

## **Engaging girls and women with disabilities in the global South: Beyond cultural and geopolitical generalizations**

Xuan Thuy Nguyen<sup>a\*</sup> & Deborah Stienstra<sup>b</sup>

<sup>a</sup>Carleton University, Canada; <sup>b</sup>University of Guelph, Canada. Corresponding Author- Email: [XuanThuyNguyen@cunet.carleton.ca](mailto:XuanThuyNguyen@cunet.carleton.ca)

This article invites readers to engage with girls and women with disabilities in the global South. It challenges the epistemological domination of Western disability studies in Southern bodies and contexts, and provides one specific way to read the intersection between disability, gender, and ethnicity in the context of Vietnam. Drawing on the politics of engagement developed within the Transforming Disability Knowledge, Research, and Activism project, we argue for recognizing the lingering impacts of colonialism and imperialism in producing disability and impairment in the South, while suggesting new ways of engaging with disabled girls and women through the use of inclusive, decolonial, and participatory methods.

**Keywords:** disabled girls; Vietnam; colonialism; imperialism

### **Introduction: Critical disability studies as a discursive practice**

This article invites new ways of ‘unsettling’ the epistemic foundations that privilege global Northern disability studies and theory. In his provocative challenge of Eurocentric disability studies, Grech (2015) challenges readers to rethink the political meaning of ‘the colonial’ (6). He argues that the colonial is usually deployed as a metaphor about subjugation and domination of the colonized subject. But these theorists, he goes on to note, rarely account for the historical events that gave rise to such metaphor. Colonialism created differential lived experiences between the colonized and colonizer. The colonial, then, is an historical process that marks relations of domination, subjugation, and disablement on Southern bodies within contested spaces occupied by colonial and imperialist forces (Erevelles, 2011; Connell, 2011; Soldatic and Grech, 2016).

The shift to a multi-layered understanding of the contingencies and intersectionalities of disability and power dynamics has signified greater diversity of disability accounts. Chaudhry (2018:76) calls attention to ‘intersectional privileges’, reminding readers of the complexities of disability research within a post-colonial context. Instead of seeing disability identity and culture as static, she argues for a need for the ‘processual doing of culture’ (74), a process by which engagement with disabled participants is informed and facilitated by the researcher’s

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reflexivity on and consciousness of the changing and evolving human relationships that are enacted within and through the research process.

As a discursive and material practice that produces social relations, disability studies is historically privileged from its origins in the global North. Research, as a discursive practice, is historically codified, governed, and disciplined by colonizing institutions (Tuhiwai Smith, 2013). While Northern disability studies can produce knowledge that is valuable within its own distinctive political contexts, when applied to the South, it reproduces a new form of ‘epistemic injustice’ (Tremain, 2017: 175) that fails to recognize epistemological and contextual dynamics in the South. Grech (2014) observes that these Western disability studies writings are usually framed by two patterns. The first is a virtual absence of disabled lives in Southern spaces. The second is a complete disengagement with Southern epistemologies and work produced by Southern disability theorists. This politics of exclusion, he argues, ‘reflects the continued dominance of Western knowledge, practices and institutions, the unfettered control over what counts as knowledge, and how it is produced, by whom, and how it should be disseminated’ (50).

And yet, the transposition of Western disability studies onto the global South has reinforced what Meekosha (2008:2) has identified as a form of ‘scholarly colonialism’ in that disability studies from the global North tends to assume that Northern disability studies is universal. She challenges the hegemony of global Northern disability studies, calling attention to centuries of colonialism with disabling impacts on Southern bodies: ‘We need to develop southern theory of disability that challenges the implicit values and concepts of contemporary disability studies and includes the lasting impact of colonialism’ (15).

Connell (2007) argues that Southern theory – a body of intellectual projects that emerged from the global South – has potential to shift this power relationship through decolonial forms of knowledge production. When applied to disability studies, Southern theory can illuminate the disabling impacts of capitalist social production and its productions of impairment in a transnational context (Connell, 2011; Nguyen, 2018). As such, Southern disability studies theorises the relationships between social dynamics and the body, and how gendered, disability, and racial relations are structured by colonial and capitalist processes of development.

