



Whose Research Is It? Reflection on Participatory Research with Women and Girls with Disabilities in the Global South — Xuan Thuy Nguyen

Abstract: *Drawing on the Transforming Disability Knowledge, Research, and Activism project, funded by the Social Sciences and Humanities Research Council of Canada (2016-2020), this article critically reflects on the project’s participatory research process that involved young women and girls with disabilities in the Global South. I discuss epistemological and methodological questions related to the deployment of decolonizing research methodologies in the Global South in relation to theoretical and methodological approaches for engaging girls with disabilities. I argue that a critical, reflexive, and decolonizing research approach that embodies knowledge from the Global South is essential for empowering these girls to express themselves through multiple forms of representation.*

Keywords: *Global South; disability; girls; participatory research; decolonizing*

Introduction

This article reflects critically on the participatory research process in the Transforming Disability Knowledge, Research, and Activism (TDKRA) project, funded by the Social Sciences and Humanities Research Council of Canada (2016-2020), which involved women and girls with disabilities in the Global South. I discuss epistemological and methodological questions in relation to what Indigenous scholar Linda Tuhiwai Smith calls “decolonizing methodologies”—a way of reclaiming Indigenous knowledges by unsettling the colonial knowledge structures that are embedded within the research process by way of claiming, honouring, and revitalizing Indigenous theories and methodologies (8, 144).

In the context of research with young women and girls with disabilities in the Global South, decolonial research is useful for resisting the hierarchy of knowledges embedded within Western theories and methods (Nguyen, “Girls” 64).

This article uses examples from the TDKRA research process to discuss in depth the challenges and possibilities of research *with* young people in the Global South. I first discuss a number of issues that Smith argues are critical for decolonizing research, including ethical considerations about insider-outsider research, in addition to the cultural perception of disability in Vietnamese communities. I then describe the theoretical and methodological interventions of the TDKRA project; specifically, I consider how this approach can be used to empower girls with disabilities in the Global South to tell their stories. I use the term “Global South” to refer to ongoing contested spaces that have been historically occupied by colonial and imperialist forces. The terms Global North/South and Western/non-Western are used interchangeably, depending on the terms originally used by various theorists.

My arguments are threefold: first, as a knowledge practice that has emerged in the spaces of the Global South, the TDKRA project has worked to decolonize the hegemony of Global North epistemologies through its engagement with the voices and perspectives of girls with disabilities in Vietnam. Second, despite our inclusive and participatory epistemologies, we must continuously interrogate our privilege in the process of engaging with participants and communities in the Global South. This includes the ethical considerations that govern traditional research relations, as well as the use of theories and methodologies in knowledge production. Finally, I argue that we must be critical of the politics of “voice” in relation to the institutional conditions that have allowed some voices to be heard while others have remained silenced.

Doing Research in the Global South: Epistemological Inquiries

Doing research in the Global South is an epistemological project that requires the researcher to critically question the ways in which research is planned, organized, and interpreted in particular contexts. Smith argues that theories that inform research are, to a large extent, shaped by Western epistemology (46). Following cultural theorist Stuart Hall, she argues that these theories function as a system of classification and representation that enables fragments of knowledge about the non-West to be preserved, arranged, and represented back to the West. These discourses construct knowledge with real material impacts on colonized

peoples. This colonizing process is reflected in the mechanisms of knowledge production that reinforce unequal power relations between the Global North and South.

Postcolonial theorist Raewyn Connell argues that the process of knowledge production operates according to “four textual moves”: first, the claim of universality (the assumption that knowledge is universal and can be studied from a singular point of view); second, reading from the centre (the assumption that there is one general form of knowledge that can be read from the Global North metropole); third, gestures of exclusion (the exclusion of ideas and knowledge from the periphery); and finally, grand erasure (the elimination of the majority of experiences of those in the South from the foundations of social thoughts) (*Southern Theory* 44). This theory illuminates the exclusion of Global South epistemologies from the foundations of knowledge in a way that renders knowledge from the South excludable.

Connell’s theoretical observations could be used in research with young people in the Global South. As Michelle Salazar Pérez, Cinthya M. Saavedra, and Janette Habashi write in a themed issue of *Global Studies of Childhood*, “Whether in our writing or research collaboratives, when global south peoples have been invited to the table, at times, it’s been with the stipulation of theorizing or giving credit/dominance to global north critical theorists” (80). They argue, then, that despite their privileged positions, theorists from the Global North have not fully captured the complexity of colonial impacts on childhood in the Global South because they speak from their specific localities in the Global North. This theoretical contestation is important for critical childhood studies because it reveals the ways in which knowledge about childhoods is not universal. Rather, childhoods are socially constructed and privileged by Western academic institutions that exclude ideas about and forms of childhood in the Global South.

