



THE TRANSFORMING DISABILITY KNOWLEDGE, RESEARCH, AND ACTIVISM PROJECT

Final Report
Ottawa, October 2022



Decolonial Disability Studies Collective

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Nguyen, X. T., Bernasky, T., Dang, T. L. (2022). *Final Report: The Transforming Disability Knowledge, Research and Activism (TDKRA) project*. Carleton University, Ottawa. DOI: <https://doi.org/10.22215/ddsc.2022.301>

Front image: A group of TDKRA women and girls with disabilities joining hands in solidarity with one another.

Photo credit: TDKRA project



Social Sciences and Humanities
Research Council of Canada

Conseil de recherches en
sciences humaines du Canada

Canada

Principal Investigator:

Dr. Xuan Thuy Nguyen – Carleton University

Co-investigators:

Dr. Claudia Mitchell – McGill University

Dr. Deborah Stienstra – University of Guelph

Dr. Marnina Gonick – Mount Saint Vincent University

Collaborators:

Nhung Huynh – Can Tho Association of People with Disabilities

Huyen Do – Bac Tu Liem Association of People with Disabilities

Lan Anh Nguyen – Action to the Community Development Center (ACDC)

Dr. Marcia Rioux – Disability Rights Promotion International, York University

Dr. Naydene de Lange – Nelson Mandela Metropolitan University

Community Partners:

Bac Tu Liem Association of People with Disabilities

Can Tho Association of People with Disabilities

Thua Thien Hue Association of Blind People

A Luoi Association of Blind People

Action to the Community Development Center (ACDC)

Research Assistants:

Linh Dang

Dr. Tammy Bernasky

Dr. Tuyen Bui

Nadeea Rahim

Hikmet Mawi

Huong Dao

Emily Hill-Smith

Thao Le

Thuan Hong Do

Alexia Miron

Gazel Manuel

This research report is in honor of Dr. Marcia Rioux, who dedicated her life and professional career to the growth of the disability rights movements around the world.

ACKNOWLEDGMENTS

This project has been made possible with the support of the Social Sciences and Humanities Research Council of Canada, Carleton University, University of Guelph, McGill University, and Mount Saint Vincent University. We would like to thank them for this support.

We wish to thank UNICEF Vietnam and its staff members, including Ms. Le Anh Lan, Mr. Nguyen Minh Nhat, Mr. Hoang Anh Nguyen, and our colleagues, Dr. Deborah Stienstra, Dr. Katie Aubrecht and Dr. Karen Soldatic, for their reviews and thoughtful suggestions to the completion of this report.

The following people and organizations have also been involved in advancing the objectives of this project in a collaborative and participatory manner. We would like to thank them for their contributions to the project.

Bac Tu Liem Association of People with Disabilities
Can Tho Association of People with Disabilities
Thua Thien Hue Association of Blind People
A Luoi Association of Blind People
Action to the Community Development Center
Linh Dang – Research Assistant
Dr. Tammy Bernasky – Research Assistant
Dr. Tuyen Bui – Research Assistant
Gazel Manuel – Research Assistant
Nadeea Rahim – Research Assistant
Hikmet Mawi – Research Assistant
Huong Dao – Research Assistant
Emily Hill-Smith – Research Assistant
Thao Le – Research Assistant
Thuan Hong Do – Research Assistant
Alexia Miron – Research Assistant
Fayssal Yatim – Research Assistant & Report designer
Sam Tran – Language translator

Most importantly, we would like to express our sincere appreciation to all girls and women with disabilities who participated in this project and who trusted us with their time and stories. Thank you, also, for trusting the process and for allowing us to work with you so that your voices and experiences could be heard. We are grateful for the opportunity.



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EXECUTIVE SUMMARY



The development of transnational human rights and disability rights over the last two decades has placed the rights of women and girls with disabilities on a global agenda. Article 6 of the United Nations Convention on the Rights of Person with Disabilities (UNCRPD) recognizes that women and girls with disabilities are subject to multiple forms of discrimination. As a signatory of the CRPD, the government of Vietnam has developed policies and laws that protect people with disabilities from discrimination. The country ratified the CRPD in 2015 and submitted its first official monitoring report to the UNCRPD committee on April 4, 2018. The Law on Persons with Disabilities (Law No.51/2010/QH12) recognizes the equal rights of persons with disabilities in social participation, independent living, and enjoyment of rights on an equal basis with others. It prohibits discrimination against people with disabilities (SRV, 2010). Following this law, Vietnamese legal systems have amended related laws and policy documents to reflect the rights of persons with disabilities.

Despite the development of these legal frameworks, there are significant barriers to the participation and inclusion of women and girls with disabilities. In Vietnam, women and girls with disabilities have experienced disadvantages in various aspects of life, such as access to education, health services, lack of employment and discrimination (UNFPA, 2009, MRGD, 2016; VFD, 2020). However, little is known about their situations. Transforming Disability Knowledge, Research, and Activism (TDKRA) was a collaborative research and activism project funded by the Social Sciences and Humanities Research Council of Canada (SSHRC) between 2016–2020. The project aimed to address the gap in knowledge about the situation of women and girls with disabilities in three disadvantaged communities in Vietnam and to build potential for their activism. The main objective of the project was to engage girls and women with disabilities in knowledge production as a form of activism for their inclusion. It also aimed to connect research and activism to build a more transformative approach to inclusion and social justice in the global South.

The TDKRA project was implemented in 5 phases. In each phase, emphasis was given to strengthening partnership with local DPOs and community, building local leadership, training, and enhancing women’s skills to be co-facilitators in various visual methods. The engagement with girls with disabilities was key to all phases of the research process.

Phase I (2016–2017) In this first phase, the TDKRA team informed the partner communities about the objectives, scope and goals of the research project using information sessions. DPOs and communities were also consulted about their needs and interests in implementing the TDKRA project. **Phase II (2017–2018)** Following the initial consultation and needs assessment stage, the TDKRA team held local fieldwork events to enhance relationships with local communities and DPOs, and to connect with women and girls with disabilities through focus groups, drawings, and media analysis.

It also undertook training women with disabilities to become key co-facilitators in engaging girls as the key informants of their lived experience with various forms of disabilities. **Phase III (2018-2019)** The main objectives of this phase were engaging participants in reflexive practices on their own productions and participation, fostering public engagement through activism, and strengthening DPOs capacity and leadership in relation to disability research and activism. **Phase IV (2019-2020)** In this phase, women and girls with disabilities engaged in mobilizing their knowledge on their right to inclusion with local leaders, policymakers, community members and DPOs through leadership. This was achieved through the screening of *Our Journey*, a documentary film co-produced by the women and girls and the research team. **Phase V (2020-2022)** In this final stage, we reported the outcomes of the project to participants and examine the impacts of the COVID-19 pandemic on women and girls with disabilities in the project. Results from this final stage will be examined in a separate report.

The TDKRA project is unique in the extent to which it utilized multiple ways of researching with women and girls with disabilities. TDKRA also aimed to resist the confluence of colonial and imperialist contexts by engaging girls and women with disabilities, creating spaces for their inclusion, fostering their voices, leadership, and activism within their respective communities, and involving girls and women with disabilities in forging strong relations with communities in the global South. There are ongoing challenges with sustainable livelihoods, inclusive education, promoting positive perceptions of disability, resisting exclusion and discrimination in all areas of life and the resulting internalized ableism the girls and women described. At the same time, experiences were nuanced by instances of inclusion, feelings of belonging and the surfacing of activism, empowerment, and opportunities for transformation. The outcomes of this project show potential for women and girls with disabilities to engage in local and transnational activism. We have centered the experience of women and girls in the Global South and worked with them to produce their desired outcomes while also respecting their agency and supporting their feelings of empowerment throughout the research process.



INTRODUCTION

Women and girls with disabilities make up more than half of the population of persons with disabilities the world over. Globally, it is estimated that the average prevalence rate of disability in the female population aged 18 and older is 19.2 per cent, compared to 12 per cent for males (UN Women, 2018). This statistic suggests that a high percentage of women and girls around the globe has experienced a disability. In Vietnam, women and girls with disabilities represent 56% of all people with disabilities, or approximately 3.5 million people (Do, n.d.). Given the number of women with disabilities globally and in Vietnam, it is important to consider and understand the multiple forms of oppression they experience at the intersections of class, race, gender, sexuality, and age. The invisibility of girls and women with disabilities within feminist movements emphasizes the need for more empirical research in this area.

The development of transnational human rights and disability rights over the last two decades has placed the rights of women and girls with disabilities on a global agenda. Article 6 of the United Nations Convention on the Rights of Person with Disabilities (CRPD) recognizes that women and girls with disabilities are subject to multiple forms of discrimination. It requires states-parties to “take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms” (Article 6.1). This article also aims to achieve “full development, advancement, and empowerment of women” (Article 6.2). Building on the UNCRPD and the 2030 Agenda for Sustainable Development (United Nations, 2015), the United Nations Women’s Strategy: The Empowerment of Women and Girls with Disabilities - Towards Full and Effective Participation and Gender Equality emphasizes the need to strengthen inclusion of rights for women and girls with disabilities. It recognizes systemic barriers and gaps to the full participation of women and girls with disabilities including legal, physical, communication, information, and attitudinal barriers (UN Women, 2018).

As a signatory of the CRPD, the government of Vietnam has developed policies and laws that protect people with disabilities from discrimination. The country ratified the CRPD in 2015 and submitted its first official monitoring report to the UNCRPD committee on April 4, 2018. The Law on Persons with Disabilities (Law No.51/2010/QH12) recognizes the equal rights of persons with disabilities in social participation, independent living, and enjoyment of rights on an equal basis with others. It prohibits discrimination against people with disabilities (SRV, 2010). Following this law, Vietnamese legal systems have amended related laws and policy documents to reflect the rights of persons with disabilities. For example, non-discrimination is stipulated in the Labor Code, the Law on Medical Examination and Treatment, and the Law on Education (SRV, 2018). Vietnam promulgated the National Plan on the implementation of the CRPD on June 21, 2016 to promote and ensure the rights of persons with disabilities. This process of legal reform also involved Organizations of Persons with Disabilities and civil society organizations, marking a change in perceptions about persons with disabilities (VFD, 2020).

Despite the development of these legal frameworks, there are significant barriers to the participation and inclusion of women and girls with disabilities. In Vietnam, women and girls with disabilities have experienced disadvantages in various aspects of life, such as access to education, health services, lack of employment and discrimination (UNFPA, 2009, MRGD project, 2016; VFD, 2020). However, little is known about their situations. The independent report of the Vietnam Federation on Disability on the implementation of the CRPD in Vietnam (hereby referred to as the CRPD OPD report)^[1] points out that although Vietnamese legislations have aimed to realize the rights of persons with disabilities, regardless of their types of impairment, sex, and age, people with disabilities still face significant barriers resulting from discrimination.

Key limitations within Vietnamese framework on persons disabilities include: 1) the lack of an inclusive definition of the concept of disability, which continues to be driven by the medical model of disability; 2) the lack of related principles such as “equality of opportunity;” “non-discrimination;” “respect for difference;” concepts such as “reasonable accommodation;” and “universal design;” 3) the lack of access to basic services such as information and transportation, education and training, health care, vocational training, and employment; and 4) the lack of inclusion of people with disabilities within disaster management strategies and policies. This reflects significant challenges to the implementation of a rights-based framework in the Vietnamese context. The CRPD OPD report observes:

A principle has not been reflected in the 2010 Law on Persons with Disabilities and other legal documents, which is “[States Parties] recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.” (VFD, p. 10)

There are specific legal challenges with the implementation of human rights for women and girls with disabilities in Vietnam. Specifically, there is no specific mention of the rights of specific groups such as women, girls, LGBTQ+, and ethnic minorities within the 2010 Law on Persons with Disabilities. The lack of attention to intersectional identities is a clear gap in this law. Furthermore, existing research fails to recognize the ways in which disability categories are culturally and historically developed by nation-states with specific impacts on people with disabilities. The Monitoring Educational Rights for Girls with Disabilities project (2016) found that girls with disabilities are more likely to experience barriers accessing education than those without disabilities. Furthermore, girls with intellectual disabilities are more likely to experience violence in school and at home than other girls with disabilities. For every ten women and girls with disabilities, four persons have experienced at least one form of sexual violence. However, there is no specific regulation to protect them from intersectional discrimination (VFD, 2020).

[1] We use the original name of the report to respect its originality. In other places of this report, the term DPOs is used to refer to Disabled People’s Organizations.

This research report outlines the Transforming Disability Knowledge, Research, and Activism project (TDKRA) and concludes with a set of recommendations. TDKRA was a collaborative research and activism project funded by the Social Sciences and Humanities Research Council (SSHRC) between 2016–2020. The project aimed to address the gap in knowledge about the situation of women and girls with disabilities in three disadvantaged communities in Vietnam and to build potential for their activism. The main objective of the project was to engage girls and women with disabilities in knowledge production as a form of activism for their inclusion. It also aimed to connect research and activism to build a more transformative approach to inclusion and social justice in the global South.



CONTEXT OF THE STUDY

As a country with a long history of socio-political struggles against colonialism and imperialism, Vietnam embodies specific forms of human rights and post-colonial struggles in the Global South. Under the French colonialism, the colonial state established specific policies, institutions, and discourses to treat bodies perceived to be sick, ill, or abnormal. This was coupled with the development of institutions such as special camps for people with mental disabilities, Hansen's disease, visually impaired and deaf children (see Nguyen, 2015). While the governmental desire to cure disabled bodies has lingered throughout the present history, this medical approach to disability – that is, the perception that disability is a departure from the healthy body that needs to be fixed, cured, and normalized – has been rooted within the colonial constructions of the native subject (Monnais, 2006) which has significantly shaped how disability is conceptualized today.

Culturally, Vietnam is home to fifty-four officially recognized ethnic groups in a country of ninety-seven million people (World Population Review, n.d.). However, little is known about the situation of minority women and girls with disabilities. According to the Vietnam Disability Survey (VDS), the prevalence of disability among adults is 8.64 percent ^[2]. Disability rates are higher among people aged 65 or over. They are also higher in rural regions. Disability rates are also found to be higher among women (10.14 %) compared to men (7.01%) ^[3].

Women and girls with disabilities are not a homogeneous group – they comprise various ages, gender identities, sexual orientations, ethnicities, regions, social class, types of impairment, and disability experiences. The intersections between their experience and systems of power produce different forms of oppressions which contribute to their marginalized and invisible situations. For example, ethnic minority women and girls with disabilities are less visible and face more discrimination than other groups (Nguyen, Stienstra, Gonick, Do, & Huynh, 2019; Nguyen & Stienstra, 2021). Ethnic minorities have experienced unequal power relations, with the Kinh ethnic majority controlling the political and socio-economic lives of minorities (McElwee, 2008). However, the intersections of multiple factors such as gender, ethnicity, age, social class, and the systemic conditions which affect their situations have not been fully investigated in the previous research.

[2] The prevalence of disability in Vietnam varies, depending on the use of different instruments. The Vietnam Disability Survey (VDS) applies both the Washington Group Short Set (WG-SS) and the Washington Group Extended Set (WG-ES), which yield different disability rates. Furthermore, the Child Functioning Module (CFM) developed by the Washington Group only asks questions of children aged 2 or older, thus excluding younger children with disabilities. For a critique of these instruments, view Eide & Loeb (2016) and Nguyen (2018).

[3] We use the data generated by the WG-ES as this is the official statistics used by the General Statistics Office of Vietnam (GSO).