Southern disability studies engages with discursive and political practices that shape what might be called ‘radical vulnerabilities’ (Kim, 2014) through contested colonial and post-colonial spaces. Kim (2017) observes complex relations of power that took place in modern Korea through the Japanese imperialist victory over the Choson dynasty in early 1900s. She illuminates how disability has been used as a vehicle of national politics without doing justice to disabled bodies within the nation. And yet, she argues that ‘it is too easy to imagine the Korean culture of disability as different from that of the West, owing to stereotypical generalizations of East Asian culture, or to attribute gendered violence against disabled persons

to some preconceived notions of Korean cultural difference' (230). At issue, she asks, 'who speaks of these differences to whom, for what purposes, and in what location?' (230).

In this article, we describe the politics of engagement developed by the Transforming Disability, Knowledge, Research and Activism (TDKRA) project in Vietnam. We discuss how girls and women with disabilities framed their perspectives on disability, access and inclusion and their capacity to resist power and take leadership in ways that respond to their local needs and demands. These forms of local activism enable them to become a catalyst for change in their own communities.

### **TDKRA project and the politics of engagement**

The TDKRA project is both a research project and a participatory engagement process with girls and women with disabilities in three communities in Vietnam: Binh Thuy and Ninh Kieu (Can Tho City), A Luoi (Thua Thien Hue Province), and Bac Tu Liem (Hanoi City). During this four-year project between 2016 and 2020, we developed our politics of engagement through participatory research methods, critical thinking, and relationships with girls, women, communities, Disabled Peoples' Organizations (DPOs), researchers and activists. Engagement is to participate, be involved in, and create meaningful connections. It also means addressing historical forms of injustice including those resulting from colonization, global capitalism, ableism and patriarchy. For this project, the goal was to engage girls and women in identifying their experiences of inclusion and exclusion in their schools, families, and communities, and to act in response.

### **Context**

As a post-colonial country with over a century of Western colonialism and imperialism, Vietnam embodies a specific form of political struggle from the global South. Culturally, Vietnam is home to fifty-four officially recognized ethnic groups in a country of 97 million people (World Population Review, n.d.). Despite the state's claim of recognizing diverse ethnic groups, many ethnic minorities groups have experienced unequal power relations with the Kinh ethnic majority group, who control the political and socio-economic lives of the minorities (McElwee, 2008; Turner, 2012).

While the Vietnamese disability movement has rarely identified colonialism as a specific condition that shapes their socio-political struggles, colonialism has influenced all aspects of policies, culture, and social hierarchy. Under the Confucius ideologies brought to Vietnam under the Chinese rules, for instance, women and girls are seen as subordinate to a structure of male patriarchy (Knodel et al., 2004). Colonialism and imperialism also produced disability and impairment in distinctive socio-political and cultural contexts. For example, some of the most challenging impacts of the US-Vietnam war are evident in the embodiments of disabled

women and girls in Vietnam across generations.

Girls and young women with disabilities in Vietnam, including those from ethnic minority groups, have been largely invisible in these cultural dynamics. They represent a contrast to how the state represents its body politics in the context of development. That is, the portrayal of the healthy body politics of the nation is in sharp contrast to the bodies of girls and women with disabilities, marked as dependent, weak, unhealthy, and vulnerable. Many girls and young women in the TDKRA project are second or third generation of those exposed to Agent Orange. Interestingly, while the state has developed social policies that claim to support ‘victims of Agent Orange’, it has at the same time adopted new forms of eugenics. This includes a law to implement technologies of screening, testing, and diagnosis to reduce incidences of disability and improve the quality of the population (Gammeltoft, 2007). While the impacts of the war, globalization, and the local politics of disability vary across Vietnam, the central regions, including the community of A Luoi with whom we work, have experienced more daily challenges especially from the use of Agent Orange (Ngo et al., 2013).

TDKRA emerged as a way of tackling the lack of knowledge about and by girls with disabilities in the global South. As an interdisciplinary team, we recognize a need to engage disabled girls and women in the global South in shaping their knowledge through participatory, decolonizing, and community-engaged knowledge production as the key driving force for TDKRA to transform traditional approaches to knowledge production (Nguyen et al., 2019). This approach aims to tackle the ways in which voices from the global South are historically silenced, and when researched, they are interpreted or appropriated from perspectives of researchers from the North without considering relations of power between the researchers and the researched. We also engaged disabled women and girls in the global South in strengthening their advocacy by building connections, mobilizing their networks, and creating potential for change.