Nidhi Singal and Nithi Muthukrishna argue that writings on disability and inclusive education *about* the Global South are usually steeped in the colonial “civilizing mission,” with little understandings of the lived realities of disabled children in the Global South (294). Drawing on disability studies in the Global South, they argue that “there is a need for acknowledging that impairment is not always ‘natural’, but it is often the outcome of deeply politicised processes of social dynamics *in* bodies that then become medicalised and then

normalised through a raft of moral discursive and real practices” (295). The domination of Global North theory can be seen in research on “girls with disabilities” as vulnerable bodies, typically portrayed as such in human rights discourses and research published by Western institutions. For example, the bodies of girls with disabilities are usually seen as being “at great risk . . . of violence, injury or abuse, neglect or negligent treatment” (United Nations 4). As such, their inclusion in programs such as humanitarian assistance primarily aims to “reduc[e] their risk for gender-based violence” (Pearce, Paik, and Robles 129). The challenge of such discourses is that they discursively construct these girls as a homogenous social group while ignoring the material and historical heterogeneities of girls with disabilities in the Global South (Nguyen, “Girls” 53).

I argue elsewhere that we must interrogate the cultural locations of knowledge—that is, where knowledge about disability and childhood are read, by whom, from where, and in which particular socio-political conditions (“Critical” 21). This decolonizing practice is critical for childhood studies because, as Pérez, Saavedra, and Habashi argue, “these perspectives can enact knowledge-making that politicizes, unsettles and (re)stories place-based studies of childhood” (81).

Research as an Act of Decolonization: The Transforming Disability Knowledge, Research, and Activism Project

As a postcolonial country subjected to over a century of Western colonialism and imperialism, Vietnam embodies a specific form of political struggle. Its postcolonial struggles for decolonization are manifested in different aspects of Vietnamese socialist policies as well as cultural productions of its healthy body politics. Culturally, Vietnam is home to fifty-four officially recognized ethnic groups in a country of ninety-seven million people (World Population Review). Despite the state’s claim of recognizing diverse ethnic groups, many groups of ethnic minorities have experienced unequal power relations, with the Kinh ethnic majority controlling the political and socio-economic lives of minorities (McElwee 82). Girls with disabilities are multiply marginalized by their social locations. The intersections between and among their disability, gender, ethnicity, and childhood within an ableist, sexist, racist,

and adultist society construct them as some of the most marginalized people in Vietnamese society (Nguyen, Stienstra, Gonick, Do, and Huynh 1050).

Historically, French colonialism constructed disabled childhoods through a gendered, racialized, and sexualized hierarchy which subjugated and essentialized their difference. Under the colonial administration, colonized subjects were infantilized and deemed essential for justifying the colonial power in civilizing Indigenous peoples through its Enlightenment ideologies (Nguyen, *Journey* 146). In the 1900s, the American periodical *Silent Worker* published colonial photographs of disabled girls as representations of gendered, silent, and conforming bodies.¹ The depictions of their traditional clothes and non-normative bodies situated them as exalted subjects in need of curing and normalizing (Nguyen, *Journey* 33).

Culturally, disability in Vietnam is discursively constructed as a stigma resulting from an action that a disabled person is believed to have committed in their previous life. This cultural interpretation is influenced by the Buddhist notion of karma and continues to shape the public perception of disability in many rural Vietnamese communities (Gammeltoft 834). Tine M. Gammeltoft observes that “within the karmic moral world, physical and intellectual impairments are interpreted as forms of misfortune which result from previous moral misdeeds” (834). Disabled bodies are seen as resulting from moral breaches and therefore positioned at a lower status within the Buddhist hierarchy of values. Furthermore, within a traditional kinship system, the difference between disability and normalcy is culturally marked by a person’s ability to perform her traditional roles. To be normal means to be able to handle one’s own life, to sustain relationships, to perform gendered relations, and to be able-bodied. By contrast, to be disabled signals an inability to perform such roles.

