	0.155*
	(0.046)	(0.046)	(0.051)
2015	0.339***	0.285***	0.347***
	(0.053)	(0.053)	(0.059)
2016	0.559***	0.504***	0.615***
	(0.057)	(0.058)	(0.064)
2017	0.666***	0.617***	0.728***
	(0.059)	(0.060)	(0.068)
Constant	-0.239	-5.106***	-11.233***
	(0.216)	(0.667)	(1.001)
Observations	29,741	29,741	20,106
Number of institutions	6,165	6,165	4,640

Notes: Robust standard errors in parentheses; *** p<0.001, * p<0.01, * p<0.05

Model 1 included all institutional-level time invariant characteristics across the entire population (N=6,165). Data indicate SWD were less likely to enroll in associate's, special focus, or non-Carnegie classified institutions ($p < 0.001$) than bachelor's institutions,

institutions in town/rural settings ($p < 0.001$) than urban settings, and private institutions (nonprofit = $p < 0.001$, for-profit = $p < 0.001$) than public institutions.

Model 2 included both institutional-level time invariant and varying characteristics across the entire population ($N=6,165$). Data indicate SWDs were less likely to enroll in associate's, special focus, or non-Carnegie classified institutions ($p < 0.001$) and institutions with very high research activity ($p < 0.05$) than bachelor's institutions, institutions in town/rural settings ($p < 0.001$) than urban settings, and private institutions (nonprofit = $p < 0.001$, for-profit = $p < 0.001$) than public institutions. Instructional expenses were also associated with greater percentages of SWDs ($p < 0.001$), echoing prior qualitative studies suggesting increased instructional support may benefit SWDs (Bursick et al., 1989). Controlling for institutional-level time invariant and varying characteristics, longitudinal data also suggest a steady increase of enrollment of SWDs.

Model 3 included both institutional-level time invariant and varying characteristics, while also including student-faculty ratio and average institutional grant aid which were reported by 4,640 institutions across the five-year panel data period. Data indicate SWDs were less likely to enroll in associate's, special focus, or non-Carnegie classified institutions ($p < 0.001$) and institutions with very high research activity ($p < 0.001$) than bachelor's institutions, institutions in town/rural settings ($p < 0.05$) than urban settings, and private institutions (nonprofit = $p < 0.001$, for-profit = $p < 0.001$) than public institutions. Academic support expenses ($p < 0.001$), instructional expenses ($p < 0.001$), and average institutional grants ($p < 0.001$) were also associated with greater percentages of SWDs enrolling in U.S. institutions of higher education. Across Models 1, 2, and 3, longitudinal data also suggest a

steady increase of enrollment of SWDs in U.S. higher education, a result echoed by prior research (Postsecondary National Policy Institute, 2023; Yssel et al., 2016).

Discussion and Implications

Over a longitudinal period, data in this study suggests institutional characteristics may influence the enrollment of students with documented disabilities in U.S. institutions of higher education. From this work, many connections to prior research can be made, as well as implications drawn for future research, policy, and practice.

To begin, this study extends Fichten et al.'s (2013) work into U.S. contexts, with both studies finding that the geographic setting of an institution may influence the enrollment of students with documented disabilities in those institutions. In U.S. higher education settings, this study suggests SWDs enroll and document their disability in urban institutions at higher percentages than institutions in any other geographic setting. Recent U.S. population research suggested that people with disabilities are more likely to live in rural areas than urban areas (Crankshaw, 2023). In fact, according to the U.S. Census Bureau, only 19.8% of the U.S. population in 2023 was classified as rural, but 14.7% of this population reported having a disability. Inversely, the U.S. Census Bureau found 80.2% of the U.S. population in 2023 was classified as urban, but only 12.6% of this population reported having a disability. Here, given U.S. population data, one may assume that greater percentages of SWDs would enroll and document their disability at rural institutions of higher education, yet this study suggests that the inverse is true. Subsequently, disability studies researchers and policymakers should explore how urban institutions support SWDs and whether an institution's geographic setting is more or less conducive to SWDs enrollment and disability documentation in higher

education.