There is marked inequality between children with and without disabilities in accessing education. This inequality is intensified for ethnic minority students with disabilities (GSO, 2016). Specifically, fewer children with disabilities (88.7%) attend school compared to children without disabilities (96.1%) at primary level. There are 72.14 percent of ethnic majority groups (Kinh and Hoa) with disabilities attended primary education, compared to 54.44 percent for the ethnic minority groups (categorized under the “Others” status). The gap widens at higher education levels^[4].

At the upper secondary level, 33.6 percent of children with disabilities are in school, compared to 88.6 percent of children without disabilities. This report reflects what was learned from data collected by the end of July 2019. It introduces the research process, key findings, and outcomes of the TDKRA project, and policy recommendations from the perspectives of girls and women with disabilities. While all the TDKRA fieldwork had completed before the onset of the COVID-19 pandemic, it is important to acknowledge the unprecedented impacts of the pandemic for women and girls with disabilities and their families across all three communities in relation to education, employment opportunities, income, domestic and gender-based violence (personal communications with DPOs leaders, 2021, see also UNDP report, 2020).

We are currently evaluating the impacts of COVID-19 pandemic on the participants in the TDKRA project. At the request of our local DPO partners, we are developing a new research stage to document the impacts of COVID-19 on the situations of women and girls with disabilities in the three communities. The results of this development will be reported in other TDKRA project’s materials and reports. TDKRA was implemented in three disadvantaged communities in Vietnam: A Luoi (Thua Thien Hue Province); Bac Tu Liem (Hanoi City), and Binh Thuy and Ninh Kieu (Can Tho City). These communities were selected due to their diverse and distinct social, historical, and cultural conditions. Specifically, A Luoi (Thua Thien Hue Province), a mountainous area in central Vietnam with the majority of ethnic minorities heavily affected by Agent Orange during the Vietnam war. We selected A Luoi to achieve a better understanding of the lived experiences of participants impacted by the Agent Orange as well as other intersectional barriers. Furthermore, Bac Tu Liem (Hanoi City) and Ninh Kieu district (Can Tho City) have had a relatively strong disability activist network with the disabled women and girls and a relatively strong relationship with the local DPOs. With distinctive socio-economic levels of development, Binh Thuy and Ninh Kieu districts are adjacent communities with distinct levels of development in Can Tho city. Ninh Kieu is more socio-economically developed compared to the rural location of Binh Thuy district.

To engage women and girls with disabilities in the selected communities, we used decolonizing, community-engaged, and participatory research methods. We organized local community workshops involving local researchers/research assistants in years 2, 3, and 4 to keep participants engaged in the project and help sustain their local networks. Training was conducted by the researchers prior to the workshops. The women with disabilities were trained on conducting interviews, focus groups, and using arts-based methods.

[4] The GSO study also shows that while the net enrolment rate between ethnic groups is more equal at the primary education level, the gap widens at secondary and post-secondary education levels (GSO, 2016).

They facilitated the data collection with the girls, while also participating in focus group discussions in relation to their experiences with disability, gender, and ethnicity. We also conducted virtual training and invited some women with disabilities to be the co-facilitators for the community workshops.

The girls were the key informants in the project. They participated in arts-based workshops, interviews, and focus group discussions in their communities. Several girls and women who were the representative of their groups were elected to speak to local leaders during community engagement events. One girl and one woman in addition to their DPO representative in each community were invited to participate in a national workshop in Hanoi to share their collective voices with the participants in other communities and stakeholders working on disability and inclusion. The workshop, titled *Inclusion from Perspectives of Women and Girls with Disabilities*, was co-hosted by the Hanoi Organization of People with Disabilities and the TDKRA research team. This local and translocal network built and enhanced the relationships between participants in the project while contributing to the emerging network of women and girls with disabilities in Vietnam as a part of the global South.

The term “global South” is used in this study to refer to transnational spaces historically colonized by the colonial and imperial forces. The term global South is not geographical but rather is socially constructed through its unequal power relationships with economically advanced countries, usually referred to as the global North. To support the leadership of partners in the global South, we engaged three Disabled People’s Organizations, including Can Tho Association of People with Disabilities, Bac Tu Liem Association of People with Disabilities, and A Luoi Association of Blind People, as research partners. The local DPOs assisted with participant recruitment in their communities. We took into account recommendations from the DPO partners for selecting communities which could best respond to their needs. Throughout the duration of this project, we encountered instances of policing due to the sensitivity of our research topics. Whether or not disability should be framed as a political or a social justice issue was carefully considered because the politicization of disability is a very sensitive thing in Vietnam. Advocates are reluctant to call themselves activists in the Vietnamese context because the government would not approve. However, how these issues get raised then becomes important. In this report, we discuss the struggles of women and girls with disabilities in these communities, recognizing their potential in fostering positive social change in their own communities.

Stages of the research project

The TDKRA project was implemented in 5 phases. In each phase, emphasis was given to strengthening partnership with local DPOs and community, building local leadership, training, and enhancing women’s skills to be co-facilitators in various visual methods.

Phase I (2016-2017) In this first phase, TDKRA team informed the partner communities about the objectives, scope and goals of the research project using information sessions. DPOs and communities were also consulted about their needs and interests in implementing the TDKRA project. These information sessions provided the team with important key concerns and needs of potential participants, both women and girls with disabilities. This phase established relationships and built trust with community members and DPOs for successful consequent years and phases.

Phase II (2017-2018) Following the initial consultation and needs assessment stage, the TDKRA team held local fieldwork events to enhance relationships with local communities and DPOs, and to connect with women and girls with disabilities through focus groups, drawings, and critical media analysis. During this phase women with disabilities were trained to become key co-facilitators in engaging girls as the key informants of their lived experience with various forms of disabilities. In the final day of this fieldwork, local communities were invited to partake in a photo exhibition and walk-about display of productions by the girls. These photos and drawings depicted the stories of the women and girls with disabilities in how they experienced social inclusion or exclusion.

Phase III (2018-2019) The main objectives of this phase were to engage participants in reflexive practices on their own productions and participation, foster public engagement through activism and strengthening DPOs capacity and leadership in relation to disability research and activism. These were achieved through multiple workshops and focus groups which reflected on the girls' stories and engagements. The participants engaged in participatory activities such as co-producing the documentary *Our Journey* and community-asset mapping to engage in reflective practices and reposition themselves within their own communities.

Phase IV (2019-2020) In this phase, women and girls with disabilities engaged in mobilizing their knowledge on their right to inclusion with local leaders, policy makers, community members and DPOs through leadership. This included an "I Am a Leader Because..." workshop where girls portrayed and imagined themselves as leaders. These research processes were used to mobilize the knowledge production process through an exhibition to community members, leaders, and policy makers by way of activism.

The screening of *Our Journey*, a documentary film co-produced by the women and girls and the research team, took place in July 2019. The transnational screening of the film was successful in engaging disability activists, researchers, community members, students, and policy makers in the global South and in bringing them in conversation with those in the global North. These knowledge mobilization events were well received with engagements in Can Tho, A Luoi, and Bac Tu Liem as well as Ottawa and Montreal, in Canada.

Phase V (2020-2022) Due to the COVID-19 pandemic, we experienced some interruption in the project's planning. We reconnected with the participants in April and May 2022 to report the outcomes of the research findings to their communities. We also expanded the final stage of the project by examining the impacts of the COVID-19 pandemic on women and girls with disabilities in three sites of the project. Results from this stage will be published in a separate report.

PARTICIPANTS

We approached Disabled People’s Organizations (DPOs) to recruit participants from the three selected communities. Criteria for inclusion and exclusion included: a) aged 10 – 21 years old; b) experienced some forms of discrimination in and by the educational system; c) experienced one or more disadvantages associated with their disability, class, gender, and ethnicity; and d) interested in advocacy work and have potential leadership for educational rights. The DPOs used the recruitment procedures and criteria to recruit participants in their local communities and consulted with the team when questions arose. Some participants had prior relationships with the DPOs, which we view as positive since one of the key objectives of the project was to build and support relationships between the girls, women, and the DPOs as a way to further their activism for inclusion. We recognize that this means that girls and women who were not already connected to DPOs may not have had access to the project.

Over the four years of fieldwork with researchers and additional local gatherings, we engaged 85 participants with disabilities (54 girls and 31 women) 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. The women also participated in focus group discussions to share their knowledge and experiences. Several girls who participated in a previous project in Hanoi were also recruited to prepare for the transition in the women’s group. 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).

The participants in this study had a relatively high level of education compared to the general situation of women and girls with disabilities in the Global South. Specifically, the majority of participants had primary education (16.67%) secondary education (32,14%), and high school (10.71%). A small number of women with disabilities received college and university levels (13.10%) and 2.38% of all participants had a master’s education. There were 11.90% of the participants in special school while 1.19% of all participants had no schooling at all. The participants’ education levels are distributed below:



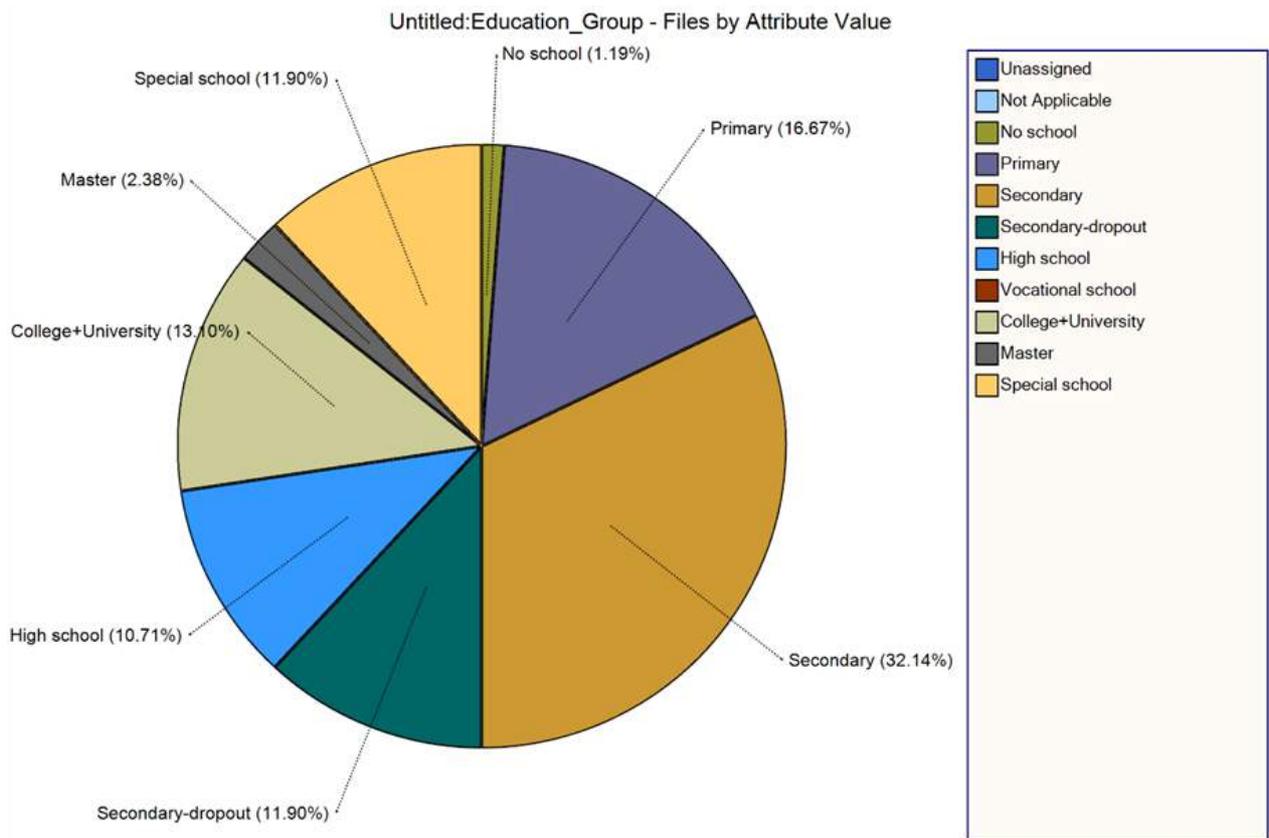


Figure 1: Distribution of education levels of participants across three communities.

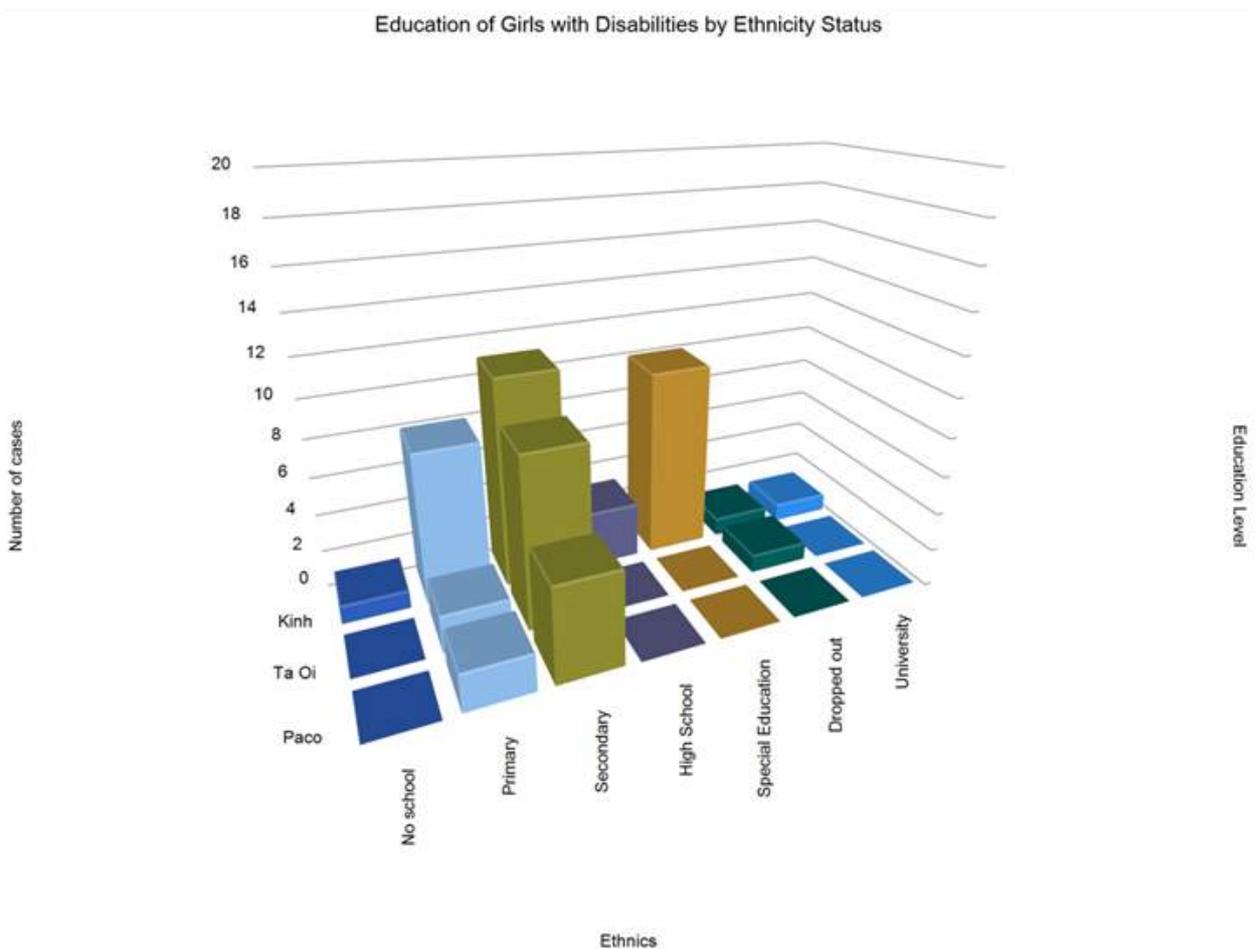


Figure 2: Distribution of education levels of girls with disabilities by ethnicity status.