## **Methodologies**

As a collaborative research project, TDKRA brought together researchers in Canada and South Africa, with partner organizations and individual girls and women with disabilities in three communities. The research team involved researchers in disability studies, human rights, inclusive education, political science, and childhood/girlhood studies. In each community, TDKRA partnered with a Disabled Persons’ Organization (DPO). Their role was to contribute to making project decisions, organize the local fieldwork, and reflect on their activism in addressing disabling issues in their own communities.

Over the four years of fieldwork with researchers and additional local gatherings, we engaged 54 girls and 31 women with disabilities in the three communities. The girls (10-21 years old) played the role of knowledge producers while the women (20-53 years old) participated in the research training as co-facilitators and mentors of the girls. That is, while 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 actions. Participants were equally spread across the communities with 16 girls (30%) from Hanoi, 20 girls (37%) from Hue, and 18 girls (33%) from Can Tho. Many participants came from rural and disadvantaged backgrounds. The majority of participants (34 girls or 63%) from Can Tho and Hanoi identified as Kinh people (the majority ethnic group in Vietnam), while 19 girls (37%) from Hue belonged to ethnic minority groups (7 Paco and 12 Ta Oi).

Most of the girls (and women) had no exposure to the global Northern social model of disability, and with our commitments to deep listening and decolonization, we asked participants to share with us experiences from their everyday lives. As a team, we were also aware that we needed to use methods that enabled girls with diverse interests, skills and abilities to share their knowledges. With that in mind, we combined participatory arts-based methods such as drawing, cellphilmaking, photovoice, participatory film-making, with community asset mapping, interviews, focus groups, and media analysis. Participants also reflected on the results in public gatherings which included family members, community members, organizational and government representatives. The combination of different participatory methods enabled the participants to engage in different ways.

Prior to the initial fieldwork, the questions and protocol were reviewed and approved by university research ethics boards of the Canadian researchers. For each fieldwork, we developed questions in collaboration between the researchers and representatives of partner organizations and with input from the women with disabilities. Researchers provided the women with some training in focus group and interview techniques and the women practiced their skills with one another before meeting with the girls. In interviews with the girls with disabilities in 2018, the women began by asking about the girls' lives and their family contexts, and then moved to questions about inclusion and exclusion in the context of schools, family relationships, friendships, and jobs. They also asked about changes the girls experienced through the TDKRA project. The facilitators supported the girls by developing relationships with them and building their advocacy and leadership skills. They also assisted with data collection through participatory research methods.

Throughout the field work we also had group discussions, facilitated by the research team, during which the women with disabilities shared their experiences on disability, inclusion, and exclusion. We asked, for example, the women to share their own stories as well as how they thought their mothers and grandmothers understood disabilities. This helped us to understand their disability experiences within their own contexts.

In this article, we draw on data from the interviews and cellphilmaking- short videos made using cellphones (Mitchell, De Lange, and Moletsane 2017)- produced by girls and women with disabilities to provide some in-depth discussions on the participants' perspectives on disability, access, inclusion, and exclusion.

### *Ethics*

TDKRA uses research as an act of decolonization. Decolonizing methodologies resist the hierarchy of knowledge structured within Western theory and methods by embracing Indigenous knowledges, epistemologies, and methodologies (Smith, 1999). A part of our ethical considerations was rooted from and in response to families and communities' concerns about the social situations of the girls with disabilities. We engaged with community members in every stage of our local fieldwork and developed a collaborative relationship with the local community members, including Disabled People's Organizations. The women and girls, as well as the girls' parents were invited to sign an informed consent form annually to ensure that they can withdraw from the project at any time during the project. The informed consent forms also enabled the participants to grant permission for using their interview data, focus groups, films, and photos. The women also assisted the team in explaining to the girls aspects of visual ethics (Mitchell, De Lange, & Nguyen, 2016), ensuring that the girls could take ownership in the visual data that they produced.

### **Findings**

#### *Perspectives of disability*

Participants expressed divergent perspectives on disability based on their lived experiences and social locations. While both women and girls with disabilities shared their experiences as persons with disabilities, their perspectives on disability varied. The women with disabilities associated disability with 'accidents' and 'misfortune', while also attributing their impairments to a lack of access to care, livelihood and employment. By contrast, girls with disabilities experienced negative perceptions of disability due to the ways they were teased, bullied, marginalized, and excluded by peers. Both women and girls shared their experiences being laughed at by their peers. When asked how the participants understood their disabilities, some women described their disability as inborn or from birth, while others saw it as a lack of access to treatment that prevents a person from performing their daily activities.