Results also suggest SWDs are less likely to enroll and document their disability in associate's, special focus, or non-Carnegie classified institutions and very high research Carnegie classified institutions. Here, prior research has suggested that students pursuing certain careers may face unique challenges in enrolling in degree plans and documenting their disability at their institution, including students pursuing science, technology, engineering, and mathematics (STEM) degrees (Prema & Dhand, 2019) and professional education programs (Squires & Counterline, 2018). Building upon this research, data suggest SWDs may struggle to enroll and document their disability in special-focus institutions (e.g., rabbinical schools, chiropractic colleges) and research intensive-majors (e.g., chemistry, engineering) at very high research intensity institutions. Such a phenomenon may lead a SWD to attend less research-intensive institutions that offer general education majors and fewer specialized, research-intensive plans of study. These results are difficult to interpret, as no research has explored how the difficulty or lack in provision of accommodations for SWDs may differ across majors and institution types.

Recently, Mamboleo et al. (2020) surveyed college students with disabilities (n=289) across six different four-year universities and learned that these students often struggled with the same issues related to documenting their disability, including instructors' lack of understanding, lack of knowledge of institutional documentation processes and accommodations, and students feeling a sense of stigma while navigating the disability documentation process. However, Mamboleo et al. (2020) did not analyze data to uncover institutional differences, rather reporting aggregate statistics. Relatedly, Bursick et al.'s

(1989) study found smaller schools were more likely to facilitate individualized group tutoring and remedial mathematics instruction than larger institutions, while two-year institutions were more likely to review secondary IEPs and provide broad remediation services than four-year institutions. However, institutional enrollment or two- or four-year classification may not correlate with research output and Carnegie classification: Here, disability studies researchers should explore institutional differences regarding disability documentation guidelines and accommodations provision to determine whether certain institutions or institution types facilitate a more equitable learning environment for students with disabilities.

This study's data also suggests that enrollment of students with documented disabilities has been greater at public institutions in recent years, suggesting public institutions may streamline their enrollment or disability documentation process for students with disabilities when compared with private peers. Prior research suggests public K-12 schools serve a larger proportion of SWDs across the U.S. (Kimball et al., 2016), while private K-12 schools are not required to follow the special education regulations of IDEA, mandating that SWDs receive a free, appropriate public education. This phenomenon suggests that SWDs may be better served and accommodated at public K-12 schools, leading these students to pursue a postsecondary education at public institutions.

To date, no studies have explored how secondary students with disabilities view public versus private higher education options, and future research could explore how SWDs perceive public versus private higher education, investigating whether enrolled college SWDs have experienced more or less institutional support at different sectors of institutions.

Additionally, researchers could explore how SWDs and their support networks procure long-term documentation of a student's disability and how that documentation is communicated to disability services offices at institutions of higher education. It may be that there is a disconnect in communication between public K-12 schools and private institutions of higher education, or that a student's support network is more familiar communicating with public schools and prefers their student to attend a public institution of higher education. In either case, further research is needed to explore the disconnect between public K-12 school enrollment and private higher education enrollment of students with disabilities.

Finally, academic support expenses, instructional expenses, and average institutional grants were also associated with greater percentages of SWDs enrolling in U.S. institutions of higher education. These results are supported by prior research suggesting institutional support positively impacts SWDs on college campuses (Bursick et al., 1989; Mamiseishvili & Koch, 2012; Plotner & Marshall, 2015; Quick et al., 2011; Wiseman et al., 1988). Although prior work has not examined how institutional grants affect the higher education enrollment patterns of SWDs, institutional grant aid has been effective in enrolling students in higher education from other minoritized backgrounds, including low-income students and students of color (Hu, 2010). Thus, a positive relationship between institutional grant aid and higher education enrollment of SWDs has numerous implications. Perhaps awarding institutional grant aid to a student with a disability helps establish a positive relationship between an institution and a student, encouraging communication. Moreover, such an award may render any accommodations or individualized education services more affordable, such as a personal assistant, transcription services, or assistive technologies. Ultimately, data in this study

suggest institutions who spend more on academic support services, instructional expenses, and institutional grants per student enroll greater percentages of students with documented disabilities than institutions that do not spend, urging researchers and policymakers to explore institutional spending on student services, possibly increasing higher education access for students with disabilities.