Within this normative order, a disabled child is viewed as a misfortune for the family. Parents see their children’s impairments through conflicting ideologies: they express care and love for their children and at the same time view them as defective and inferior to others (Gammeltoft 834). Interestingly, while the Vietnamese ideology of childhood has embodied the idea of becoming—reflected in the cultural expectations of children to grow up and fulfill their gendered roles—a disabled child is seen as bringing shame to the entire family by what might be seen as their “defectiveness” (*tàn tật*). The disability (read as defectiveness) is seen

¹ *Silent Worker* was published between 1888 and 1929, and the images I collected were published between 1914 and 1916. Gallaudet University Archives has digitized their collection of *Silent Worker*.

as constituted by not only an individual's but also her ancestor's past actions. The disabled girl thus culturally represents a shame for the family and community due to the commonly held assumption that because she is disabled, she is amoral, asexual, and thus, unable to perform her reproductive role (Nguyen and Mitchell 329).

Transforming Disability Knowledge, Research, and Activism (TDKRA) aims to tackle the cultural and historical forms of injustice that have been perpetuated in communities in the Global South by engaging disabled girls in Vietnam in developing their knowledge and building potential for their collective activism. We use an intersectional and postcolonial approach to working with participants from various disability communities through participatory research in order to unsettle the boundaries between research and activism and rebuild research relations with communities in the Global South. Our decolonial approach is reflected in different aspects of knowledge production: building partnerships between the research team and Disabled People's Organizations (DPOs) in Vietnam; training women with disabilities to build relationships with and mentor girls with disabilities; using participatory visual research *with* girls with disabilities to tackle their exclusion; and fostering community-engaged efforts to mobilize knowledge across national and transnational borders while ensuring that local communities can raise their voices and awareness (Nguyen, Stienstra, Gonick, Do, and Huynh 1047).

This project was implemented in three communities: Bắc Từ Liêm (an urban district in Hà Nội, in northern Vietnam), A Lưới (a rural district in the central province of Thừa Thiên Huế), and Bình Thủy and Ninh Kiều (urban districts in the southern province of Cần Thơ). These communities are distinct in terms of their socio-economic, ethnic, and political locations. For example, while the communities in Bắc Từ Liêm and Ninh Kiều represent emerging urban spaces with diverse socio-economic conditions, A Lưới is a highly disadvantaged community populated primarily with ethnic minorities heavily affected by Agent Orange—one of the most toxic herbicides, which has caused impairments for many generations in Vietnam.

In our participatory research, we engaged seventy-six girls and women with disabilities in three disadvantaged communities in Vietnam. The girls (between ten and twenty-one years old) played the role of knowledge producers, while the women (between the ages of twenty

and forty-eight) were co-facilitators and mentors to the girls. The majority of our participants came from poor and working-class families. Some older girls had participated in one of our earlier research projects in Hà Nội. They continued to participate in TDKRA to support younger girls and to prepare for their transition to the women's group in later years. The ages of the girls and women overlapped because girls aged eighteen to twenty-one were given the choice of which group they identified and preferred to work with. The girls were the key informants in this research; they worked with the women through their mentoring relationships to build their knowledge and foster collective action.

The girls went to schools in their communities. A few had dropped out and went to the vocational training centres in their neighbourhood. Some girls with intellectual disabilities in Cần Thơ attended a school for children with disabilities during the day and returned home at night. Others stayed at home to take care of household responsibilities. In A Lưới, girls from ethnic minorities went to primary and secondary schools with the children of the Kinh ethnic majority, and they were usually discriminated against because of their minority status. In the Bình Thủy and Ninh Kiều districts, many girls went to special schools for deaf and intellectually disabled children. This reflects the diversity of contexts and social locations of the participants.

Decolonizing Methodologies

As a Global South intellectual project, decolonizing methodologies include a body of research and knowledge that is centred on the recognition of Indigenous struggles against the history and process of imperialism. Research has historically been used as a mechanism of power that othered Indigenous bodies and communities. Its forms of knowledge were produced through a colonial process whereby research was codified and regulated by the colonizers. In contrast to the objectivist paradigm of knowledge production, decolonizing methodologies resist the hierarchy of knowledge structured within Western theory and methods by embracing Indigenous knowledges, epistemologies, and methodologies (Smith 9). Decolonizing methodologies highlight the need to tackle the social relations formed within this process by embodying an inclusive, respectful, and collaborative knowledge practice with regard to Indigenous communities. These discursive practices challenge the colonial structures of knowledge and foster what might be seen as a possibility for transformation (Smith 130).

In line with the decolonizing and emancipatory approach to knowledge production, participatory visual methods are designed to foster social change by shifting power away from the researcher to the researched. This approach aims to empower young people to use research to identify and tackle their own problems. Claudia Mitchell has coined the term “participatory visual methodologies” (PVM) to refer to an ensemble of research methods and tools that use such visual approaches as photovoice, participatory videos, and drawing to engage with marginalized communities (4). To challenge the deficit approach embedded in the Global North constructions of African people and in rural contexts, Relebohile Moletsane uses a decolonial PVM approach in her work on gender-based violence and the AIDS pandemics. She argues that such research methods can assist participants not only in understanding their own situations but also in developing strategies to tackle such challenges (6).