Pai, an ethnic minority woman in A Luoi, expressed her understanding of disability:

Pai: I think that we got an accident with broken limbs ... that is a disability, being affected with Agent Orange is also a disability. That's how I understand about disability.

Facilitator: Can you explain it more clearly?

Pai: People often laugh at people with disabilities like me. I am a person with disabilities since I was born. Actually, no one wants to be a disabled person, for example, you got an accident that broke your leg, not because you wanted, but it was a bad luck.

Another ethnic minority woman, Ngo, saw disability, as a 'disease', and in the context of the

Agent Orange, which spreads from generation to generation:

I think about disability in another aspect. For example, the disease is caused by a fever, or a catastrophe is also a disease, you need to go to the hospital for treatment. Or mothers with disabilities may give birth to children with disabilities. For example, blindness, which is not inborn, but by accident and parents do not have money to treat their children, then their children become a person with a disability. It is also a disease, just like a normal person who has a catastrophe. It is very few inborn people with disabilities. The parents who suffered from Agent Orange may give birth to the children with being paralyzed or being disabled in the leg and arm. In general, there are many types of diseases such as inheritance, from mother to children.

Pai illustrates how she sees disability as a negative experience caused by social discrimination and as bad luck for a person with such an experience. In contrast, Ngo saw disability as not inborn but rather a consequence of multiple factors including the lack of access to health care, which caused children to be disabled. They both identified Agent Orange as a condition which caused impairments. Another woman from this region, Ms. Xuan, a grandmother of a girl with intellectual disabilities, discussed the ongoing impacts of Agent Orange:

Every member in my family is the victim of war. I want the policymakers to increase the salary requirements to raise my grandchildren because they are affected by the Agent Orange. I think everyone wants that as well. It affects 2, 3 generations, not just 1. Now you can see plenty of trees but in past, they weren't there. From the years of eighty, the new trees began to grow little by little. Trees were also affected by toxic, not to mention were human beings. In general, this area and mountainous areas in QT is completely poisoned. In the plains, they evacuated local people to find the Viet Cong. Not only me but also everyone wants to increase the allowance for the victim of Agent Orange.

Here, she describes disability as a consequence of war, with the toxic spray of Agent Orange causing suffering for many generations. A veteran with visual impairment, Ms. Xuan participated in every project workshop. While her participation was informal at the beginning, she engaged with us in discussions about disability and community. Her stories vividly illustrated the real impacts of Agent Orange on every member of her family- her husband, son, granddaughter and grandson, and her community.

Like many girls and women from this region, Thao's family members, including her father and brother, were affected by Agent Orange. As a disabled girl growing up poor, she experienced class and disability discrimination. Even though they received some small subsidies for 'victims' of Agent Orange from the local government, her family was still often in debt. They borrowed money from the bank to raise cattle and grow cassava and pay for her tuition fee for school. She said: "I am sad because we lack money to pay the debt and to pay [my] tuition."

Hien, another girl from an ethnic minority, shared her experience being teased:

Facilitator: Are you an ethnic minority?

Hien: Yes

Facilitator: Do you think that because you are an ethnic minority, so they bully you? Are they also ethnic minority?

Hien: I think they treat me like that because I am weak or they hate me.

Hien and Thao linked their negative perceptions of disability to their experiences as ethnic minority girls, using words such as ‘hate me’ to illustrate the emotional violence they experienced.

In contrast, Hom Hinh, from Bac Tu Liem and not part of this minority group, talked about disability in terms of disabled people’s capacity to function a different way and recognized the diversity of disability:

Hom Hinh: ... not all people with disabilities are the same. There are many people with disabilities, they still can work, can study, can have jobs like able-bodied people, even some people with disabilities are better. Maybe there some tasks that they cannot do by the same way like able- bodied people, they can do by other ways. This is my opinion.