Conclusion

A wealth of qualitative research has provided a voice to countless students with disabilities pursuing U.S. higher education (Cawthon & Cole, 2010; Getzel & Thoma, 2008; Mamboleo et al., 2020), yet this study sheds new light on which institutions may best facilitate higher education access for students with disabilities. Data suggest that perhaps the most fertile, supportive higher education environment for SWDs may be at urban, public, bachelor's-level institutions that provide adequate academic and instructional support and award adequate institutional grant aid. If this is the case, researchers and policymakers must engage with these institutions to develop inclusive, supportive policies for SWDs pursuing U.S. higher education, in hopes that other institutions replicate this work and adopt more inclusive enrollment and disability documentation policies and practices.

Understanding that Section 504 and IDEIA protections are greatly reduced at institutions of higher education compared to K-12 schools, U.S. researchers and policymakers must continue to advocate for SWDs in higher education, encouraging students to share their experiences and pave a path for future students. However, enrollment could be greatly increased if institutions themselves begin collecting and reporting more detailed, robust data regarding SWDs, thus informing the disability research and policy community. This effort

could start with the U.S. Department of Education requiring public K-12 schools to create standardized Summaries of Performance (SOP) that SWDs and their support networks could attach to college applications or have electronically shared between K-12 schools and institutions of higher education, namely their disability services offices. Moreover, the U.S. Office of Federal Student Aid includes a question related to disability benefits on the Free Application for Federal Student Aid (FAFSA). Instead of asking a student or their contributor about disability benefits, the FAFSA could be updated to include one question about a student's disability status or disability services received, allowing students with disabilities to share their status safely and securely with institutions of higher education. This data-sharing mechanism would allow institutions of higher education to proactively communicate with students with disabilities during the enrollment process, facilitating a potentially smoother process for a student to document their disability and advocate for appropriate accommodations.

Ultimately, of the over 6,000 institutions in this study, simply determining that urban, public, bachelor's-level institutions tend to enroll greater percentages of students with a documented disability is not enough. The disability studies community should not have to ask, "Where are they?" Until data collection and reporting policies change and are mandated by the federal government to inform radical action to improve accessibility and inclusion, students with disabilities will continue to experience hurdles on their path toward a higher education, even if we have a baseline understanding of where they are.

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Appendix

Institutions enrolling more than 3% students with disabilities and institutions enrolling 3% or less than 3% students with disabilities, by Carnegie classification, location, sector, and type in 2016 (n=6,071)

	Institutions enrolling more than 3% students with disabilities		Institutions enrolling 3% or less than 3% students with disabilities	
	N	% Share	N	% Share
Carnegie Classification				
Baccalaureate	314	47.29%	350	52.71%
Master's	295	45.52%	353	54.48%
Doctoral	33	40.74%	48	59.26%
High Activity	54	56.84%	41	43.16%
Very High Activity	57	53.27%	50	46.73%
Other*	540	12.06%	3,936	87.94%
Location				
Urban	566	19.71%	2,306	80.29%
Suburban	367	20.16%	1,453	79.84%
Town/rural	360	26.11%	1,019	73.89%
Sector				
Public	653	33.94%	1,271	66.06%
Private non-profit	578	37.27%	973	62.73%
Private for-profit	62	2.39%	2,534	97.61%
Type				
Four-year	893	36.08%	1,582	63.92%
Less-than-four-year	400	11.12%	3,196	88.88%
Total	1,293	21.30%	4,778	78.70%
Student Services Expenses	\$3,553	-	\$2,356	-
Academic Support Expenses	\$2,679	-	\$5,470	-
Instructional Expenses	\$10,176	-	\$8,236	-
Average Institutional Grant	\$10,593	-	\$5,474	-
Student-to-Faculty Ratio	15.02	-	6.72	-

*Notes: Other includes associate's institutions, special-focus higher education institutions, and Carnegie unclassified institutions.