Located within a decolonizing and participatory framework, the use of PVM opens up the possibilities for dialogue and conversations about participants’ issues and concerns through visual art making (Mitchell, De Lange, and Moletsane 23). For instance, drawing is a method that can facilitate “the expression of and engagement with one’s own ideas and understandings of the issue under study” while at the same time enabling “engagement with one another’s work” (24). Mitchell and her colleagues note that this method is particularly useful for research with young children, youth, and adults, particularly in contexts where participants have difficulty expressing themselves in language. Furthermore, drawing not only gives participants immediate access to their self-expression but also helps them to think about action, in so doing acquiring agency and empowerment (25).

Insider-Outsider Research Relations

One of the key challenges for researchers trained in Western institutions is that we have to constantly negotiate our insider-outsider positioning with our subjects’ communities because “our Western education precludes us from writing or speaking from a ‘real’ and indigenous position” (Smith 14). Although the term “Indigenous” and what it means to be Indigenous is contested, Smith suggests that what unites Indigenous Peoples is “the unfinished business of decolonization” (7).

As a Vietnamese researcher trained by Western academic institutions who led a research project funded by a funding body in the Global North, I was put in a difficult position with respect to the communities I was researching. My embodied experiences and identities as a researcher growing up in Vietnam were important in allowing me to engage my participants in more culturally relevant ways than my Canadian colleagues could through the use of, for instance, the Vietnamese language. And yet my genealogy as a researcher who currently resides in the Global North reminds me that I must constantly reflect upon my own positioning as constantly shifting, depending on the community in which I participate. In many instances, I found myself being positioned as an outsider in these communities due to my distinct accent from Central Vietnam along with my socio-economic class and able/disabled status.

There were contested spaces in which I found myself speaking *with* the communities while at the same time embodying the (inter)disciplinary practices codified by a certain set of protocols regulated by the Western academy. Specifically, the Western hierarchy of knowledge places its focus on the need to minimize the “harms of research” to participants while engaging little with the values and relationships of the participants’ communities (Canadian Institute 7). For example, although the Tri-Council Policy Statement (TCPS2) issued by the Canadian Institute of Health Research, the Natural Sciences and Engineering Research Council of Canada, and the Social Sciences and Humanities Research Council of Canada asserts respect for persons, concern for welfare, and justice as the key principles of research ethics, it deals little with any relational aspects of community in the Global South. Hierarchical family structures within Vietnamese rural communities, for instance, required not only the researcher but also other community members from my partnered institution to meet with parents and explain the research procedures to them so as to gain their trust before working with their children. Furthermore, some girls could not fully participate in the workshop because they had to take care of their siblings or do housework. Interestingly, while this may be seen as a form of “child labour” according to Western framings of children’s rights, the girls expressed their need to care for their family members as a duty that they felt important to fulfill.

In the research process, it is interesting to read these cultural norms through the relationships between the researchers and the local communities. Specifically, while the

communities showed respect to me and my colleagues through such communal practices as food-sharing and storytelling, they were conscious of my social position as an outsider. For example, when asked about the kinds of barriers that they faced in their lives, participants avoided blaming the government or local authorities for failing to address their needs. While this practice could be traced back to the hierarchical structures within communities heavily influenced by Confucian ideologies, their consciousness of my social position and relationships with them was poignant. It is a reminder that we need to decolonize the researcher's knowledge and expertise, recognizing that our participants have long established cultural competencies and relationships—well before the researcher engages with their communities.

There were also power dynamics between the girls and their parents, the girls and the women, and among the girls themselves. For example, some girls found important sources of support and encouragement from the women. Some girls had difficulty expressing themselves when they felt “surveilled” by their facilitators. For example, there were instances when the girls hesitated because they feared saying something inappropriate that could be “corrected” by their mentors. This is interesting because it reflects the power dynamics between children and adults that tend to be sidelined in research with women with disabilities. Furthermore, cultural prejudices against disability, a highly prevalent factor in many communities in the Global South, reinforced these power dynamics. Yet this prejudice is rarely among the ethical considerations for a research project. The importance of considering cultural prejudice became clear on the first day of our fieldwork in 2017 when a parent came to the workshop with a concern that her daughter was not “disabled”—meaning she had “nothing wrong” in her body and mind—and thus her daughter should not participate in the project. The fear of stigmatization present in this parent's concern suggests that being identified as a “girl with disabilities” would reinforce prejudice against not only the girl but also the entire family.