We saw a change in how some participants perceived disability over the four years of TDKRA as they were able to find their circles of connection. For example, in a later comment, Hom Hinh showed her changed perspective on disability:

I expect community not to scorn people with disabilities using wheelchairs that they can’t stand up by their legs. I don’t want to be scorned by others and I don’t want either people with disabilities to be scorned. Scorning people with disabilities means that they look down on us because we are people with disabilities and we don’t want to be like that.

### ***Perspectives of access and inclusion***

The disabled girls and women identified various barriers to access and inclusion through their drawings, interviews, focus group discussions, and community engagement when they talked about what they hoped to achieve. Many girls experienced being looked at and treated differently which made them feel excluded. Their perspectives link their experiences of being marginalized because of their difference and how they feel about that. For example, Meo Nhi talked about feeling different from her peers because of the ways her disability is treated:

Facilitator: How do you feel about your disability?

Meo Nhi: I feel the difference.

Facilitator: What is the difference?

Meo Nhi: My arm.

Facilitator: Does it result to any other difference?

Meo Nhi: People in school are not disabled, I feel lonely.

Meo Nhi suggests that she feels she is different from others because of the way others acted in response to her impairment. Many girls shared this feeling of isolation and powerlessness because of their exclusion. Phu Dien makes the link between exclusion and discrimination at the community level:

Facilitator: Do you think community has taken care of people with disabilities?

Phu Dien: I think there are some people who scorn people with disabilities, like “she is person with disability, certainly she can’t do”.

Facilitator: What do think when everyone thinks “she is person with disability, certainly she can’t do”?

Phu Dien: I think they are discriminatory. And if I were in this situation, I would try to do it to make them not discriminate against me anymore.

As one of the most important things to tackle this discrimination, the girls expressed a need for care and belonging. Here they identify care as reciprocal relationships between community members, such as helping to push a wheel-chair for their disabled friend, having community members pay hospital fees for their family, and being inclusive in play with one another. Mickey, from Can Tho, talked about being given “pots with flowers, squared or rounded sticky-rice cakes” during Tet holiday while others such as Be Cao, also from Can Tho, conceptualized care as her relationship with her friend who walked her to school every day: “I felt so happy because she understood me”.

Importantly, access and accessibility were also a part of the conversation on inclusion. While participants talked about accessibility issues such as building a ramp in their school, park, or shopping centre so that people with physical disabilities can use these places, their perspectives of access went much further. For example, the conversation below between the girls with visual and hearing impairments showed that the girls are very knowledgeable about what kinds of support they need to make society more accessible to them:

Facilitator: What do people with visual impairments need in order that it can support you the best?

Mickey: sign language.

Facilitator: sign language for hearing impairments. Now, according to Bé Cao’s experiences, how to guide you when we want to guide you?

Mickey: use voice.

Facilitator [*asked Be Cao*]: use voice? Mickey said using voice. Do you think it is correct?

Bé Cao: yes, it is.

Facilitator: it's the best way to support you, right? So can you speak out your voice? Can you let the community know what kinds of support visually impaired people need?

Bé Cao: voice.

Here the participants discussed accessibility in concrete terms. The facilitator created an opportunity for Be Cao to say what kind of support she needed as a girl with visual impairment. The girls also demonstrated that they are aware of different accessibility needs for people with visual and hearing impairments. Other girls drew on their personal experiences to talk about access. For example, Bup Be, from Can Tho, shared that she was not allowed to go to the park because of her disability. Her proposal, then, was to “have a playground for children to play” and for friends with and without disabilities to play together. Here, she talked about access not merely a tool or device but as a means to inclusion in itself.

Finally, the participants demonstrated that, while inclusion must come from a change in the community's awareness and transformation, they needed to strategically take actions to create this change. A woman in Can Tho told of her persistence in getting recognized as a skillful tailor:

At the first time, I had to sew clothes for my parents, my family members. When they wore these clothes, other people saw them beautifully, they asked and they gave me chances. A girl in my neighborhood would like to learn sewing from me, I accepted to teach her with lower tuition, she loved to learn with me. Then I had two, three more girls for sewing learning. I have a stable life gradually from sewing. I appreciate my family members; they gave me helpful advices about my job. Be patient and listen to your family, I believe that you will be successful.