Institutions enrolling more than 3% students with disabilities and institutions enrolling 3% or less than 3% students with disabilities, by Carnegie classification, location, sector, and type in 2015 (n=5,966)

	Institutions enrolling more than 3% students with disabilities		Institutions enrolling 3% or less than 3% students with disabilities	
	N	% Share	N	% Share
Carnegie Classification				
Baccalaureate	278	41.80%	387	58.20%
Master's	275	42.50%	372	57.50%
Doctoral	31	38.27%	50	61.73%
High Activity	50	52.63%	45	47.37%
Very High Activity	51	47.66%	56	52.34%
Other*	502	11.48%	3869	88.52%
Location				
Urban	516	18.36%	2295	81.64%
Suburban	329	18.46%	1453	81.54%
Town/rural	342	24.91%	1031	75.09%
Sector				
Public	595	31.01%	1324	68.99%
Private non-profit	540	35.20%	994	64.80%
Private for-profit	52	2.07%	2461	97.93%
Type				
Four-year	803	33.07%	1625	66.93%
Less-than-four-year	384	10.85%	3154	89.15%
Total	1,187	19.90%	4779	80.10%
Student Services Expenses	\$3,480	-	\$1,827	-
Academic Support Expenses	\$2,622	-	\$1,525	-
Instructional Expenses	\$10,194	-	\$6,590	-
Average Institutional Grant	\$10,276	-	\$4,237	-
Student-to-Faculty Ratio	15.34	-	15.32	-

*Notes: Other includes associate's institutions, special-focus higher education institutions, and Carnegie unclassified institutions.

Institutions enrolling more than 3% students with disabilities and institutions enrolling 3% or less than 3% students with disabilities, by Carnegie classification, location, sector, and type in 2014 (n=5,840)

	Institutions enrolling more than 3% students with disabilities		Institutions enrolling 3% or less than 3% students with disabilities	
	N	% Share	N	% Share
Carnegie Classification				
Baccalaureate	255	38.35%	410	61.65%
Master's	248	38.27%	400	61.73%
Doctoral	28	34.57%	53	65.43%
High Activity	47	49.47%	48	50.53%
Very High Activity	43	40.19%	64	59.81%
Other*	484	11.40%	3760	88.60%
Location				
Urban	468	17.11%	2267	82.89%
Suburban	323	18.61%	1413	81.39%
Town/rural	314	22.94%	1055	77.06%
Sector				
Public	557	29.19%	1351	70.81%
Private non-profit	497	33.24%	998	66.76%
Private for-profit	51	2.09%	2386	97.91%
Type				
Four-year	717	29.99%	1674	70.01%
Less-than-four-year	388	11.25%	3061	88.75%
Total	1105	18.92%	4735	81.08%
Student Services Expenses	\$3,304	-	\$1,752	-
Academic Support Expenses	\$2,519	-	\$1,493	-
Instructional Expenses	\$9,865	-	\$6,440	-
Average Institutional Grant	\$9,956	-	\$4,253	-
Student-to-Faculty Ratio	15.60	-	15.48	-

*Notes: Other includes associate's institutions, special-focus higher education institutions, and Carnegie unclassified institutions.