Figure 2 shows the education of girls with disabilities by ethnicity status. It shows that girls with disabilities with ethnic majority (Kinh) status tends to have better access to primary, secondary, high school, and special education. There is no significant difference between Ta Oi and Paco ethnic minorities regarding access to education except for secondary school level. Given the relatively high level of participation of ethnic minority girls in the project (37%), their lack of access to education compared to ethnic majority girls is consistent, suggesting the unequal opportunities for ethnic minority girls with disabilities.

TDKRA used a mentoring approach which provided training to women with disabilities, who acted as co-facilitators to conduct research with girls with disabilities. The women offered their own insight and reflections during the focus groups discussions or community engagement events. Some women also participated in drawings, photovoice, and cellphilms where they were given a space to do so. Thus, we focused on working with girls with disabilities as the primary informants. Data produced by women with disabilities or caretakers were utilized to provide additional insight into the research questions.

The participants came from disadvantaged backgrounds, from poor and working-class families. In both the South and North of Vietnam most of the participants are Kinh majority ethnicity, while in A Luoi, central Vietnam, the majority of participants are ethnic minorities. We mention geographical location, as well, because the spaces participants occupied within urban and rural divide added to the complexity of the context that participants came from.



RESEARCH QUESTIONS, APPROACH, AND METHODS

TDKRA used a post-colonial and intersectional approach to document the situations of girls and women with disabilities in Vietnam (Nguyen, 2019). This approach aimed to co-create knowledge with women and girls with disabilities and communities in the global South as a way of claiming their rights. Drawing on Indigenous scholar Linda Tuhiwai Smith's decolonizing methodologies (Smith, 1999), we sought to unsettle power relations between researchers in the global North and activists in the global South by creating inclusive, accessible, and decolonial spaces for engagement with the research participants (Nguyen et al., 2019; Stienstra & Nguyen, 2020). In this process, we developed an important set of tools to understand the situations of girls and women with disabilities including cellphilm, participatory film-making, photovoice, drawing, as well as creating knowledge mobilization spaces such as community workshops, photo exhibitions, and public film screening across transnational, national, and local contexts (Nguyen, Dang, & Mitchell, 2021). This research approach shifts from research on to research with and by people with disabilities in the global South. This paradigm shift is critical for centering the participants' perspectives, ensuring that the lived realities of disabled people in the global South are critically engaged with (Mehrotra, 2020). We also used intersectionality to break down homogenizing social categories such as 'disability' and fosters a more inclusive understanding of differences. Our primary research questions were:

1. How do girls and women with disabilities understand and identify their experiences of inclusion and exclusion?;
2. How can their knowledge be produced, utilized and transformed by girls and women with disabilities through participatory methodologies? and
3. How can such knowledge be used and supported by their community?

TDKRA engaged girls and women with disabilities and their communities in the participatory research process by creating inclusive and decolonial spaces for the women and girls to engage their local and trans-local networks to share their stories, generate ideas, construct awareness, and mobilize knowledge across these communities. Participatory research is a research paradigm that is grounded in the values of the community. It aims to contribute something of value to the community in which the research is conducted (Kirby, Greaves, & Raid, 2006). 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 collaboratively between the researchers and representatives of partner organizations and with input from the women with disabilities. By engaging these girls and women and DPOs through different phases of the research project, TDKRA provided more inclusive spaces for engagement, building connections, mobilizing women and girls with disabilities' knowledges and networks, and creating potential for social change in their local communities.

Participatory visual methodologies (PVM)

PVM can be conceptualized as a set of methods that has the potential to contribute to knowledge production in ways that address the power differential between the researched and the researchers through the creation of visual production (Mitchell, 2011). We use a number of participatory visual methods including drawing, photovoice, cellphilm, and participatory film-making in TDKRA.

Drawing is one example of PVM which is mostly accessible to girls with various abilities, with minimal technical and material requirements. We used a specific discussion topic or prompt to engage the girls in art productions without the need to use words. Its accessibility makes drawing ideal for working with individuals with various abilities. Participants had the opportunity to create oral or written captions to go with their drawing, with the possibility for also narrating a story or participating in a semi-structured interview. We also organized on-site exhibitions which gave participants the opportunity to engage with and respond to the collection of drawings. The participants' drawings were published in the catalogue *Envisioning Inclusion* (Nguyen, Miron, Rahim, et al., 2019).



Image 1: Artwork produced by Thuy, age 13, titled Tet holiday, A Luoi, 2018.

Photovoice is the use of photography to capture what and how one views a particular issue from their own perspective. This method shifts power relations from the researchers to the participants through the use of cameras to represent their own views (Nguyen, Mitchell, De Lange, & Fritsch, 2015). It emphasizes how young people can impact social change as allies in the process of knowledge production (MacEntee, Burkholder, & Schwab-Cartas, 2016). TDKRA used photovoice to challenge the deficit-thinking and imposition of victimhood on women and girls with disabilities traditionally depicted in visual representations. Their own visual productions acted as a springboard for dialogue and discussion on inclusion. As a part of the photovoice process, we provided participants with a prompt as a starting point to help them brainstorm their ideas. Participants then used cameras provided by the research team to take pictures that represented their ways of seeing about inclusion and exclusion. Then, they created photo narratives, followed by presentations in small groups. These practices built a participant's consciousness of the meaning of their own photos. They fostered their dialogues, reflections, relationships, built self-confidence, and led to rich discussions. It is through these discussions that alternative narratives emerged in the path to challenging ableist societal narratives about disability.



Image 2: A poster presentation during a photo voice exercise in Bac Tu Liem, 2018.

Cellphilm is a creative method that utilizes cell phones to produce short videos to document or construct participants' perspectives or experiences. The use of cellphones builds on a youth-friendly tool (cellphones) based on relatively widespread access to mobile technology (See MacEntee et al., 2016). The process of participatory video and cellphilm as mapped out elsewhere (Mitchell & DeLange, 2019) involves a number of steps based on small groups working with a specific prompt or question: brainstorming, reviewing filming techniques and logistical concerns such as sound, creating a storyboard or plan, filming, small group reflection, whole group screening and discussion. The participants were invited to review their cellphilm in their groups and tell us about their creations. We also asked participants to comment on the relevance of their creations to their own lives.



Photo 1: A cellphilmimg process in Bac Tu Liem, Hanoi, 2017.



Photo 2: Girls using cellphilmimg as discussion and production in Can Tho City, 2018.

Critical Media Analysis: Critical media workshops were implemented to engage participants in analyzing the media. The main purpose of critical media analysis was to engage the participants in critical thinking on the representations of girls with disabilities in the media. This helped them to identify biases in the media and to identify ways in which they could re-construct their stories. We found that while the women were able to challenge the media portrayals in critical engagement, girls found it difficult to challenge narratives from the media.

Participatory filmmaking: Alongside cellfilm productions and critical media analysis, we co-produced a documentary film *Our Journey* with the women and girls in all three communities and the TDKRA research team. The process of filmmaking was important because it generated important discussion on multiple narratives of the participants in ways that countered a single narrative about women and girls with disability in mainstream media and invited participants to engage in dialogues about their inclusion, exclusion, barriers to participation, and struggles for change. Participants also participated in the process of film editing, including commenting on footage that should be removed or included in the film and explaining why. The process of participatory film-making enabled them to construct consciousness about their representations in social media and how this could have been better represented from their own lenses.

Our Journey was used as a Knowledge Mobilization tool applied in different sites across Vietnam and Canada. The participants also shared the film in their social media accounts to engage wider audiences in mobilizing their knowledge and activism. The film was also used to engage policymakers, NGOs, and the United Nations agencies such as UNDP and UNICEF.

Focus group & in-depth interviews: In the first and second stages of the project, researchers provided the women with 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, the women began by asking about the girls' lives and their family contexts, and then moved into 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 working together to develop their advocacy and leadership skills. They also assisted with data collection through the use of participatory research methods.

DATA ANALYSIS

Thematic Analysis and Coding

The range of data collection methods provided a unique and exciting opportunity to explore the research questions. We applied multi-layered analysis to understand the data, including thematic analysis, textual analysis, and visual analysis. These methods, when used together, strengthened the research process and outcomes.

A qualitative analysis of the interviews and focus groups was administered using Nvivo software to identify major themes emerging from the interviews, focus groups and participatory visual methodologies. In total, the data set included 114 drawings, 16 cellfilms, 54 interviews, 82 photo images, 111 poster-narratives, 293 audio recordings of the workshop sessions, and 1 documentary film. We also included fieldnotes, participant observation, reflections, meeting minutes and reports.



Figure 3: Nvivo Coding Scheme.

Six research assistants were trained to conduct data analysis. The translation from Vietnamese into English was conducted by our research assistants, including three young women with disabilities who assisted the project from the early stages of the research. The translation from ethnic minorities dialects such as PaCo, Ta Oi, and Co Tu into English was conducted by one ethnic minority woman who speaks English and Vietnamese.

A coding scheme was developed using open coding (Smith, 2021) whereby emerging codes were identified. The coding scheme was developed by manually testing out a number of interviews to establish key codes. The codes that were similar to one another were grouped into key categories to ensure consistency across the data set. The coding fell into the following categories: Social contexts of inclusion and exclusion in school, family, and community; interectionality, perceptions of disability, hopes, and activism.

The categories on 'community perspectives' and 'power' were included in the coding scheme in a later stage of the project (Figure 3). We then identified the themes and sub-themes from these categories. The coding tree was constantly revisited, revised, and modified to reflect new, emerging, and collapsed themes.

At the same time, we assert that "data" are not merely objective and transparent, but rather, partial, incomplete, and are always in the process of re-telling, re-membering, and re-constructing (Jackson & Mazzei, 2013). Factors such as the research design, methods and methodologies, and the researcher's ways of interpretation all impact the result of the analysis. Thus, for instance, in the context of qualitative research for social change, the process and relationships with the participants is a part of the research process. This might not be fully captured through "data". We tackled this by ensuring that our analysis must be situated within the context in which the data was produced to provide us with a better insight into the context of the conversation. We triangulated them by mapping different data sources, including interview data, visual data, visual discussion, and the researchers and research assistants' fieldnotes to enhance the quality of analysis.

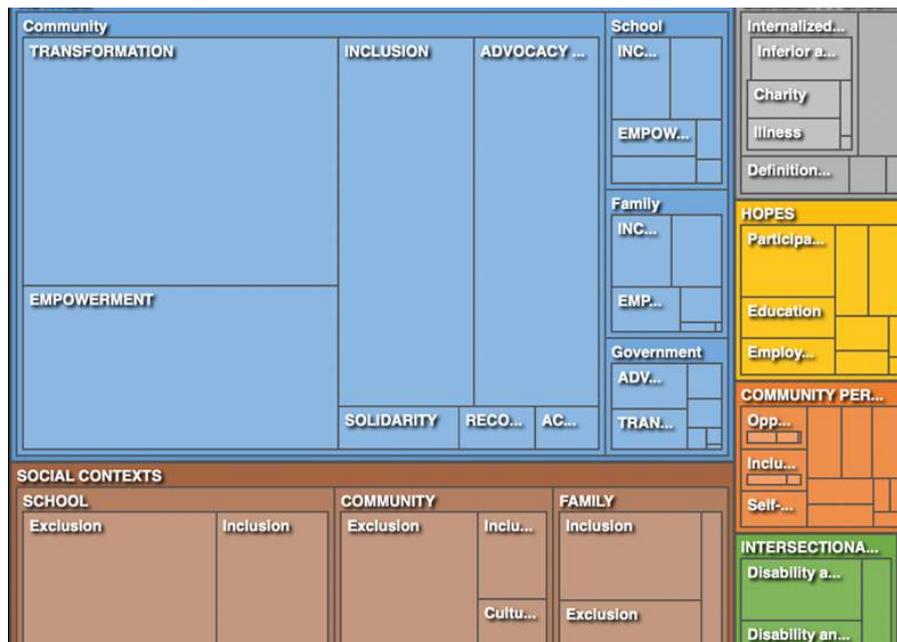


Figure 4: Visual Representation of Coding Scheme.

The visual representation of the coding scheme in Figure 4 reflects the key themes that emerged from the data. Each color represents a theme from the data. Within each theme there are subcategories and in some cases there are three levels of categories. From the representation we can see that activism was the most strongly represented theme, followed by inclusion and exclusion in various social contexts, followed by representations of disability, then participant hopes, community perspectives, and finally intersectionality. Interestingly, although we had started the study by focusing on the participants' experiences with inclusion and exclusion, the visual representation suggests that activism evolved as a more poignant theme in the later stages of the research process. Some of the sub-themes such as transformation, empowerment, inclusion, solidarity, and advocacy were established in the later stages of the research process. Interestingly, these themes became some major findings, compared to other sets of data. This reflects the transformative aspects of knowledge and activism underlying the TDKRA project.

Textual analysis

Based on the key themes identified in the Nvivo software, we conducted a textual analysis of the interviews and focus groups in relation to their implications for inclusion and exclusion (Fairclough, 2003). We annotated the focus group and interview files by breaking the text down to closely examine the narratives. Issues such as language use, silences, or possible omissions of the text were closely examined in order to make sense of their meaning and implications. We also verified original meaning and considered if there were any misinterpretation in the translation process. When we encountered some difficulty in terms of language, we went back to the original text and carefully reviewed the translation to ensure that the translation did not change what the participants originally said.

The annotations were then transferred to an excel spreadsheet that identified the filename, a coded reference, the content related to the code and the meaning of the content within the context of the location of the interview, the interviewer–respondent relationship, and the overall experience of the participant represented in the interview. The types of discourses that emerged related to participant experiences were perceptions of disability. This included notions of cure and punishment, internalized negative perceptions as well as challenges to them. Discourses of inclusion and exclusion emerged in family, community, school, and work life. Each location was given a separate excel sheet in order to maintain awareness of the geographic / socio–political context.

Visual Analysis

Visual data (cellphilm, photos, drawings, and documentary film) was analyzed to understand the perspectives of the girls and women through their productions. The analysis was conducted using the following visual framings: 1) context and authorship (In which context the visual is produced? Who produced the data?); 2) content of the image (What does the content of the text/image/cellphilm tell us? How does the text/image/cellphilm reflect the participants’ ways of seeing? What and how is the narrative being told? How does the production counter or ‘speak back’ to the dominant discourses on disability, gender, and/or ethnicity?); and 3) Interpretating the image/narrative in relation to the “bigger” stories (What does the image tell us about participants’ consciousness about inclusion and exclusion? How does it reflect their activist perspectives? What has been silenced, excluded, or left out? Why?).