While participants recognized barriers to access and inclusion, they also understood that creating change required them to identify and implement strategic actions. For example, reflecting on a community engagement event with stakeholders in Hanoi, a group of women and girls set their activist agenda: 'We want to continue to engage in more practical activities, such as influencing leaders to improve policies that are more appropriate for people with disabilities, girls and women with disabilities in the three regions' (Reflection on community engagement event, Hanoi, 2019).

### ***Speaking back: the politics of resistance***

Over the duration of TDKRA, and with the nurturing support of their mentors, the girls became

more engaged in activist strategies and actively participated in community engagement activities. The participants showed they could speak up and challenge power when they had a community and a safe space to share their stories. For example, in A Luoi, while disabled women and girls discussed their experiences with racism, a young woman with disabilities shared her experience when being called “dumb” by an ethnic majority woman.

Hong: There was one time when I went to the hospital and I go to the guest-house to rest, one person asked me: "Are you from ethnic minority group?" I replied, "Yes". I am from an ethnic minority group" and then she said, " people from ethnic minority groups are dumb. "I just asked her: "Why did you say I am dumb?" She said, "Because you are a member of an ethnic minority group." I asked, "Auntie, do you know how to speak in ethnic languages?" She said: "No." I said: "So why did you say like that, you are dumb because you do not know the ethnic minority languages." She had no words to say. I was so angry because they said people from ethnic minority groups are stupid.

Hong's story described ethnic minority women treated as 'dumb' because of the beliefs that linked ethnic minority people and incapacity.

The girls expressed their resistance differently than the women. Rather than directly confronting a bully, the girls used performance as a way of speaking back to violence. A group of girls in A Luoi used their 3-minute cellphilm to act out their resistance. The cellphilm shows Thao, the main character, bullying another girl in their school. The bullied girl, who is an ethnic minority, was asked to serve a drink to her presumably non-disabled friends. Thao, who acts as an able-bodied and class privileged individual, slammed her hand on the table to express her anger. In another scene of the film, the bully ejects the girl from the room: "Get out of here so that we can chat!" At the end of the film, the girls and women said: "Don't discriminate against us!" as the key message they wanted to convey in their film. At a later point in the project, when talking about their mobilizing strategies of a documentary film that they co-produced with the team, one group said: "We would like to use the results of the film screening to have an effect on teachers, friends, family, neighbors, and officials in other departments as well as in social media industry to help people get a better understanding about girls and women with disabilities".

The girls and young women with disabilities used different tools and strategies to challenge dominant power. While the women were more vocal in their resisting strategies, based on their strengths and lived experiences, the girls expressed themselves through visual methods such as cellphilm. This finding rejects the assumption, often evident in lived experiences and the literature (Nguyen, 2016; United Nations, 2016), that girls with disabilities are merely victims incapable of speaking for themselves and shows that with appropriate tools and methods, disabled girls and women in the global South can effectively share their stories. That is, by creating participatory spaces and methodologies for girls with disabilities to re-imagine their

social positions, this research offers one way to decolonize methods that enable disabled girls to reframe their stories from the standpoint of the colonized (Nguyen, 2016).

### ***Leadership and engagement***

Over the life of TDKRA, the participants identified how they had changed and demonstrated their leadership and self-determination. Towards the final stage of the project, we found that many girls and women expressed confidence in themselves and their ability to engage within their communities. They saw themselves being transformed because of the experience participating in the project.

In a workshop entitled “I am a leader because...” the participants were asked to draw a picture of themselves and write about their skills and capacities to become a leader (Nguyen et al., forthcoming). Many girls and young women with disabilities drew pictures of themselves as a martial arts teacher, stakeholders, and sometimes, simply a person who knows how to assist her other friends and community members. Their leadership messages are clear and loud as illustrated in Can Tho: “Well, we want to be the representatives to bring the voices of the girls and women in this room to everyone outside the community.”

The participants were determined to articulate their self worth and confidence by talking about themselves as leaders. A disabled woman in Can Tho shared her experience: “I used to think that I couldn’t do anything because I am disabled. But I can earn for my daily living and support my mother. Nothing we cannot do, remember that. Be strong.”

### **Discussion**

From our practice of deep listening to the stories of the girls and women and our intent to practice decolonization, we reflect on what we learned from what the girls and women shared in the themes above. We come to this as critical disability studies, childhood and global human rights and justice scholars. But we also come as two people who identify as cis-gendered women- one from the global South, the other from the global North- working in Canadian universities in critical community-engaged scholarship. From these perspectives, we illustrate how we believe what the girls and women discussed is similar in some ways, and challenging one another in others, and in doing so, unsettles and provokes change.