Institutions enrolling more than 3% students with disabilities and institutions enrolling 3% or less than 3% students with disabilities, by Carnegie classification, location, sector, and type in 2013 (n=5,711)

	Institutions enrolling more than 3% students with disabilities		Institutions enrolling 3% or less than 3% students with disabilities	
	N	% Share	N	% Share
Carnegie Classification				
Baccalaureate	252	37.95%	412	62.05%
Master's	232	35.80%	416	64.20%
Doctoral	21	25.93%	60	74.07%
High Activity	37	38.95%	58	61.05%
Very High Activity	35	32.71%	72	67.29%
Other*	456	11.08%	3660	88.92%
Location				
Urban	428	16.05%	2239	83.95%
Suburban	297	17.59%	1391	82.41%
Town/rural	308	22.71%	1048	77.29%
Sector				
Public	517	27.20%	1384	72.80%
Private non-profit	465	31.19%	1026	68.81%
Private for-profit	51	2.20%	2268	97.80%
Type				
Four-year	673	28.72%	1670	71.28%
Less-than-four-year	360	10.69%	3008	89.31%
Total	1033	18.09%	4678	81.91%
Student Services Expenses	\$2979	-	\$1082	-
Academic Support Expenses	\$2349	-	\$1015	-
Instructional Expenses	\$9369	-	\$6310	-
Average Institutional Grant	\$9573	-	\$4216	-
Student-to-Faculty Ratio	15.86	-	15.83	-

*Notes: Other includes associate's institutions, special-focus higher education institutions, and Carnegie unclassified institutions.



U.S. Postsecondary Students with Disabilities: Where Do They Enroll and Document Their Disability? by Z. W. Taylor and Ibrahim Bicak
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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

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***

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 through 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), Sheila 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 special 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 disabilities. 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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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* by Elisheba Kiru

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Notes from the Field:**Call for 2025 Pac Rim Presentation Proposals:****Pacific Rim International Conference on Disability and Diversity****April 15th and 16th, 2025 • Honolulu, HI, USA • (In Person with Virtual Options)**

Sandra Oshiro

Center on Disability Studies, University of Hawai‘i at Mānoa

The Center on Disability Studies at the University of Hawai‘i at Mānoa is excited to announce the opening of the Call for Presentation Proposals for the 40th Annual Pacific Rim International Conference on Disability & Diversity.

We invite you to Honolulu on April 15th and 16th to celebrate this 40th Anniversary year! Come join us both to honor the past and to consider the future of the global movement we create together. Let’s all recognize our achievements, share our struggles, and develop strategies for the work that remains.

This year’s theme, “By Us and For Us: Legacy and Future of Our Movement,” will highlight the following timely and important conference categories related to disabilities and diversity:

- Adapted Physical Activity
- Disaster Resilience & Built Environments
- Employment
- Early Childhood and Early Intervention
- Health Justice and Equity
- Indigenous Epistemology
- Low Incidence Disabilities
- Neurodiversity
- STEM Pathways
- Emerging Technology

We welcome proposals from researchers, advocates, practitioners, businesses, educators, students, and all who are committed to supporting the full inclusion of people with disabilities and those from diverse backgrounds.

- Priority consideration will be given to proposals received through September 15, 2024.

- Proposals will be anonymously peer-reviewed; acceptance notifications by 11/5/2024.
- **Final deadline for submissions is October 1, 2024.**

For more information on proposals, visit <https://pacrim.coe.hawaii.edu/cfp-2025/>.
Questions? email prcall@hawaii.edu.

Conference registration is now open (with Early bird specials until 12/31/2024):
<https://pacrim.coe.hawaii.edu/registration-2025/>

We look forward to seeing you in beautiful Honolulu next year!

In its 40th year, the Pacific Rim International Conference on Disability and Diversity is the premier global gathering for people committed to improving the lives of people with disabilities. Since 1988, it has been organized by the Center on Disability Studies, University of Hawai'i at Mānoa.



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Dissertations & Abstracts v19i3-4

Sandra S. Oshiro

University of Hawai'i at Mānoa

Abstract

The following provides a listing of select recent citations of dissertations and theses relevant to disability studies.

Keywords: disability, disability studies, dissertations

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