To involve the women and girls in the participatory analysis of visual data as knowledge–producers, we invited them to write captions about their pictures. Each group created a poster narrative representing what they meant through their visuals. Each group was then invited to present their poster board to the bigger group and other groups to exchange their conversations. The research team also involved the participants in analyzing disability stories which were created from their individual narratives. To do so, we created composite digital media stories (see Image 3 below) from the interview data in a way that did not reveal the participants’ identities. The composite media stories were digitized by our research assistants and used as a part of participatory data analysis tools to engage the participants in reflecting on their own stories, or stories from their peers. To do so, we invited the participants to view the composite stories and share their perspectives about these stories. This process generated further discussion about the “characters” being depicted in these stories. By engaging the participants in the process of visual analysis, we engaged them as knowledge producers while at the same time tackling the ethical dilemmas of focus group discussions, where participants tended to recognize their peers’ stories.



Image 3: A story of Binh on poverty and disability – a composite digital media story created from the participants’ narratives.

FINDINGS

The key findings about the situations of women and girls with disabilities involve perceptions of disability, experiences of survival, discrimination, disrespect, exclusion, inaccessibility, violence, and internalized ableism. In other instances they describe experiences of inclusion which took on several forms. Their experiences are distinctive in the specific contexts of the global South. Against these experiences participants also developed strategies for activism, empowerment and expressed their hopes for the future.

Perceptions of disability

The participants’ perception of disability was not monolithic. They expressed a range of cultural, religious, cosmological, and modern scientific perspectives on disability and functioning. Interestingly, while they shared similar experiences of disability and discrimination, they held various perspectives on what it means to have a disability. Across the three project sites, we found that negative perceptions of disability have lingered within these communities. This reflects the cultural prejudice against disability that has continued to be reinforced in these communities. While the participants rejected the Buddhist interpretation of karma as a form of God’s punishment to their ancestors or their own deeds in a past life, some participants seemed to adopt a more modernist perspective on disability as a functioning issue. Specifically, both girls and women referred to their disability as an inability to do what able-bodied people do. The language of “normal people” (người bình thường) is usually referred to as a frame of reference in their language.

Some women associated disability with 'accidents' and 'misfortune' while also attributing their impairments to a lack of access to care, livelihoods, and employment. 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 or as something that prevents a person from performing their daily activities. For example, 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.

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. However, the girls argued that even with a disability they were still capable of doing things, being successful, and beautiful, but sometimes they needed to do those things differently. Hom Hinh from Bac Tu Liem recognized the diversity of disabilities:

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 are some tasks that they cannot do by the same way like able-bodied people, they can do by other ways. This is my opinion.

The ethnic minority girls with disabilities from Paco and Ta Oi experienced multiple oppressions due to institutional racism, ableism, and classism. One girl revealed that others treated her as "ugly": "They spoke badly about me ... like I was disabled, I was ugly" (GWD 10). Other girls expressed vulnerabilities when being looked down by their peers: "I feel hurt... I feel ashamed" (GWD 11). A girl with epilepsy, That Tha, shared the same feeling: "I felt timid, sad. Sometimes I cried." Ut, a girl with a disability in A Luoi affirmed that she was ashamed not because of her disability but because of people's negative attitudes, thus she hoped people could change their attitude towards her disability, then she would not feel ashamed.

Some Deaf girls described being unable to communicate with their family members who did not learn Sign Language. One mother who accompanied her Deaf daughter to the interview defended not allowing the use of Sign Language at home, "She talks with her friends with Sign Language at school, but she isn't allowed to speak in Sign Language at home. I am afraid that if she uses Sign Language for communication, she will be lazy in talking." Instead of learning to communicate with her daughter in an accessible way, this mother neglected her daughter's communication needs.

It should be noted that during this interview, Meo Con did not communicate except with one or two words, and the interviewer subsequently turned to focus on the mother – an indication that the mother’s efforts to have her daughter communicate verbally. The lack of understanding and accessible modes of communication among the girls and their family members may have reinforced their negative perceptions of disability.

On the flip side, Hoa Ly explained the effects of having parents who did not learn Sign Language, “My mother knows a little bit about Sign Language. My father just points. Now I’m teaching Sign Language to my younger brother. When I teach him, I really want him to help me communicate with other family members.” During the interview she admitted that her parents did not talk to her very often, so she just focused on reading her Bible. Here, Hoa Ly used her disability as a pedagogical tool for teaching her non-disabled parents about communication with Deaf people. While her efforts were not always successful, disability is transformed into a space for making connections with others and for affirming her Deafness.

Some children could identify the moment they felt that they were different from their families or peers – or that their differences were viewed negatively. Powerfully, Hom Hinh described not knowing that the other children were laughing at her disability and so she laughed with them. At this point in her life, Hom Hinh did not know that people would have negative perceptions of her disability. It is the interactions with society that form and inform how children see themselves and their disabilities. Living with a disability, women and girls can not necessarily predict others’ reactions and this can be complicated. They may come to expect negative reactions based on previous experience but then encounter people who react more positively. This may have to do with life experience, or the way people with disabilities learn to address their own disabilities with others, or maybe people just become accustomed to knowing the person with a disability. Whatever the reason, it is not straightforward. Later in the project, Hom Hinh explained the shift in her perception of her disability and her feeling that she should hide it if she could, to avoid the ridicule. She said,

After that, everyone told about it many times, I wondered “Why I was like that?”. Clearly, I looked like a normal person, but in reality I was ill. So, I felt I should not tell about it because everyone could discriminate. In secondary school, my parents told the teacher about my illness, sometimes other students teased me because of my illness. After that, when I studied in high school, I didn’t want my parents to tell my teacher that I was ill...finally my mother had to tell her. She told my classmates, but I found their expressions normal. So, I found my illness wasn’t a problem, because many people are ill, even they have expression and they have more difficulties, more discrimination. Now, I find if I say about it, that is normal. After that, everyone pay attention to me more, and even some friends don’t care about whether I’m ill or not.



Clearly, how other people reacted to her disability has influenced the participant's disability perceptions. This reflects a social-relational perspective of disability that was revealed through the disability narratives shared by many participants. For example, during her childhood Hom Hinh did not want to reveal her disability (defined as illness in her perception) because she was concerned that other students would ridicule her, which rendered her perception of disability as not normal. In contrast, during her high school, she thought that her disability is "normal" when other students treated her with respect. Here, her perception of normalcy is closely related to how her friends treated her. This reflects the social constructions of normalcy that shape the participants' perspectives.

Many participants themselves understood that there was stigma attached to having a disability, but they did not necessarily feel that their disability was a negative thing. They shared the various ways disability has been characterized in their schools, families, communities, and even within themselves. These characterizations are discussed next.

Perceptions of disease and illness

Several participants from communities vastly impacted by Agent Orange viewed their disability as a disease or illness, especially where their access to health care and resources was very limited. While perception of disability as illness was not the only way participants characterized disability, the medicalized discourse of disability was often expressed. For example, when asked about their disability, participants usually referred to parts of their bodies that do not function properly due to the consequences of 'disease':

Facilitator: ... Could you please discuss more about disability?

Woman 1: There are some diseases that cause disability.

Woman 2: The disease can cause disability but it is not a disease, but it is a disability.

Perceptions of disability as illness tend to be more pervasive in communities where access to livelihoods and health care is often unavailable. For example, due to their urgent and constant needs for access to medical treatment for blindness, many women in A Luoi associated their disability with an illness as a way of drawing attention to their personal and collective struggles.ⁱⁱ In so doing, their discourse of illness was deployed to claim access to care. An 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.

Ngo's perception of disability as a 'disease' may be seen as associated with a 'personal tragedy' – an individualistic view of disability in the Western context (Oliver, 1990); however, we posit that this perception needs to be understood in its historical context where their bodies were rendered disabled because of the generational impacts of the imperialist war (Nguyen, forthcoming).

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 two, three generations, not just one. 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.

Stories of illnesses are indicative of the struggles for survival which impact the lives of women and girls with disabilities in the global South (Nguyen & Stienstra, 2021). These stories need to be contextualized within the broader context of socio-political conflicts such as colonial and imperialist violence in the global South, which rendered their lives as suffering. To make sense of this perception, it is necessary to reflect on Vietnam's history with war and the intergenerational impact of Agent Orange. Many participants in A Luoi felt the consequences of Agent Orange on their bodies or their family members' bodies. This reflects the debilitating impacts of Agent Orange on their ways of understanding disability and impairment (Nguyen, 2018)ⁱⁱⁱ. While not all of them linked the impact of the imperialist war on their bodies, older women recognized this socio-historical impact. For example, Ms. Xuan describes disability as a consequence of war, with the toxic spray of Agent Orange causing suffering for many generations. A veteran with visual impairment, she engaged with us in discussions about disability and community. Her stories vividly illustrated the material impacts of Agent Orange on every member of her family – her husband, son, granddaughter and grandson, and her community.

Consequently, the economic condition related to the context of war as well makes this complicated because the war has had several intergenerational impacts on families. One girl said that her father and brother were affected by Agent Orange. 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."

Disability, livelihoods, and survival experiences

Most women and girls with disabilities in the TDKRA experienced poverty and exclusion in many aspects of their lives but their experiences with exclusion varied significantly based on their spaces, social positions, and relationships with their families and communities. They shared common struggles in their everyday lives such as illnesses, deteriorating health conditions, lack of access to health care and education, and exclusion from schools. Many women embedded their discourse of illness within the story of family struggles for livelihoods. A woman said, "My arms and legs are numbed, so I am not able to work. However, if I do not work, I cannot afford to pay the cost of living. Therefore, I try hard to work. Very difficult!" It appears that her perception of disability as an illness has been associated with her struggles for livelihoods within the context in which access to resources were scarce and unaffordable.

Critically, while poverty was a common experience among participants in all communities, we found that ethnic minority girls and women with disabilities tended to experience more intensive poverty and exclusion than the girls and women in other communities. Their experience ranged from not having access to health care, to constantly being in debt and unable to pay it off, as well as struggles to buy food, suggesting steep levels of poverty compared to the participants in other more advantaged communities in the project.

One ethnic minority girl associated her family struggles with poverty with illness: “Like other girls with disabilities, I am also bearing aches and battling against poverty”. Another girl in the same community said that her family constantly struggled for food: “When my family do not have money to buy rice, my mother borrow chicken [and] eggs. In the afternoon, she borrows money to buy rice for us.”

The need for the girls with disabilities to secure their livelihoods was also expressed in their desire to get a job in order to help support their families. Housing and livelihood security was a motive for some of the girls, whether it was to help their families find a permanent place to live or because they were aware of family struggles to pay off their debts. If a parent also had a disability, this impacted the financial stability of the family. Image 4 was produced by a 14-year-old girl with visual impairment whom we refer to as Thuong^[5].



Image 4: Artwork produced by Thuong, age 14, A Luoi, 2017.

This drawing reflects how Thuong wants to present her everyday life – a rural space with a banana tree, a range of mountains, and a glimpse of sunshine in the background. At the center is a woman standing by a house with two chickens on her left. At the bottom of the picture is a farmer who appears to be harvesting in the field. There is another field coloured in blue with some trees across the field. As she described: “My drawing is about my parents. My father is working and my mother stays at home. My mother is not able to work because of her hand pain.” Her story reflects the relationship between disability and the lack of livelihoods. The images of plants, harvesting, and chicken reveal how important livelihoods are for her and her family. However, the very fact that her mother could not work because of the pain in her body reveals the struggles for livelihoods in her family.

This story resonated with many women with disabilities who expressed their struggles with illness and poverty, and yet, their desire to live a productive life. The girls generally came from families who worked hard to meet their daily needs.

[5] We use the participant's nickname in this report to protect their identities.

Out of necessity the young girls helped in the home with cleaning, cooking, and washing or selling vegetables. They saw this as their contribution to the family who was facing financial difficulties. One participant expressed pride in her ability to help and contribute to the family. She would point out to her mother that she cooked as soon as her mother returned from work. Several participants helped at home but they also wanted a job to help their mothers who were working hard. The girls often talked about being close to their grandmothers who was living with them or because they visited their grandmothers regularly. This may be because the parents often worked long hours at difficult jobs.

Some participants said that they wanted to go to school, but their families argued over whether it was better to send the daughter to school or to send her to work to earn an income. These individuals' situations reflected broader power dynamics which shaped the lived experiences of these girls and women. Interestingly, there were conflicting desires within the participants to finish school or to help the family. On the one hand, school was costly and on the other, the young girls could earn money for the family by working. One participant who was not in school said she didn't want to be in school because she needed to work and help make money for her family. Decisions about sending children to school were also made based on the need to have someone at home to help with domestic chores. While some girls dropped out of school to help out at home, other girls stayed in school or boarded at a school despite the family's financial difficulties.



Image 5: Artwork produced by Hong, age 32, titled Production, A Luoi, 2017.

The women also expressed a desire for livelihoods through their visual productions. The drawing above shows a woman pouring grain to the ground to feed two little chicks. Her house is surrounded by a field of growing crops in the top left corner. In the bottom right, she draws another field, some plants, and a pond besides it. There is a tree along with a dome-like haystack. In her presentation, Hong said: "The topic of my painting is 'Production.' I hope my family will have a garden to provide food, grow vegetable, raise chicken and fish." Here, the picture seems to reveal her hopes for securing livelihoods through representations of her everyday lived experiences.

Interestingly, in both drawings, there was no indication of “suffering” because of disability, but rather, representations of their everyday lived experiences and participation. This seems to suggest that women and girls with disabilities wanted to fully participate in a productive life in their own communities in ways that marked their existence. Thus, although their struggles for survival was a part of their everyday life, the participants envisioned their struggles in more optimistic and perhaps hopeful light than what may have been assumed about their suffering (Groce, Kett, Lang, & Trani, 2011).

Critically, the girls’ desire for survival is associated with relationships within their families, communities, and friend circles. There was a feeling of belonging expressed by many of the girls. For example, when the girls shared about their families, they tended to discuss their relationships with extended family members such as their parents, grandparents, siblings and also aunts and uncles. Many felt loved by their families and at times felt like they were treated better than their siblings. Some described getting presents or celebrating accomplishments. Several of the girls talked about visiting their aunts or their grandmother’s houses. Sometimes they cooked for the girls and other times they visited the girls at their homes. Extended family was important to the girls in various ways. In some cases, the neighbors were family members who helped and supported them. The girls also described their mothers or fathers taking them to school or even to the project location.

The women expressed a need for job opportunities as a part of their survival needs. However, they associated discrimination against their disabilities in employment opportunities. For the women who were either single mothers or breadwinners for their families, livelihoods were the most critical need. The degrees to which livelihoods were important to the participants’ survival and development varied among different communities. For example, most women in the Paco and Ta Oi ethnic communities in A Luoi expressed a desperate need to sustain their livelihoods, to have a small house, a piece of land to grow their crops, or some money to raise cattle and chicken. One woman shared that farming was not enough of a livelihood to save money or even to buy water and food. Other women described hard living conditions with sick family members and families who could not afford the cost of living. Their experiences with disability and illness within their family or by themselves further intensified their struggles for life and survival.

Consequently, participants felt excluded through their experiences of discrimination, disrespect for their differences; unequal treatment in schools, families, communities; lack of access to schools; being denied of employment opportunities; as well as forms of physical, verbal, emotional violence (see also Nguyen et al., 2019, 2021).



Discrimination

More girls with disabilities experienced discrimination in primary, secondary, high school and university as compared to those who did not. Figure 5 shows experiences with discrimination in schools. Levels of discrimination were higher among primary and secondary school girls with disabilities than in other settings. This finding may have been skewed due to the fact that the majority of girls in TDKRA attended primarily and secondary schools.