In TDKRA, we asked the participants to contribute to a research process designed to create multiple spaces for their voices and engagement. Before we began recruiting participants, we organized information sessions with educational authorities, teachers,

community members, and women's associations in each community. In each community, we brought together twelve to fifteen local girls and worked with them over a period of three years. Consent was given every year to ensure ongoing voluntary participation.

In the first phase, the women took part in a five-day training in participatory research methods. They then worked with the girls to facilitate the participatory process, including visual productions of cellfilms and drawings. As a part of this reflexive process, we invited participants to display their drawings in their workshop space. The girls engaged in self-reflexivity by viewing their own pictures as well as those of others during a walk-about. They then worked together to identify common themes and issues that they were encountering in their lives. This participatory process allowed participants to be self-reflective and engaged (Mitchell 58).

In the second phase, the women conducted interviews with the girls, who shared their stories and experiences with inclusion and exclusion. The participants continued to produce visual products such as photovoice and contributed their ideas to a filmmaking process. A film was produced through the collective work of the research team and our partners, the women and girls, and a group of professional filmmakers. In the final stage, their productions were displayed at multiple public sites as a way of representing their ways of seeing. Stakeholders from the government, Non-governmental Organizations (NGOs), community leaders, teachers, and media agencies were invited to engage in dialogues with the girls. This process of public engagement created participatory spaces for self- and collective consciousness that fostered transformation within their communities and public institutions at large (Nguyen, Mitchell, De Lange, and Fritsch).

In what follows, I use examples from the visuals produced by girls with disabilities to exemplify the potential that participatory visual research informed by decolonizing methods has to engage the perspectives of girls with disabilities in the Global South. While this is not meant to be exhaustive, it demonstrates how researchers, through the embodiment of Global South theories and decolonizing methodologies, can create more inclusive and accessible spaces for disabled girls' participation and, in so doing, disrupt the colonial constructions of their silences and vulnerability.

“What’s It Like to be a Girl with Disabilities?”

The first phase of fieldwork asked the girls to self-reflect through a thirty-to-sixty-minute drawing workshop. We invited the participants to reflect on their identities through the following prompt: “What’s it like to be a girl with disabilities?” Each girl who chose to draw was free to draw whatever they liked in response to the prompt. Some girls chose to write captions for their drawings, while others did not because writing was not always accessible to them. We then invited the girls to display their drawings to their group, which their peers viewed through a “walkabout” in order to get a more holistic view of the collection. Their drawings were published in a catalogue entitled *Envisioning Inclusion* (Nguyen, Miron, Rahim, Dang, Mitchell, and Nguyen). The catalogue was printed and given to the girls, their families, and their community members, enabling the participants to take ownership of their own products.

This demonstrates that drawing is a relatively accessible technique that allows participants to position themselves in relation to others in a culturally engaging way. Their stories were more imaginary representations of what the participants desire to have in their lives. The participants drew images of their homes, families, schools, public parks, and landscapes within their communities. Interestingly, instead of drawing themselves alone, they drew themselves with friends, teachers, and family members. The drawings expressed a strong sense of community and a desire for building social relationships.

The drawing in figure 1, by Hoa Ly, is of two girls in a public park. There are trees and benches on both sides of the pathway. One girl is using a wheelchair and the other girl is standing next to her. Their gesture of hand-holding suggests their friendship and willingness to support each other. Interestingly, the artist chose the colours blue and orange for the wheelchair and the dress, drawing attention to the presence of disability in public. The caption says, “...people with disabilities can help each other. We can help each other to go to the park.” This suggests that disabled people need help from their non-disabled peers in order to access such a space. Ly’s drawing sends a loud and clear message that disabled people need to be recognized as integral members of their community and that disabled girls need to be more visible in public spaces.



Figure 1: "Hanging out in the park," created by Hoa Ly, age 19
(Hà Nội, 2018).



Figure 2: "My break-time," created by Phu Dien, age 12
(Hà Nội, 2018).