Both the girls and women understood disability in the context of their experiences and relationships- as individuals, as members of families and communities, and in the historical, colonial and governmental context of Vietnam. As we have discussed in other publications (Stienstra and Nguyen, 2020; Nguyen et al., 2019; Nguyen, 2015), experiences of disability in Vietnam also need to be understood in the context of different manifestations of colonization:

ten centuries of Chinese imperial rule and the importation of Confucianism; roughly one hundred years of French colonial rule and perception of Indigenous people as social diseases to be ‘cured’; the attempts by the United States to colonize Vietnam, the related war and use of Agent Orange; and the shift since the 1980s called Doi Moi (renewal or renovation) by the Vietnamese state to ‘liberalize’ and ‘privatize’ its economy in order to participate in the global neo-liberal capitalist markets. Specifically, while French colonialism constructed ideologies of the diseased and sick bodies in need of cure to rationalize its civilizing mission, this ideology has been embedded within the on-going cultural politics of the nation and the ways in which some participants saw themselves as diseased bodies in need of cure. While the liberalization of the central planning economy within the context of Doi Moi marked a shift in the governing of disabled women and sexualized bodies (Nguyen, 2015; Nguyen-Vo, 2008), this economy has created new spaces of inclusion and exclusion through the inclusion of more capable disabled people into the market while continuing to rationalize the exclusion of more disabled bodies from the public.

For example, when the women talked about disability as the result of ‘bad luck’ or ‘misfortune’, we recognize the women are part of a culture where disability is seen as something wrong that happens to the body (Gammeltoft, 2008). What is understood to be wrong with the body has changed over time and reflects the colonizing influences in Vietnam. Early in the project, when talking about how their grandmothers viewed disability, many of the women in Can Tho suggested a link to the Buddhist understanding of karma where disability was seen as a punishment for something done in a previous life. The women rejected this view and identified disability as a sickness or deficiency in human functioning that may need medical interventions. This perception reflects the lingering effects of French colonial practices on women and girls in Vietnam in that Indigenous bodies must be ‘cured’ to become normalized and civilized (Nguyen, 2019). Furthermore, the on-going and inter-generational impacts of Agent Orange on their bodies and future generations further solidifies a medical perception that disability is a problem with the body. This suggests a need to understand the genealogies of disability and embodiment within specific social, historical, and political conditions in the global South.

As party to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the associated disability and development agenda, the Vietnamese government, in its current law and policy reforms, has inadvertently reinforced the medicalization of disability within Vietnamese social policy using the language of rights (Nguyen, 2015; Nguyen et al., 2015). For example, the Vietnamese Law on Persons with Disabilities (SRV, 2010) requires disabled people to be diagnosed by a professional committee to determine their levels of disability and, on this basis, distributes benefits. Yet there are significant inequities especially for those in the mountainous regions, which were also most affected by Agent Orange. Specifically, disabled women and girls in A Luoi have often been excluded from getting access to diagnosis because they lived far from the hospitals. When they

have been diagnosed, doctors determined their medical classification and, in some cases, rejected their cases. For example, some visually impaired women involved in TDKRA believed that they were affected by Agent Orange because their family members participated in the war. Yet their cases were not confirmed by doctors, which resulted in them being stripped of the social assistance they desperately needed. Not surprisingly, with access to medical treatment required for disability certification and benefits, many women seemed to conceptualize disability according to the medical model. The interplay between their materiality of disability and the socio-historical condition in which they live demonstrates the impacts of the social dynamic on their bodies (Connell, 2011).

Campbell (2008) uses the concept of ‘internalized ableism’ or disabled self-hatred, to explain why many people with disabilities feel ashamed of themselves. She argues that within societies where being able-bodied is the assumed and expected way of being, disabled people often feel they have no choice but to try to pass as able-bodied, or reject their own disabilities. Campbell also suggests that this ableism is sustained by preventing people with disabilities from coming together. Many of the girls appeared to internalize the dominant ideologies that their disability is a misfortune and a personal problem, which made them feel “ashamed,” “sad,” or “self-pity.” These links between shame and self-pity and disability are deeply embedded within dominant ableist cultures. Near the end of the project, the girls spoke of their appreciation of differences and the strength and support they received by being together. They highlighted both how they increased in their own self-confidence and capacity to engage and take actions in their communities. They also noted how important organizations of people with disabilities and the mentorship of women with disabilities were in their increased confidence.