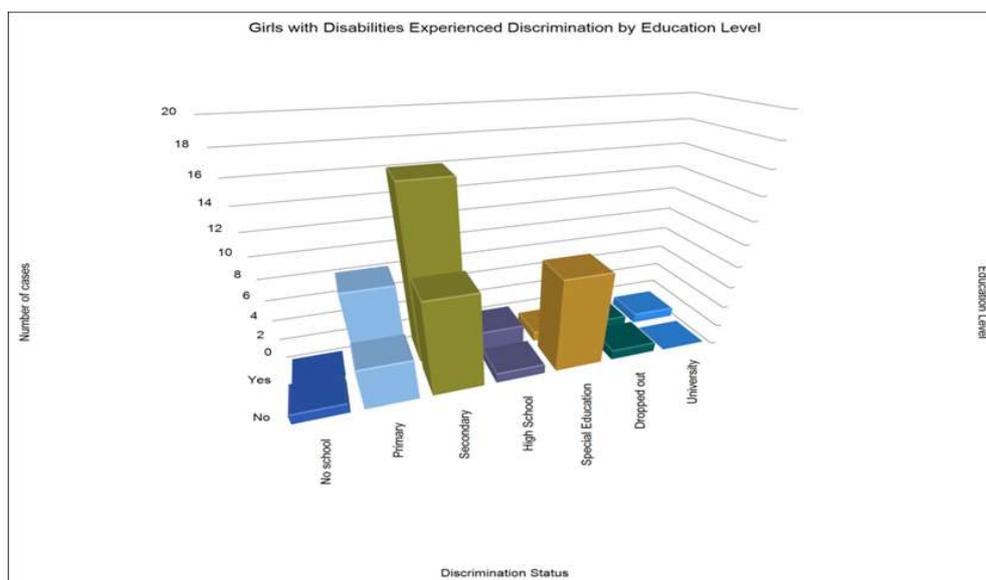


Figure 5: Discrimination by education level.

The women and girls with disabilities experienced discrimination in accessing school, the community, in their families, and employment. For example, several girls shared their experience being discriminated in school. Chanh told her interviewer that friends “swore at me and spoke badly to me.” An ethnic woman with intellectual disabilities reflected on her schooling when she was teased by boys as having something wrong with her body. She said that her teacher told her and her mother to “stop [letting her] go to school.” When asked about disability, the participants expressed more concern about being teased for having a disability rather than their experience of living with a disability. One girl said she is “afraid of being teased by everyone that I am a person with disability.” This shows a concern for being discriminated against.

Ori was an eighteen-year-old girl with a mobility disability who completed primary school. Her family was poor and she described wanting to work as a noodle delivery person for a small street vendor but she was rejected. She articulated, “I want to go to work, but people don’t accept me.” A woman with a disability tells her story about being denied employment because of her disability,

Facilitator: Is it because your family is poor that they bully you?

Chanh: Sometime I heard that my house was poor like pig's house, bull's house...

Facilitator: Are you an ethnic minority member?

Chanh: Yes

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

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

In many discussions, including the focus groups, ethnic minorities described experiencing discrimination, and the girls recognized this collectively when they viewed the digital storytelling which was created from their interviews - one those stories focused on ethnic minorities. In the story below, Minh said she was usually made fun of in class because of her grey hair, which she interpreted as a sign of "bad blood." Her ethnic minority parents were usually in debt. While she did not explicitly indicate either social class, disability, or ethnicity as a cause of violence, the exchange below revealed some forms of verbal and emotional violence which ethnic minority students experienced in their schooling:

Linh: Is there the Kinh in your school? How does the Kinh treat you? Have they ever teased or discriminated against you?

Minh: Yes.

Linh: What did Kinh people say about you?

WWD9 (Interpreter): They said I was crazy.

Linh: Did they tell only you or others?

WWD9 (Interpreter): They often speak badly of her parents. They talk about their story. She feels ashamed and does not want to talk about it.

Chanh and Minh also 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. While Minh explicitly linked her violent experience with ethnicity, Chanh seemed to interpret her experience with discrimination due to her being "weak" - something associated with her disability and ethnic position. The language of "my house was poor like pig's house, bull's house" revealed how her minority status, along with her disability and poor socio-economic condition, has positioned her at lower status than her able-bodied and majority peers.

Critically, participants showed that they had an ability to tackle such forms of discrimination. They raised the importance of addressing discrimination during the interviews, focus groups, and film making activities. When asked why she wanted to include discrimination in the film production, Hom Hinh said, "Because in general, people with disabilities experience discrimination everywhere including school, surrounding community or even in the family." This same girl also expressed the effect of discrimination on livelihoods and employment opportunities for people with disabilities,

At the present, many people are unemployed and people without disabilities can be unemployed, so it is very difficult for people with disabilities to get a job. They cannot depend on others for the rest of their lives. They also want to find a job but many companies that recruit employees look at the resume including a medical examination. And often people will immediately remove those who are in poor health and of course, those with disabilities will not be able to be hired. Thus, I think we should create more jobs for people with disabilities.

Disrespect for difference

Often disability comes with different ways of communicating or doing other daily activities and possibly also looking different from peers. When there is a lack of awareness about disability or there are misconceptions about what it means to have a disability, this can result in disrespect for difference. In this project, this commonly manifested in school through bullying or calling children ugly.

Many girls experienced being looked at and treated differently, which made them feel excluded. Their perspectives are linked to their experiences of being marginalized because of their difference to how they feel about that. For example, Meo Nhi talked about feeling different from her peers and lonely because of the ways her disability was treated. Many girls shared this feeling of isolation and powerlessness because of their exclusion.

Disrespect for difference can be seen in several ways whether it is exclusion, bullying or violence. The girls understood that they were being treated badly because they were seen as different from others. One girl described feeling like the other children teased her before they had gotten to know her and indicated that they treated her better once they got to know and understand her.

Sometimes the participants were teased for looking different or were excluded out of fear that the disability was 'contagious.' In another instance, boys teased one girl saying that she had a coarse voice. She explained that other students told her she had eyes like the devil. Importantly, she had confidence despite these perceptions about her. When asked if other students played with her, her answer provides clues into how she felt about herself and her perceptions of beauty as it related to disability. She said, "Yes, in my class, we do not discriminate between rich and poor, or ugly and beautiful." Sadly, though she was saying she was not discriminated against, she still described being teased and she expressed that she feels ugly because of her disability. At the same time, she wanted to show that she could respond to her friends by reclaiming her beautiful soul:

Facilitator: Is there anyone who speaks badly of you, tease you?

Moon: There are some older students who often said my eyes were like a devil.

Facilitator: When they said that, how did you feel?

Moon: I said: "Although my eyes are not beautiful, my soul is more beautiful than others."

Similarly, a Deaf girl who used sign language, Hoa Ly, affirmed her disability, saying that “About my disability, I think it is no problem. I am the same like other hearing people or I do not know what they think about me.” (Interview with Hoa Ly, 2018). Here the girls showed that although they struggled with ableist attitudes against their difference, they were able to respond back to discrimination through their self-affirmation of their difference.

During the focus group discussions, the women with disabilities involved in the project also discussed the impact of the disrespect for difference they encountered in school and in the community which resulted in being excluded and discriminated against or being treated with disrespect because they were different in some way or because they did things differently than expected. One woman with a disability explained,

After university, I had trouble with discriminations on my disabilities from other persons; I also had problems with my family members because I didn't get a job. Let me share some experience about my time when I was in university. At that time of 11 years ago, I went to school by three-wheel bike, and the perspectives of people in community were bad. They have few chances to face persons with disabilities who were in community, so using a strange vehicle made them a point for discussions. They told that I was a child as I used a 3-wheel bike. I tried my best to bear it, but it hurts me a lot.

For the women also, there was ridicule that came with being discriminated against which is very hurtful just as it was for the girls in the project.

Social exclusion

The girls and women with disabilities identified various barriers to participation and recognition through their drawings, interviews, focus group discussions, and community engagement when they talked about what they hoped to achieve. For example, one girl makes the link between social exclusion and discrimination in the community. She explains that some people scorn people with disabilities, and this is discriminatory.

The interpretation of what the girls discussed during their interviews was sometimes more nuanced than first appeared. Context is important for understanding why the girls had their experiences. It may appear as though families were excluded from communities when they did not have visitors, for example, because of their intersecting identities related to disability, ethnicity or socio-economic status. In one instance, the interviewer asked the young girl if her family was visited by the neighbors and she said no. The interviewer inferred from this that it was only her family who did not have visitors, but the girl explained that no one visited each other in the community because they are tired from working. Not having visitors was not an indication of exclusion. In this case though, the adults did not interact with her but the children did. She felt this was because the adults saw her as 'weak.' This shows that exclusion can be complex and hard to identify based on one set of experiences. So perhaps the family was not excluded from the community, but the girl was.

At times, exclusion in the community was evident. It was common for participants to express that they felt they were being alienated and isolated by people in the community. Bup be, who lives in Can Tho, expressed that her neighbors do not like her, invite her to their houses, or play with her. She said, "Nobody likes me.... Nobody invites me to their houses." Ori firmly stated that her neighbors and family saw her bodily impairment as an excuse to isolate her, "Everything and everybody stay away from me. My parents don't love me, neither does my sister... They said that I couldn't play these games".

Access and accessibility

Participants shared their experiences with exclusion through many inaccessible problems with education, the public space, as well as support and social services. They also suggested strategies for tackling inaccessibility.

School settings

The finding shows that schools were not accessible for many participants with mobility needs. Many participants would not use the toilet at their school. Some girls with disabilities felt it was inaccessible while others described it as dirty or scary. Alarmingly, Huong Duong said that she had never used the school toilet during her school years.

Huong Duong: I drank at home, went to the toilet at home then I didn't do these things when I was in class.

TL: Did you mean you refrained from going to the toilet all classes?

Huong Duong: Around 3 hours, I did not dare to eat anything in class.

TL: Was it not accessible for you to go to the toilet? And it wasn't at the same floor with your class, was it?

Huong Duong: Yes, that's right. You had another block to go the toilet.

TL: Did you ever reach there once?

Huong Duong: No, I did not. I didn't ever go to the toilet during my school years.

Other participants, however, said that their toilet was easy to use. It was not clear whether the participants had a clear definition of accessibility in mind. For some participants, "accessibility" meant "easy to access." For others, this was not a concept that they felt familiar with. It suggests, however, that the washroom was inaccessible for those with mobility needs.

Furthermore, for childhood disabilities, being a part of games and activities at school is important for their social development and feelings of belonging. The girls described being excluded from play at school when other children would not play with them or when they were called names because of their disability, gender, and ethnicity. Sometimes they were made fun of. Be Cao, who is blind, described being excluded from play at school by a girl who was her age because the girl believed she could not play any games. When asked how she felt she said, "I felt so sad, and I wish I could see anything to play with friends." Again, this girl took personal responsibility for her experience. She was being socially excluded at school but believed if she could see then they would play with her.

Public space

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 center so that people with physical disabilities can use these places, their perspectives of access went much further. For example, a conversation between the girls with visual and hearing impairments showed that the girls were very knowledgeable about what kinds of support they needed to make society more accessible to them. They discussed using Sign Language for Deaf people and using their voices to help guide people with visual 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 as a tool or device but as a means to inclusion in itself.

During the workshop, participants discussed how to make the environment accessible. One participant had an insightful suggestion that thought beyond what should be done, but also to what happens when accessible spaces do not work the way they are intended to,

WWD1: In your opinion, people who use wheelchair, go to school, do they have difficulties?

Phu Dien: I think there are lot of difficulties because they can't go out. For example, playing a chase game, they use wheelchair, maybe they just can see.

WWD1: What do you think about stairs? How can people with disabilities access?

Phu Dien: I think this problem is quite hard to solve. I think if they want to go, they will need to [have] many supporters.

WWD1: Do you think people with disabilities should ask for help or school need to change the stairs to be accessible so people with disabilities can access easily?

Phu Dien: I think both.

WWD1: So, do you think it will be better if school has elevator and wheelchair access or people with disabilities ask for their family members help?

Phu Dien: I think asking for other people's help is better. Because if they uphill, just have a small mistake, they may fall down. And sometimes the elevator can be short-circuited, they can be locked in the elevator. I think if asking for family members will be better.

Clearly, those with different disabilities had different perspectives on what they needed to make the environment more accessible. Although not all participants could clearly indicate what they needed to make the environment more accessible to them, they called for a need for the community to support women and girls with disabilities. A cellphilm produced by the girls and women with disabilities in Bac Tu Liem, titled "Accessibility", showed a girl was trying to move her wheelchair over the curbside. However, because the school does not have a ramp, she had a hard time to move her wheelchair onto the curb. Interestingly, rather than merely identifying the inaccessible space, the girls demonstrated their capacity to identify a solution. The next scenario showed that the teachers and students were coming to move her wheelchair to the pavement. Their message of solidarity and community support was clearly articulated in the film.

Support and services

Another type of inaccessibility which could be found in an inaccessible policy landscape is the lack of services and supports for girls and women with disabilities. There were significant inequities in terms of access to social services especially for those in the mountainous regions. Specifically, women and girls with disabilities in A Luoi have often been excluded from getting access to diagnosis because they lived far from the hospitals. The Vietnamese Law on Persons with Disabilities (SRV, 2010) requires disabled people to be diagnosed by a committee to determine their levels of disability and, on this basis, distributes benefits. Many participants in TDKRA identified the lack of government support for their disabilities. In A Luoi, for instance, a young girl named Miu Miu said that it was challenging for her to receive social security disability assistance despite having a mobility disability that causes her pain when walking. She described the complex process to get the certificate of severe disability from their commune to the district and provincial level. The women with disabilities in the workshop helped her to apply for the certificate and the assistantship a few times but were not successful.

In another conversation that we had with the women with disabilities, the women believed that they were exposed to Agent Orange. However, due to the lack of documentation and certificate by medical experts, they were not entitled to receive the benefits. Even when they received allowances, the benefits they received were considered too small to meet their needs. A grandmother of a girl with intellectual disabilities in the project, who was herself a woman with visual impairment, commented that "Not only me but also everyone wants to increase the allowance for the victim of Agent Orange."

The lack of access to health services in the communities in relation to the legal status of being a person with disabilities made women with disabilities invisible. A woman with disabilities expressed,

Because normally [when] women with disabilities go to the hospital, the doctors will say we are not sick. So when they go to the workshop, they can see how much difficulty we have to face. Then they can clearly examine and identify our illnesses and disabilities. It will be easy for our paperwork and policies at the commune as they do not accept our papers before when they said we are 'normal.' For example, we have visual problem, but they always say it is 'normal' because they can't see it.

Due to the inaccessibility to the government's benefits, many women with disabilities in the project managed to self-employ in order to meet their families' needs. While some women and girls were able to get some skills training through their DPOs or their social networks, others could not live independently due to the lack of opportunities and supports that they received.

Violence

Violence can take many forms and affect all aspects of life; school, social, and home life. The girls described being teased, hit, having their hair pulled, their notebooks stolen, or being cursed at. The girls commonly explained that students said mean things to them because of their disabilities; things like their parents should not send them to school if they have a disability. Sometimes the girls blamed themselves for the violence they experienced.