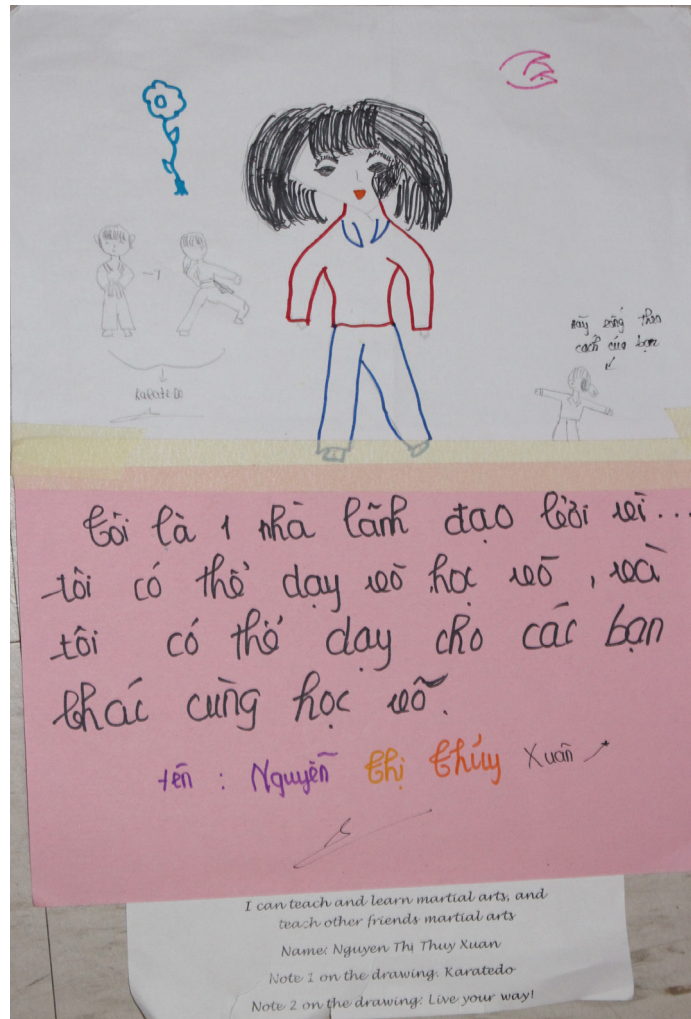


Figure 3: "I Am A Leader Because..." arts-based workshop created by Linh, age 13 (A Lười, 2019).



Figure 4: A walk-about in a community display in Bắc Từ Liêm district (Hà Nội, 2017).

In contrast to Hoa Ly, Phu Dien depicts the relationships between boys and girls in school in her picture (see fig. 2). Standing next to a tree is a girl. Her head faces down and is turned away from the viewer, suggesting that she feels sad because no one is playing with her. The arrow pointing to her shows that she is “a disabled person.” At the bottom of the drawing is a girl turning her face to the viewer. While the drawing does not show that she is disabled, the heart-shaped bubble on the left side reads: “I want non-disabled people to play with disabled people like me.” Phu Dien’s drawing (see fig. 2) suggests that she wants to play with friends, and yet, she is marginalized from others.

When asked what she wanted to say with the drawing, Phu Dien replied: “. . . I drew this painting because it is related to women and children with disabilities. I want disabled and non-disabled children to see the drawings so that disabled children will not feel inferior and will integrate with non-disabled children.” In her interview, Phu Dien said, “I think there are some people who scorn people with disabilities, like ‘she is person with disability, certainly she can’t do [things that an able-bodied person can].’” She talked about this in terms of discrimination. When asked how she would react to this situation, she replied, “If I were in this situation, I would try to do it to make them not discriminate against me anymore.”

Phu Dien sent a clear message to the non-disabled community: “I expect that community not to scorn people with disabilities using wheelchairs. . . . I don’t want to be scorned by others and I don’t want people with disabilities to be scorned. Scorning people with disabilities means scorning us because we are also people with disabilities” (TDKRA 0:11-0:24). By engaging girls with disabilities in telling their stories, a participatory visual approach enabled them to identify their shared problems of exclusion and work together to tackle the problems.

The art produced by the girls also expressed a transformative way of being girls with disabilities as a way of countering ableist assumptions about their abilities. The art in figure 3 was produced within a workshop entitled “*I Am a Leader Because...*,” which we organized as a part of our community engagement events in 2019.

In her art, Linh drew an image of a girl practising martial arts (see fig. 3). The girl’s posture makes her look strong and energetic. Linh carefully sketched a birthmark on the girl’s face as a unique representation of her embodiment. This birthmark was remarkable, as it reflects

how she identified herself as a disabled girl with strength and beauty. On the left-hand side of the picture is a karate match between a boy and a girl, assumed to be Linh's representation of herself. In her karate uniform, the girl demonstrates strength through moving her body, ready to get on the stage, while the boy looks not yet ready to engage in the match. Linh's depiction of this gender relation is interesting and telling. This visual representation challenges essentialized assumptions about disabled girls embodying vulnerability. Instead, this representation conveys the girl's desire to act firmly and confidently. On the right-hand side of the picture, the girl once again depicts herself as moving her body freely and relaxingly. The caption within the drawing reads "Live in your own way," reflecting her desire to challenge gender and disability discrimination. The caption underneath reads "I am a leader because I can teach and learn martial arts and teach martial arts to other friends."