The girls and women introduced a relational understanding of disability that is often not evident in global Northern disability studies. They understood disability as directly related to how members of their families, friends and communities treated them, both in including and excluding them. In contrast with the global Northern social model of disability which identifies barriers in the systems, structures and the environment as most important in addressing disability, the girls and women saw social relationships as most important in their lives. The ways disabled girls were treated differently from others, by being excluded from play or bullied by their non-disabled friends, illuminated the forms of exclusion which they faced within a culture that values normalcy. Their views of access and inclusion were embedded within what they see as a need to understand and respect their differences, share their stories collectively, and transform exclusion through their own actions.

The social model of disability does address stigma and attitudes, and some feminist and post-colonial scholars identify and critique the global production of impairment (Erevelles, 2011; Connell, 2011; Meekosha and Soldatic, 2011), but there is little in the literature that speaks to the relational mechanisms by which inclusion and exclusion happen, especially for girls with disabilities. For global Northern disability discourses to come to terms with the socio-relational

and material aspects of disability in the South is epistemologically challenging without recognizing its own privileges in disability theorizing and its exclusion of non-Western forms of thought. For the TDKRA participants, reciprocal caring relationships were essential to inclusion. They talked about accessible playgrounds not to remove barriers, but to ensure their belonging and mutual relationships. They identified their important role as individuals, and as part of organizations, to act for change in their communities.

The understanding of these reciprocal relationships echoes some African approaches to disability. In Ubuntu epistemology, we are always in a relational cycle with everything on the earth (Mucina, 2013). Thus, a person is a person through their relationships with others. As Mucina argues, we have to try to live with difference because humanity depends on it. Despite its own political struggles in creating the insider and outsider, Ubuntu philosophy recognizes that ‘If it is our experiences and knowledges that give us our diversity, then let us support all our knowledges without creating a hierarchy of importance and power’ (28). This theory offers another form of understanding about difference and political struggles that are rooted in Southern spaces and epistemologies.

The girls and women also took an intersectional approach as they spoke about inclusion and exclusion they experienced as a result of being part of minority ethnic groups and speaking minority languages. For girls and women from minority ethnic groups, race and language were how they first entered discussions of differences. Their experiences were of being unwanted in schools, among peers and in communities. At the same time, they showed their ability to resist power, as Hong illustrated when she challenged those who stereotyped her ethnicity. In recounting her memories, she was not only able to re-tell her own story; she also disrupted the authority by making the ‘auntie’ who insulted her have “no words to say.”

Finally, the girls and women demonstrated their own strengths and capacities in mobilizing their movements. By telling their own stories, documenting their own experiences and engaging with their DPOs and communities, disabled girls and women in the global South demonstrated they are conscious of their strengths and strategic in having others recognize their capacities. For us as the authors of this article, the girls and women with disabilities in TDKRA answer the question: ‘What would it mean in our social interpretation of meaning to have certain voices which have been disempowered into silence speak from an empowered position?’ (Mucina, 2013:33), by illustrating their knowledge, strengths and capacity and identifying what living with disabilities means for girls and women in Vietnam.

## **Conclusion**

This article highlights the need to engage and decolonize research with girls and women with disabilities in the global South. We emphasize the necessity to interpret such perspectives within specific social, political, cultural, and religious contexts (Ghai, 2015). This post-colonial

reading aims to decolonize the ways disability in the global South is historically read and interpreted from the global North. As Nguyen (2018) argues, a critical engagement with Southern theory reminds us that not only *how*, but *where*, *when*, and *why* we read disability matters. She argues for a re-theorizing of disability from the periphery- an act of meaning-making that repositions relationships between and across the global North/South, disabled/non-disabled, as well as between disabled people and their communities. Grounded in an historical understanding of the colonial relations and interactions among disability, space, embodiment that produced violence on bodies (Chaudhry, 2018), this work reminds us of the lingering impacts of colonialisms within colonized, gendered, and disabled bodies, while opening up a more inclusive space for scholars from the global North to learn from Southern spaces, relationships, and experiences.

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