Many girls described being bullied or hit at school by both boys and girls. Some girls felt that they could tell their teacher and had the confidence to do so. The teachers often told the other students to stop their bullying. In Can Tho, one girl explained that she did not tell the teacher she was being hit because she did not want the other students to hate her more. Sometimes, the girls experienced a 'victim blaming' attitude from adults when they reported incidents of violence. The same girl explained that she stopped telling the teacher when she was being scolded because when she did the teacher hit her as well. Instead of helping or having a way to prevent future bullying, some adults ignored or blamed the girls for being bullied going so far as to say if the girls did not play with the bullying child, then they would not be hit.

Occasionally, the girls themselves resorted to violence out of frustration. One girl described feeling frustrated when she could not properly communicate with students who were teasing her, so she used violence and hit people out of frustration. Classmates sometimes prevented other children from playing with girls with disabilities. A number of girls felt excluded at school because friends did not want to play with them due to their disability and they describe feeling sad about this. One participant recalls, "From grade 1 to 3, I did not have any friends. I have made friend since I was at grade 4."

Other girls described an understanding of power dynamics in the classroom saying that the bullies feel like they are stronger, so they pick on weaker students. One student said she did not fight back because she was timid and shy. Though the interviewer repeatedly asked if it was because she was a girl, she insisted that it was because she was shy.

The girls also worried they would get in trouble for being bullied. One student had her books stolen and thought she would get in trouble by her parents for losing her books.

Trai Tim, a girl with a disability, frequently described violence at home from her father and stepmother. She loved her father but blamed her stepmother for making him become angry with her. She described wanting to do better so she would not be hit. She said, "I want to find some way to correct my faults. Don't scold, don't hit me. I'm wrong, I will correct my faults." Self-blame again surfaced in discourses of violence. After she described being abused by her father or stepmother, she would share memories of her biological mother without being prompted. She felt that since her mother was gone, only her grandmother loved her. She also became silent after saying she thought her siblings were ashamed of her. This silence occurred when difficult feelings were being discussed.

Some participants were scolded, chided, or shouted at by their parents and siblings for doing things incorrectly. Cho recalled her sadness when being hit by her mother while Cong Chua shared that she felt scared when being lectured by her mother for being silly and being chided by her father every time he was drunk. In addition, she also revealed that her parents locked her inside the house to prevent her from going out to play with friends.

Internalized ableism

When children with disabilities are treated poorly because of their disability or they are told that their disability is bad for long enough, they may start to believe it and internalize those negative feelings about their disability. This was found on several occasions within this project. The girls commonly described feeling inferior. For example, Moon expressed similar negative feelings about her disability, "Occasionally, I feel inferior because I am different. I sometimes do not have much self-confidence."

Similar to the others, in talking about her disability, Miu Miu said of her peers who called her disabled and ugly, "I want them to know it wasn't my will that I became like this. I hope they can understand." Each of these girls explained that the disability was not their fault. They see having a disability as a bad thing because of how they are treated by their peers and as something they have to defend. This reinforces the notion of disability as a punishment and something that is undesirable. Ori described also being poor and internalizing feelings of being unworthy due to both disability and economic status.

Ori: When I sat down, [the other children] went away, I played by myself.

Interviewer: Did you know the reason why they treated you like that?

Ori: I thought that they were rich, they didn't like playing with me. My brother often came to my class and gave me candies.

Interviewer: Do you think that you are disabled so you aren't love by them?

Ori: Yes, I do.

BC: Do your friends play with you?

Ori: No, they don't.

BC: Do you think that because your family is poor they don't want to play with you?

Ori: Yes, I do. I am poor so I am not worthy to play with them.

Instead of pointing out social prejudices against people with disabilities as the causes for being excluded, participants such as Ori and Mot again tended to think that it was their fault or their destiny for being disabled. Being excluded or discriminated against led to feelings of self-blame or punishment. It is difficult to have confidence about disability when experiencing isolation because of it. Ori thought of disability as a sickness and her destiny and wanted to be able to change her destiny so that the other children do not stay away from her and hate her.

In one particularly powerful account, Ori explained that because of her disability in the early part of her life her father asked her mother to let her die. Then he told people she had indeed died. She said, "Everything and everybody stay away from me. My parents don't love me, neither does my sister." When asked if she thought she was unloved because of her disability, she said 'yes' and added, "I wish I [could] get over my sickness, [so that] my mother doesn't stay away from my father and me." Here, the perception of disability as a burden is overwhelmingly clear. This young girl not only understood that her parents thought her disability was a negative thing; she lived with knowing that her father wanted to let her die because of it. Not surprisingly, though not warranted, she blamed herself for her family not being together, thereby internalizing these perceptions of disability rather than resisting them. In fact, Ori expressed negative perceptions of her disability and the feeling that nobody loved her several times during her interview.

One girl explained that her siblings took her to school but that they felt ashamed of her. When asked why they were ashamed of her, the girl stayed silent. Another girl described contracting polio when she was three years old. She said that her mother felt sad and took her to several doctors to try to cure her. Of this she said, "When I was young, I didn't know anything so I didn't feel ashamed about my impairments." These young girls have learned to be ashamed of their disability and to see it as a burden creating complicated and negative feelings for the girls about things they did not choose. Being stared at by other children often made the girls with disabilities feel sad as well.

Internalized ableism surfaced throughout the project in more subtle ways as well. There is isolation that is often experienced along with the internalized ableism. Ut, a girl with a disability in A Luoi, describes feeling ashamed of herself because her peers tease her due to disability. Huong Duong in Can Tho described spending most of her time in her house or in her room. She did not wish to go outside because she felt she did not know anything, and so other people would laugh at her. Her feelings and negative self-perception extended to work where she said she tried various jobs but could not do them because she was scared, or because she felt she was not smart enough to do the jobs.

Again, when asked about participating in the cellphilms, Huong Duong's explanation about not wanting to appear in the film or draw attention to her disability while at first it may seem as though she had internalized the ableism she encountered in her life, and perhaps to some extent she did, but there was also a desire to resist negative perceptions such as pity about disability. When asked why she didn't want to be filmed she said, "If filming for a pity or for people giving me a pity, I don't need that. I find it is a discrimination rather than a pity."

Self-blame is another consequence of on-going exposure to negative perceptions of disability. For example, sometimes the girls with disabilities blamed themselves for not doing well in school or another aspect of their life when in fact their performance was due to not being properly accommodated. In one instance Hoa Ly, who is deaf, tells about being excluded by her coworkers because they cannot communicate with her, but she rationalized it as 'okay' because having conversations with coworkers hinders productivity in the workplace.

However, the girls did not always blame themselves for what they experienced. They seemed to have a deeper understanding of the ignorance of the bullies. Multiple times Hom Hinh talked about a boy who was bullied with violence because of his disability, and also described being bullied by younger students. She felt that the young children did not understand what they were saying. Despite all of this, she said that she saw herself as 'normal' even if her friends did not.

Sometimes internalized ableism can be found in silences. A young woman in Bac Tu Liem expressed such silence when she was asked about how she feels being a girl with an intellectual disability. Perhaps because it is difficult for her to talk about this when she experienced exclusion in her daily life.

The women with disabilities who participated in the project were not immune to internalized ableism. They discussed feelings of insecurity and inferiority. During the focus group discussion in A Luoi where the women were discussing the films they had produced, one woman with a disability expressed feeling self-conscious about her appearance indicating that she changed her mind and did not want to be included in the film. In part, she said:

Ms. Ly: just remove my face.

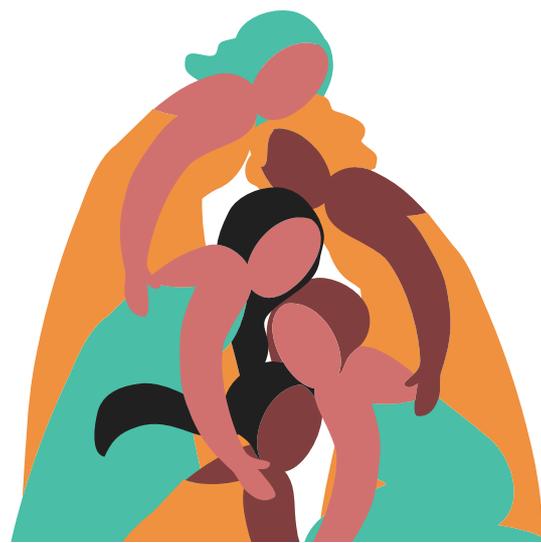
Interviewer: Why?

Ms. Ly: Because I feel ashamed.

Interviewer: Why are you embarrassed?

Ms. Ly: Because if they see they will judge, they will laugh at me. In that scene I was ugly.

We can see here that fear of judgement and ridicule can span a lifetime for women and girls with disabilities because this was what they had experienced in their lives. This was revealed through their interviews and focus group discussions, where they expressed their experience with discriminatory attitudes, violence, and exclusion.



Participants' perspectives of inclusion

Inclusion was discussed in several ways throughout the project. Being meaningfully engaged in activities and events on an equal basis with others was described by the participants during the interviews and research activities. The participants decided it would be best to use the films to portray experiences of disability more positively so that people without disabilities would have a more positive perception of disability which would help improve inclusion in all areas of life. Feeling included, for the women and girls, meant feeling like they were a part of their school, family, or community. There were sentiments of belonging, reciprocal relationships, participation, accessibility, rights and hopes that all contributed to feelings of inclusion. In school it could be that teachers supported students to meet their learning goals or when students were bullied the teacher warned the bullies, or the girls were included in playtime with their classmates. Critically, however, while the discussions on inclusion took place in various instances, this tends to be framed as apolitical within the context of school and family relationships, as well as individual well-being. This may be due to the sensitive topics of disability and inclusion in the context of institutional policing.

Feeling included

The girls often discussed inclusion in the family in terms of helping with domestic chores. None of participants thought that doing house chores was a hardship. Most of the girls accepted and were influenced by their parents and grandparents' view that girls had to do house chores while boys did not have to, and they even believed it was a way to promote participation and inclusion. Mimi, who was an ethnic girl, repeated the word "happy" three times when being asked about feelings of helping her parents with the house chores. Chanh, a girl with multiple disabilities in A Luoi, also expressed her happiness when she helped her mother with the housework: "Happy because I can help my mother. My mother comes back home so she is also happy." Hoa Cuc, a girl with intellectual disabilities in Can Tho, helped her mother by babysitting her younger siblings while Be Cao, a girl with sensory disabilities helped her younger brother learn math because he struggled with his math lessons. Participating in home duties helped the girls develop a sense of self-worth, thus increasing their self-esteem. On at least one occasion the participant's family celebrated her accomplishments in school.

A sense of equality that comes from inclusion could also be felt when the girls described how their families came to their defense if the community did not respond well to the girls. This could be complicated. Cho explained, "When I was at home, my neighbours told that I am a person with a disability, I am crazy, I don't know anything but I can get an allowance. My mother was very upset and she said that "My children and everyone are the same, she can do everything that everyone can do." When asked how she felt about her mother defending her, her response demonstrates the complexity of relationships. She said, "I felt both happy and sad. Because there are still people who treat me like that but I don't want to upset my mother, I said to her I am OK." It seems that she was happy that she was included and treated equally in her family but felt sad that the rest of society did not necessarily see her as equal. Thus, the participants' feelings of inclusion and exclusion varied, depending on the context in which they were treated.

Some girls said that their community members treated them the same as others. One girl indicated that the people in her surrounding neighborhood treated her and her family well. Some of the girls stated that their neighbors spoke to them in a friendly way and invited them into their houses. Cong Chua, a thirteen-year-old girl with a hearing impairment, expressed how she felt included in her community. Interestingly, this feeling of inclusion and exclusion was more nuanced than what it appears to be. At first, she said that she did not want to play with children in her neighborhood and that she kept her door locked, but then when asked, “Do you like playing with your friends in your neighborhood?” She said, “Yes, my neighborhood, it’s ok.” This may suggest that she felt more included when playing with friends in her neighbourhood.

Many of the girls described feeling included in the project itself. For example, when asked about their participation in the project, the girls described feeling comfortable interacting with the other girls. They liked being included in activities with their other friends. As we will discuss further in the “Activism” section below, engaging in this project was a step for building the girls’ relationships and fostering their activist skills and knowledge. For example, by participating in various spaces such as filmmaking, the participants were able to express their desire to disrupt ableism. For example, one participant explained her message: “Well, my message is: don’t alienate people with disabilities.” This message was echoed in various instances where the girls and women were asked to convey their messages to their communities.

Belonging

A sense of belonging can have a positive impact on many aspects of life. Being included in the family and in school was discussed by the girls during their interviews. Sometimes they spoke about specific accommodations such as being given a microphone in class. In one instance a young girl spoke about being in a school play and being permitted to hold the script during the play. In another instance, Jelly My, who offered very little in response to being asked about her experiences, was able to show what it feels like to be included and to belong among her friends through her drawing (page 50). She drew a picture of receiving flowers from friends, showing gestures of kindness towards each other. Several participants shared that they felt happy at school because it allowed them to go out, have friends, and play.





Image 6: Artwork produced by JellyMy, age 13, titled I received flowers, Bac Tu Liem, 2017.

Belonging can also be found in the ways in which the girls felt loved by others. One girl, when asked about her teacher, said, “Love me.” Most participants thought they were treated the same as nondisabled students in school and treated with dignity. One participant even believed the physical education teacher prioritized her when he exempted her from a difficult session of the physical education. Clearly, while this may not necessarily suggest that the girls felt included, it may suggest that they felt a sense of belonging due to the relationships and treatment they received in school.

Inclusion was also expressed through the participants’ resilience to realize their dreams. One woman with a disability described her resilience in establishing a business for making clothes. It was not that she was able to easily make clothes and sell them. Instead, she started with making clothes for her family who supported her by wearing the clothes she made. She describes feeling supported in her efforts to make a career as a seamstress,

At the first times, I had to do 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 advice about my job. Be patient and listen to your family, I believe that you will be successful.

During the focus groups, one of the women described how she would not have been able to succeed at school were it not for the extraordinary ways her mother supported her,

My education was so difficult at that time. My mother drove or rowed a boat to take me to school, and she was waiting for my school finish then took me home. During my school time, my mother was my partner, and resulting from that I attended school. And because of my mother's love, I was more confident, and tried my best. I am proud of her and love her so much.

Reciprocal relationships: Care and support

Participants recalled the positive attitudes, as well as the care and support they received from their classroom teachers. When participants spoke about feeling supported in school this was usually when teachers helped the students with their work. Other times the girls spoke about being supported in their schoolwork by their peers who would help carry books or help with schoolwork.

The girls with disabilities also felt included when they received care and attention from their family. Many girls shared stories of travelling or going on outings with their families. Other times they described receiving gifts on the Lunar New Year. The Lunar New Year is an annual traditional festival when Vietnamese show care and linkages among family members and community. Receiving gifts, lucky money, and new clothes from seniors such as parents, uncles, aunts, and grandparents helps children feel family love, belonging, and bonding. One participant with a hearing impairment, Con Moe Hien, expressed her feelings about her parental care and support: "My parents love me much."

Several of the girls described feeling supported by their local communities as well. Some said that people in the community knew that their family was poor, and they were kind to them as a result. Inclusion in the community was demonstrated in one instance where the community helped to pay for a participant's eye surgery. In another case, the community helped a family who was struggling by sharing food. In Can Tho, Mickey, a girl with a disability described the following:

BC: How do you think people treat your family?

Mickey: Well.

Interviewer: Do they treat you different than others?