Figure 4 illustrates the walk-about step within a community engagement event, where the participants, family members, teachers, and community leaders are engaged in a viewing and reflective process.

The art productions demonstrated disabled girls' capacities to imagine themselves through visual production and, in so doing, fostered their participation, engagement, and self-transformation. This approach opens up a decolonial space for rethinking justice in the Global South.

Decolonizing Methodologies: Whose Research Is It?

Questions such as "Whose research is it? Who owns it? Whose interest does it serve?" and "Who will benefit from it?" are critical because they shed light on the political implications of knowledge production (Smith 10). The participation of girls and young women with disabilities in the TDKRA project reflects this politics of research because it illustrates how communities in the Global South can participate in reclaiming their knowledge. While many girls demonstrated their transformative experiences by expressing how they have changed over time, Smith reminds us of the ways in which theory and research methods are part of an imperialist project:

One of the problems . . . is that the methodologies and methods of research, the theories that inform them, the question which they generate and the writing style they employ, all become significant acts which need to be considered carefully and critically before being applied. In other words, they need to be “decolonized.” (41)

The TDKRA project is a new way of doing research. It aims to disrupt the ways in which knowledge has been privileged by Western academic institutions by working *with* and *from* the perspectives of girls and women with disabilities in the Global South. Its participatory and decolonizing approach has engaged with their voices through multiple forms of representation. We created dialogues on inclusion and exclusion with girls and women with disabilities in their local communities, recognizing the intersectional oppressions in relation to their class, gender, age, ethnicity, and disability status. The intersections among these categories of difference shed light on the heterogeneity of disabled girls’ voices and discourses. They also require us to understand the cultural, political, and historical forces which silenced them.

To some extent, this intersectional and decolonial approach has been successful in unsettling the traditional power relations between researchers in the Global North and participants in the Global South. Its capacity to reclaim knowledge about girls with disabilities in the Global South reinvigorates dialogues on disability, girlhood, and social institutions. The discourses and representations of girls with disabilities exemplified in this article suggest that critical, reflexive, and decolonial research can lead to change in the lives of young people in the Global South. By engaging young people and their communities in dialogue, this type of research can open up a critical space for girls with disabilities in the Global South to reframe their knowledge.

At the same time, we must be critical of this research approach because a failure to do so would be a missed opportunity to unpack the complexity of power relations in a research process. As the lead researcher, and cognizant of my insider-outsider relationships with the participants and their communities, I was required to constantly reflect on and renegotiate my power relations with participants. I must take into account the contextual and conflictual

power dynamics between my lived experiences growing up in the Global South and my academic training in research in the Global North to keep me informed of my epistemological inquiries. That is, how could I make sense of my participants' perspectives from my social locations?

Southern theory reminds us that we must situate our research within the spaces and epistemologies of the Global South as a central place for repositioning the global dynamic of knowledge production (Connell, "Southern Bodies" 1372). The spaces in which I am situated to frame this research across the Global North and South are complicated because they are fluid and constantly changing. Walter D. Mignolo and Catherine E. Walsh argue that decoloniality seeks to "make visible, open up, and advance radically distinct perspectives and positionalities that displace Western rationality as the only framework and possibility of existence, analysis, and thought" (17). This politics of knowledge is situated within the transnational contexts in which colonialism and imperialism have produced and reproduced marginalized, invisible, and excluded bodies.

The findings of the TDKRA project reflect the global dynamics of impairment embodied within the participants' personal experiences. For example, many girls and young women had intergenerational experiences with impairment due to their family being exposed to Agent Orange during and in the aftermath of the Vietnam War. They had traumatic experiences resulting from their impairments and the associated pain. Their embodied experiences reflect the impact of the global dynamics of colonial and imperialist powers on young people with disabilities in the Global South.