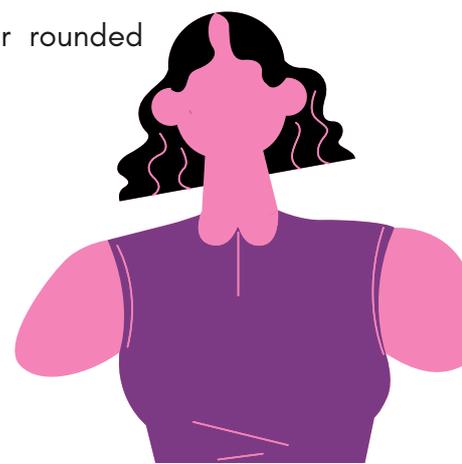
Mickey: No.

Interviewer: In your opinion, why do they treat your family well? Because they are relatives or because it's the way your neighborhood?

Mickey: Because it's the way of my neighborhood.

Interviewer: How is it when you said they treat you well?

Mickey: Like they gave us pots with flowers, squared or rounded sticky-rice cakes (bánh tét, bánh chưng).



The girls expressed a need for care and belonging. They identified care as reciprocal relationships between community members, such as helping to push a wheelchair for their friend with a disability, having community members pay hospital fees for their family, and being inclusive in play with one another. Above we see that Mickey 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.” Reciprocal care is also reflected in the instances we mentioned previously, when, for instance, Phu Dien chose to get other people to support girls with physical disabilities to get inside a building, rather than building an elevator, as a solution to accessibility.

Similarly, in their visual productions, the girls demonstrated ways they would feel cared for and supported. They drew various depictions of care and support. In her drawing, Hoa Ly drew two girls helping each other. One girl in an orange dress is a wheelchair user. She is holding the hand of her friend who is standing next to her while they visit a park:



Image 7: Artwork produced by Hoa Ly, age 17, titled Hang out in the park, Bac Tu Liem, 2017.

In her drawing, Hoa Ly seems to draw herself and a disabled friend sitting on a wheelchair. She was deliberately drawing a public park, a place in which disabled children are still relatively absent, in order to make disability present. The caption in the drawing reads: “People with disabilities help one another.” (See also Nguyen, 2020).

The participants’ perception of care and support extends to livelihoods as well. The women with disabilities described the importance of the government support they received to help sustain their livelihoods. Mrs. Panh, for example, spoke about being given a pig to support her livelihoods in raising stocks. Hoi expressed changes in her confidence due to the support she felt while participating in this project. She said,

Previously, I was embarrassed because when I went out, they talked bad thing about me but now I don't care what they say because I just live my own life. I don't need to care what they say about me, I just need to live.

Here we see how peer support can help to interrupt these negative feelings and help the women build their confidence by sharing with people who have similar experiences and understand them.

Participatory engagement

Our ability to participate in the things happening around us extends to all areas of life; home, school, work, community. This has significant impacts on our sense of belonging and wellbeing. As previously noted, participation in the family was often characterized by helping with chores, cooking, meal preparations, washing clothes, or helping to look after siblings. Participation in family life can enable individuals to feel like they are contributing to the family, which supports a sense of purpose. Sometimes the girls helped because families were working very hard to survive and they helped to manage the household while their mother and father were out to work, often selling vegetables or doing farming.

School participation is just as important for young children who are developing their sense of belonging. Participation was described in playing with friends and being included in games and school activities. Be Mit was allowed to hold her script on stage during a school drama entitled Kitchen God's festival and explained that she held her script because it was longer than the other children's scripts.

Again, when asked about the project, the girls liked feeling included and meeting other girls with similar experiences. Several girls expressed happiness in being a part of the project. That Tha spoke about the girls getting along with each other because they understand each other. She said, "In here everyone is happy, gets along with each other. So, I am happy, I like participating."

Rights

The girls talked less directly about their rights. While they discussed inclusion, belonging, participation, and their hopes for being included, they did not often speak about their right to these things. It could be because they were not taught about their rights and what they are entitled to in school. Sometimes they described how girls with disabilities should be treated like other girls, but the discourse around rights was less prominent (Stienstra & Nguyen, 2020). However, their visual productions such as "Gender Equality" and "Don't Discriminate Against Children With Disabilities" showed that the girls were well aware of these forms of exclusion that they were facing in their everyday life. With the use of visual methods, they were able to come up a solution to tackle the inequalities. Thus, their rights to non-discrimination, inclusion, and respect are reflected through their visual products.

During the storytelling in Can Tho, one woman described the rights of women with disabilities and about her awareness of her own rights,

I once worked for some bakeries where I had much trouble. The bosses asked persons with disabilities to work like other people. Some people helped me but with their pity. There were many differences between persons with and without disabilities, but we couldn't do anything. After that, I knew Can Tho Association with Disabilities. I went there, I felt included in there and I found that persons with disabilities had their rights, and we had to fight for them. Now, I am single and live in a small house and I am satisfied with my present life and working with the Can Tho Association [of People with Disabilities]. I wish persons with disabilities to have their rights to integrate into the society and be supported and it is necessary to be with more equity. Thanks.

Here the woman knew about her rights because she connected with an organization that promoted the rights of persons with disabilities. This demonstrates the importance of having advocates of disability rights present in communities where they are needed.

Hopes

Being able to visualize a positive future and to imagine what you want for your life is an important aspect of childhood. Also important is the ability to recognize what makes us happy. The participants expressed hopes in various dimensions, such as education, employment, family relationships, and livelihoods. In discussing the drawings, one girl expressed her hope for a bright future which means inclusion for everyone, Be Mit said, "In the life of each person, there is love and share about community inclusion for people with disabilities or people with non-disabilities. And that is our bright future."

The girls with disabilities also drew depictions of their hopes for inclusive education. For example, a girl with visual impairment drew a picture entitled "A drawing of hope" to depict her hope to be included in an inclusive school. Her drawing shows three students in front of a small, one-storey house. The girl in the middle is using a cane to navigate the path to school. In her presentation, she said: "I would like to present my dream. The topic of my painting is "Hope." It has a dream house with green trees. Students with disabilities are going to school. Our dreams will be fulfilled some days in the future."

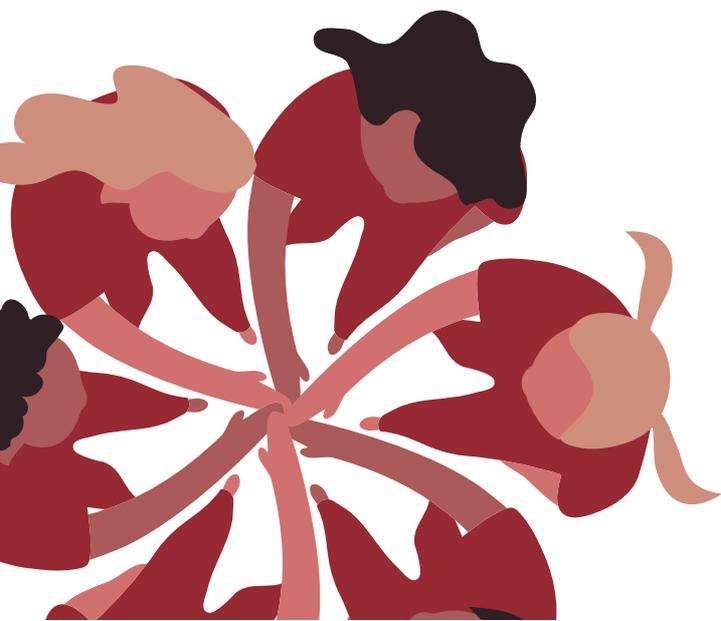




Image 8: Artwork produced by Thua, age 22, titled A drawing of hope, A Luoi, 2017.

In the project, the girls described playing with each other and expressed wanting to do that more often. One participant hoped that by being in the program, her parents would give her more freedom, but they did not. At the same time, though, she felt included when participating in the project. Participants described learning about other kinds of disability and wanting to stop violence for all people with disabilities.

Activism

One key finding of this study was that participants demonstrated that despite the political climate that restricts people with disabilities from activism, participants demonstrated their potential to engage in activism in strategic approaches which allowed them to make their voices heard. While their engagement in activism only emerged later in the project, substantial data reveals that the participants have a potential to become activists through the use of participatory arts-based research as well as through the actions which they engaged. Many of the girls, in describing what message they wanted to send with the films they made during the project, said they wanted to change societal attitudes. Moon described, "The problem is changing the view of everyone about people with disabilities because ... the reason for addressing this topic is to: removing stigmatization towards people with disabilities...Because we want to remove the stigmatization. If it is removed, people with disabilities like me, other disabled people will be happier and more confident."

Over the course of the TDKRA project, and with the support of their mentors, the girls became more engaged in activist strategies and actively participated in community engagement activities. The girls and young women with disabilities used different tools and strategies to express their perspectives, and in so doing, unsettling ableist discourses on their lack of ability to function. While the women were more vocal in their resisting strategies, based on their strengths and lived experiences, the girls expressed themselves through participatory visual methods and activities organized in their communities.

Agenda setting

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).

Leadership

Over the life of the TDKRA project, 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 their 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 (See Nguyen et al., 2021a). Many girls and young women with disabilities drew pictures of themselves as martial artists, teachers, stakeholders, and sometimes, simply a person who knows how to assist her other friends and community members. Their leadership messages are loud and clear, 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."

Countering media representations

The use of participatory arts-based research was designed to allow the participants to respond to violence in creative and playful ways. It shows how girls with disabilities could agentically engage in action in response to intersectional oppressions. The prompt we used, "explore an issue or concern in the lives of girls with disabilities," is a relatively open prompt allowing for each group's interpretation. The groups chose a theme that was most relevant and poignant to them (Nguyen, Gonick, & Bui, 2021).

Discrimination based on gender was a common experience which the girls shared through their stories and cellfilms. During a cellfilm activity, one group showed how girls with disabilities are discriminated against because they are expected to be at home doing housework. One girl explained that the girl in the film could respond to these expectations by saying "Why girls have to do this, but boys don't? We are human beings; we are equal no matter if we are boys or girls."

One cellphilm made by a group of girls in Bac Tu Liem tells the story of the family's decision not to let the girl go to school because of her gender. Clearly, they were conscious of gender discrimination in the family and community.

During the development of another cellphilm, another girl expressed similar sentiments,

Phu Dien: In this video, as everyone found that girls are weaker than boys, even in the family, or at schools. In the classroom, there were times when some girls in my class who asked the boys to play soccer, so they said, "Don't play!". I want to put this into the scene so everyone can understand that "Girls can play boy games". Or in the family, boys are coddled more than girls. Girls are often ordered many tasks. Or boys often sit and play, so in this topic, we want to send everyone the message that "Whether you are boys or girls, still equal ... gender equality"

This finding rejects the assumption that girls with disabilities are merely victims of institutional violence and are incapable of speaking for themselves. It shows that with appropriate tools and methods, girls and women with disabilities in the global South can effectively share their stories. The girls expressed their resistance differently than the women. Rather than directly confronting the bully, the girls used performance as a way of speaking back to violence (Stienstra & Nguyen, 2020; Nguyen & Stienstra, 2021). A cellphilm produced by a group of girls in A Luoi showed Thao, the main character, bullying another girl in school. The bullied girl, who is an ethnic minority, was asked to serve a drink to her presumably non-disabled friends. Thao, who acted 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!" While the film demonstrates the participants' consciousness about discrimination, 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 industries to help people get a better understanding about girls and women with disabilities."

During a focus group in A Luoi in 2018, some participants expressed a concern that the media perpetuated negative perceptions of disability, reinforcing the narrative of disability as tragic which risks upsetting the actual lived experiences of women with disabilities. One woman explained her experience with her association when the media wanted to portray women with disabilities in an inaccurate and tragic way,

We are people with disabilities, but we get support from the family, society as well as the community, we feel very comfortable with the current situation. In addition to disability, we are not inferior to people without disabilities, so you cannot make movies about us in the tragic way, but in bright colours scene.

This challenges the dominant narrative of disability that is often portrayed in media; one that characterizes disability as tragic and negative. Instead, there is a move to promote positive and happy representations of disability. This woman went further to control the narrative and ensure that what was represented in the media was something more positive.

I want my family and the society to look at [the film] and find that we are always a confident, positive person in the life, not too sorrowful. Well, I myself have asked the television to do that and they did as my request, we cannot let them tell our story in their own ways. I also asked them to show us the clip after finishing it. If there is any scene that is not reasonable, we would ask them to leave it. That is a way we have criticized them in the program "Who comes today?" Don't let the media impose yourselves on their way of thinking, or they build their characters too tragic.

She suggested a transformation in the disability narrative that is portrayed in media but also in the efforts of people to take control of how they are represented through the media. Specifically, if women with disabilities have a productive family and work life and the media continues to portray women with disabilities in a negative way, then she wanted to continue to challenge that narrative so that people know what is true and what is not,

Now the family of every member in our group is very supportive, if the clip is not true, we do not agree. They also show us the final clip they will use. That is the way our group criticizes the media. When TV6 comes, I also hope that you should raise your voice and build your own character and not let them make a mistake, it will be counterproductive. For example, our family is very supportive of us, even though I have a disability, I still have a voice in my family. I have children, stable economy and work, but now the TV station tells a wrong story, the family may say, "How can she tell like this even if we really support her". Then, we will be the bearer, the TV station will have no responsibility. This is our actual experience in Hanoi.

This statement suggests that the media plays a key role in perpetuating negative representations of women with disabilities, and yet, it barely takes responsibility for reporting false stories. This has negative impacts on the self-perception of women with disabilities and their family relationships.

Disrupting ableism

Disrupting ableism was most apparent for the girls when they were asked what they wanted other people to know about people with disabilities. Diem, a girl with a disability in Can Tho explained, "I just want to say, 'Don't look down upon persons with disabilities, don't stay away from them.'" Moon explained, "I want that other people not only understand me or other persons with disabilities, but also not say anything that makes us hurt or inferior." Many of the girls did not express a desire to eliminate their disability. Instead, they wanted to eliminate the negative perceptions of disability that they encountered which resulted in them being treated poorly. They wanted to be included and treated as equal to their peers. They wanted to be included in school and social activities.

During film making discussions in A Luoi, one woman with disabilities spoke about sharing the film with non-disabled people to redress harmful perceptions of disability.

Interviewer: So why do you want to share it with them?

Ms. Danh: Because people in society have little knowledge and little communication with people with disabilities. Many ordinary people, they often discriminate against people with disabilities, they keep saying things like "Why don't people with disabilities in this world die all but still exist in this society?"

Interviewer: do they often say that? Do they speak behind your backs or in front of you?

Ms. Danh: Not behind my back. There's a sister close to my home and she's paralyzed so her parents have to take care of her. Sadly, they don't like it and they're tired, so they say, "Why don't you die, why you still live in this life?" They said it to others behind her back.

Certainly, the view that caring for a person with a disability is a burden goes a long way to informing self-perception of disability and one way to challenge this is to resist ableist points of view.

In discussing the drawings, one girl explained that the diversity that makes up the disability community also means that people with disabilities can do a range of things. She challenged the notion that people with disabilities are unable to do things. She said,

They had difficulties in daily activities or walking. For example, they cannot walk as normal people and have to use wheelchairs or crutches. Some people cannot see, some people cannot speak. And when talking about people with disabilities, many people might have negative thinking about and even some people will despise [us] because they think people with disabilities have impairments, they cannot do things as good as other people. However, 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 are some tasks that they cannot do by the same way like able-bodied people, they can do by other ways. This is my opinion.