Interestingly, at the same time as we commit to unsettling these relations of power, we are institutionalized within the discursive practices that govern our research relations. Specifically, while the ethical guidelines of research institutions located in the Global North, such as the TCPS2, are based on the principles of human rights, which value individual autonomy to participate and to prevent harms against individual participants, it seems that these principles and guidance are highly individualized and tend to disregard the social contexts in which the right to consent is highly mediated by existing power structures. These include parental and communal power relations, as well as the forms of power that may be reinforced through

Western research. We need to go beyond the traditional ethical standards as prescribed by our research institutions to re-engage with research as an ethical research process in which we hold ourselves accountable to the well-being of communities in the Global South.

From my experience, having moved across colonial and imperialist spaces, my identity as a researcher growing up in the Global South has been fluid and contextual, reflecting the need to acknowledge the unequal power relations among the research team, local organizations, and the girls and women with disabilities. In the research process, these power dynamics ranged from matters such as the distribution of research funding, planning research timelines and meeting agendas, ensuring that the perspectives of my partners be heard and respected, and finding ways to implement their proposals and suggestions through fieldwork planning and organizing. There were times when we had to negotiate and challenge ourselves to be truly respectful. These aspects of the research process were most often “behind the scenes” and not reflected in what might be seen as “research data.” And yet they were equally important for a decolonizing research process.

Participatory Visual Approach and the Politics of Voice

A decolonial PVM approach has provided a useful tool to engage girls with disabilities in the Global South (Nguyen, “Girls” 64). This approach made visible the invisible experiences of disabled girls from their own perspectives. For example, a clear message found in the participants’ drawings is their need to build relationships with friends and communities. They expressed their perspective on inclusion by making themselves visible in public spaces. A critical approach to PVM requires us to understand the context in which colonialism and imperialism have excluded them from different aspects of social, political, and community participation. It enables us to rethink the politics of disability and girlhood through the symbolic representations by which the girls chose to express themselves.

The voices of girls with disabilities in the Global South, however, are not monolithic. The multiplicity and heterogeneity of their subjectivity must be recognized. For example, some girls with intellectual disabilities appeared to be silent when encountering questions that required them to explain their thoughts verbally or in writing. They participated well

in various spaces but were limited by their verbal expressions. This reflects the need to interrogate epistemological assumptions underlying the idea of voice. As E. Kay M. Tisdall argues, “Focusing on voice privileges comprehensible verbal utterances over other forms of communication, which risks excluding children and young people who communicate little or not at all through speech . . .” (185). That is, our focus on voice not only runs the risk of misinterpreting the participants’ perspectives but also potentially reinforces ableism through the research process.

Ableism is a system of knowledge that assumes compulsory able-bodiedness as a precondition for participation. It perpetuates oppressions against disabled bodies because of their difference from able-bodied norms (Campbell 6). In the context of research, ableism may be reflected in the ways we design and implement the research process. For example, how we organize research time, use prompts and language, and structure research sites may make research inaccessible to participants and create and reinforce ableism. Thus, while PVM may be useful to engage with the voices of girls with disabilities in the Global South, we must question the ableist assumption about voice as being merely about verbal expressions (Tisdall 185).

Furthermore, we must be mindful of the politics of voices in the context of the Global South in relation to its emancipatory endeavours. As postcolonial theorist Gayatri Spivak reminds us, the idea of giving voice to those who have been systemically excluded by colonial and imperialist practices is extremely challenging. Spivak points out the problems underlying this politics of representation. There is a tendency for the intellectual to speak *for* the subject without recognizing the intellectual’s ideological position (70). This politics of the oppressed, Spivak argues, “can hide privileging of the intellectual and of the ‘concrete’ subject of oppression . . .” (87). I cannot, therefore, speak for the participants in the Global South in a totalizing manner or assume that my politics of representation is transparent. I must, rather, understand the limits of my intellectual inquiry in relation to the politics of research in a context where knowledge has continued to be governed, disciplined, and normalized by Western academic institutions. This reflects a need for researchers to understand the systemic dimensions of power in the context of research in the Global South.

Conclusion

This article has provided critical reflections on a participatory process that engages girls and women with disabilities in the Global South. Building on my experiences with the TDKRA project, I have demonstrated the ways in which research *with* young people could be reflexive, critical, and decolonial. TDKRA has aimed to resist the confluence of colonial and imperialist contexts by engaging girls with disabilities, creating spaces for their inclusion, fostering their leadership and activism within their respective communities, and involving girls and women with disabilities in the forging of strong relations. We have further pushed against traditional research methods and sought to implement decolonial methodologies by way of epistemological engagement with Global South representation. This article suggests that while research has been historically disciplined by Western academic institutions, a critical, reflexive, and decolonizing research approach is essential for empowering young people in the Global South to express their voices and perspectives through multiple forms of representation.

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