Empowerment

This project utilized participatory methodologies as a means to empower the girls and women with disabilities based on their own knowledge and experiences. The methods created a space for them to make visual products to share their stories and perspectives. The engagement of the participants helped to empower them, especially the girls with disabilities who showed great potential when they were given opportunities to express themselves in different ways. The use of cellfilms, critical media analysis, and drawings offered alternative ways for the girls to express their experiences and concerns as girls with disabilities. It created more inclusive space for empowering these girls and women to challenge perceptions of disability in the media, and to speak back to the ways they have been discriminated against and disrespected.

Throughout the project, the participants talked about their desire to create a translocal network of girls and women with disabilities across three communities to share their lived experiences and support one another. They were given participatory tools to express their desire, thoughts, and personal expressions through arts and other visual methodologies. Some girls were not comfortable answering detailed questions in the interview process, but with artistic outlets to express themselves, they offered insights through their films, photos, and drawings in ways that the interviews perhaps could not. For example, the girls often drew photos related to playing with other children, doing housework, and being with their peers. They expressed their hopes for inclusion, or to show their participation in school or family life. This approach led to more positive changes not only in the TDKRA project, but also in their daily lives.

A young woman with disabilities, Oanh, shared about how she felt empowered since engaging in the project:

Before I joined the project, I did not dare to be confident when going out, felt being isolated. I had been thinking it was only me, and they were looking at me strange. However, since I have been engaging in this project, I got so much love, and I am more confident. And honestly, now I stand on my feet. I am not shy when going out anymore.

Also, Moon, a 16-year-old girl in Can Tho, shared that she had many positive changes since she began participating in the project; she is more open minded and talkative and able to discuss her disability more openly.

Clearly, through their participation, the girls and women with disabilities felt empowered, they become agents of positive change for themselves. The changes could be seen to start from their engagement which led to more confidence and then to actions. We see it with Moon, who started with "I could not communicate with strangers," and moved to "now I can...I told them that I had it [disability] when I was born." Hom Hinh talked about how she changed step-by-step from a secondary student to a freshman at university. The confidence she gained become a strength in her life,

Hom Hinh: Earlier I was shy. Even though in secondary school, there were some friends in my class that I could not talk. But after participating in this project, going to high school, I could communicate with everyone quickly. Even I initiated conversation. Going to university is the same, I am more active and I talk more, get to know others faster to integrate faster.

WWDI: The project brings more confidence, right? So do I.

Hóm Hính: Yes, there is confidence. Because I often have presentations in front of everyone.

Peer support

As the participants shared, the connections between them became stronger, which played a critical role in supporting their confidence. They shared experiences of being supported by their peers and how this made them feel better. For example, at school, Bup Be often stayed in her class and talked with her friends at break time. She did not play in the school yard. When asked whether Bup Be went to the canteen alone or with others, she said “Going with my friends. We were together to avoid teasing.” In this instance peer support was found through staying together at school which reduced the likelihood of being teased by other students. Similarly, Suki experienced physical violence from boys at school and her girl friends reported it to their teacher who consulted the principal who then made the boys apologize.

Build relationships

The participants expressed a strong desire to build relationships with their peers and communities through different activities and creative productions. Their drawings revealed a distinct relational approach to disability and difference that is distinctive from the Western context. In response to the prompt “What it’s like to be a girl with disabilities?” the girls drew their relationships with schooling, friends, teachers, and the world surrounding them. The disabled person that is depicted in their drawings is usually shown to be in a relationship with their peers, teachers, and families. For example, a girl with intellectual disabilities expressed her desire for inclusive play through her drawing:





Image 9: Artwork produced by Chim Vanh Khuyen, age 11, titled My beloved school, Bac Tu Liem, 2017.

The image shows a school in the centre of the picture. There are a tree and a plant filled with flowers to the left of the school. On the right side of the school are two young women appearing to be waving. The caption reads: “Friends, please play with me!” This image shows her desire for inclusion – to make friends and to be welcome by her peers and teachers in schools. Sometimes, however, the participants revealed expressions of exclusion through their drawings. In her drawing, Phu Dien showed how marginalization is taking place in school.



Image 10: Artwork produced by Phu Dien, age 12, titled My breaktime, Bac Tu Liem, 2017.

In her drawing, Phu Dien depicted the relationships between boys and girls in a school. A girl is shown to be standing next to a tree. 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.”

Another girl at the bottom of the drawing also seems to be marginalized. 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 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."

While the drawings vividly show signs of inclusion and exclusion in school, the participants wanted to emphasize that they were not mere victims of discrimination. In different discussion, they talked about strategies for activism and change. They expressed the need to have more people participating in the project: "(We) need to demonstrate (our strengths) more clearly or we can act more. The more people with disabilities engaged, the stronger the project for promoting (the movement of) people with disabilities is... So that, we can amplify our voices." (Reflection on community engagement, 2019). Here, the participants were building their disability consciousness through their relationship building. That is, if other people outside of the project can share similar experiences, then the movement to create change and resist discrimination and exclusion could grow stronger.

Self-determination

The girls felt strongly that they were capable of making decisions and dealing with the things around them by themselves. Even though she had Diem to guide her while walking to school, Be Cao emphasized her capacity to "practice" and "walk by herself". On being asked whether it was challenging or not when walking on her own, she said "If I go slowly, it's fine!" as a confirmation of her self-determination. She explained that she wanted to practice walking and if she went slow, she was fine.

Importantly, while the women played an important role in supporting the girls in expressing themselves through cellphilmimg, some girls showed their desire to be independent from the adults. One girl said,

I would like to have activities with watching videos and answering questions. There are some girls like me, we can sit together without any women. In case some girls with some certain difficult, they should have women to help them. We can do by ourselves, if we have problems we will ask, it is not necessary to have women with us." (Phu Dien, BTL, 3 Films_Big group)

This desire to be independent, however, needs to be interpreted in context. Participants facing fewer disabling conditions due to their impairment preferred to be independent from the adults whereas those with more significant needs, such as girls with intellectual disabilities, felt the need to have adults such as their own support teacher or the women with disabilities to support them.

Self-affirmation

Through creative methods such as drawing, participants showed that difference and doing things differently is an art of living. They began to shift their perceptions through new expressions that revealed the complex aspects of their identities. For example, Loan affirmed this by purposely coloring her drawing in a workshop, named “I am a leader because...” in ways that are unexpected and then explained that like the drawing, people with disabilities can be different too. She said,

Normally, clouds will be white and blue, the sun will be yellow but here we use yellow to make clouds and the sun is blue. As usual, the tree will be green, have flowers and fruits. However, the tree here is wilted, but it still has flowers, fruits and attracts bees. What we want to say is although people with disabilities are different, they can still be like people without disabilities, expressing what they want.

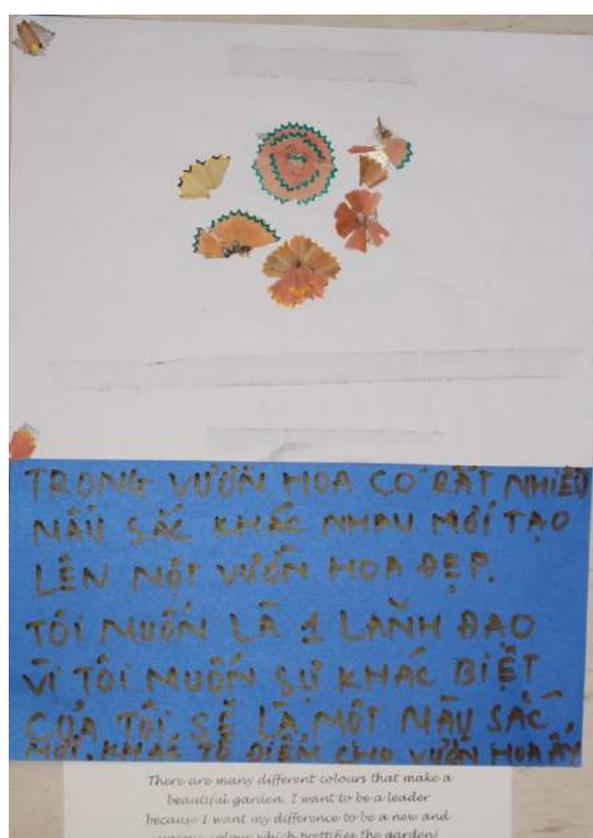


Image 11: “I am a leader because...” poster by Loan, Bac Tu Liem, 2019.



The participants challenged assumptions about people with disabilities and affirmed that their disabilities can be something to be proud of. They felt proud of their differences and talked about disability by their own definition. Loan talked about her disabilities: "Other people walk like "writing but not erasing", but I walk like "writing and erasing at the same time". One leg writes, another leg erases, so I come here.... We have to be proud of our disability." (Film discussion, Group 4, July 2019)

Some girls used their drawings as a means of visualizing their thoughts and capacities instead of using verbal language. Through the visual works, the voices were represented by the participants in different and unique ways. As a relatively timid girl who has seldom asserted herself verbally in group discussions, Linh came up with a way of representing herself as a powerful figure in the workshop "I Am a Leader Because..." She envisioned herself as a leader because she could teach martial arts to others. Her drawing conveys a powerful message challenging the assumption about disabled girls as embodied vulnerability. The caption within the drawing pictured on the right is written: "Live in your own way," reflecting her desire to act confidently and to challenge gender and disability discrimination (Nguyen et al, 2021a).



Image 12: "I am a leader because..." poster by Linh, A Luoi, 2019.

The participants called for the recognition and understanding of their difference. Talking about how the girls wanted other people to understand them and how they wanted to represent themselves on mainstream media, Hoa Huong Duong said: "It should be the efforts of people with disabilities in life, their wishes, their hopes, their working, or their travelling around. We can play, do the things we like, but being given any pity, I don't need it." (Interview with Hoa Huong Duong, Can Tho, 2018). This again relates back to disrupting ableism and focusing on the capacities of people with disabilities.

Whereas the participants expressed pride in who they were as women and girls with disabilities and their abilities to do things in the ways that work for them, their strengths were their specific gifts or abilities that allow them to contribute to the world. The participants talked about their personal strengths as means of demonstrating their potential and their contributions to enhancing activism. The strengths were acknowledged as the gifts from the girls and women with disabilities to their community through activities like community-asset mapping. Talking about her gift to the community, Be Cao said she wanted to use her voice to share with everyone. Instead of speaking directly, song lyrics are one way of delivering their messages. For example, in *Our Journey*, a documentary figuring the collective voices of the girls and women in the TDKRA project, they chose two songs to convey different meanings. The first one "Live like flowers" was an expression of their insight, thoughts, and desires to foster positive changes. Another one "Vietnam in my heart is" conveyed their connection to one another and the longevity and vitality of the community of girls and women with disabilities in Vietnam.

The participants discussed feeling empowered and having more self-confidence as a result of participating in this project. That Tha, a girl with a disability, said she always stayed at home in her daily life, and her life was "happier" when she was participating in the project and some of the other activities she engaged in with a local DPO. These were the few chances she had to go out and not "being locked at home anymore." So, this project, in addition to providing a space for the girls and women to discuss their experiences and hopes, also gave them the space to socialize and feel included with people they were comfortable with.

Another instances when the women and girls felt empowered were the moments when they realized that their stories were heard by their community leaders, as reflected upon by the women and girls in A Luoi district after their community engagement event: "I am very happy because today there are many people, the district leaders also attended so that they could know and felt what people with disabilities want, what we need." Another woman shared this sentiment: "We have shown what we have done for the past 3 years, also they could see our aspirations and dreams." (Reflections on community engagement event, A Luoi, 2019).

These are powerful demonstrations of the impact that participatory visual methodologies can have on developing the capacities of women and girls with disabilities to communicate their experiences and support one another during the process.

Transformation

Reflecting upon being involved in the TDKRA project elicited many interesting responses from the participants. Participants talked about feeling included in the program, but it was more than not feeling excluded. As we stated earlier, many expressed a sense of belonging because everyone was friendly and some shared similar experiences related to their disability. The solidarity and friendship among the girls were expressed by girls like Phu Dien who thought that because the girls shared similar experiences, they were more friendly to one another.

Participating in cultural activities and engaging with friends helped the girls feel more empowered with knowledge about their disability community. Reflecting on why she and her friends participated in the project, Mickey shared her thoughts: "Well, we participate in this program because of the voices of people with disabilities [and] to change knowledge about people with disabilities, to let everyone know about disabled people, especially girls with disabilities. We are also able to learn, have fun, integrate with the friends, share the joy, draw pictures, and watch movies about people with disabilities." One participant shared her feelings after participating in a two-day workshop: "I had never been participating in a program like this. I had never taken photographs but today I have done it. Thanks for helping us understand society and being able to integrate into the community ... Today, we want to say: 'Take care of children with disabilities more!'" (A Luoi, fieldwork 2017). A girl with a visual impairment who had dropped out of school said of her ability to speak for herself: "I have never been able to speak up my voice all the previous times, I have been suffering... but in the last two days, I have spoken up all the things that I have not talked about before" (A Luoi, fieldwork 2017).

Interestingly, shifting perceptions of disability were expressed most predominantly when participants were asked about their participation in the project. For example, some girls described understanding more about disability. We also 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, Phu Dien 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 other 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.

Furthermore, she talked about the power of the project in helping the girls develop their social skills. She said,

The project aimed to help girls with disabilities become more sociable, to open our hearts. Maybe it is the only place that the girls can express ourselves confidently. So, I think there should be more projects like this because many girls want it too.

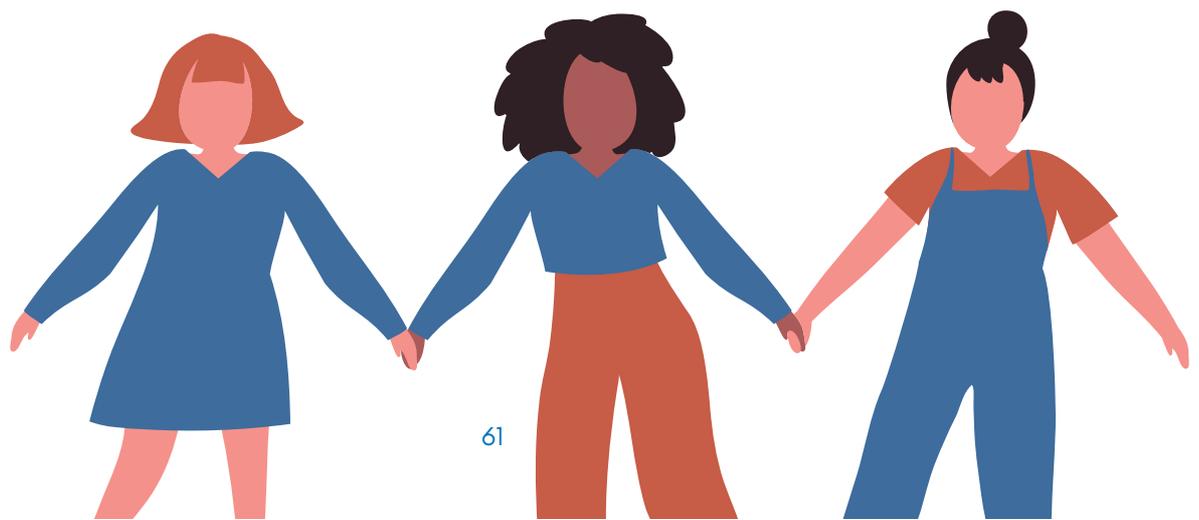
Here, the term “only place” poses an interesting question about where the girls felt empowered and confident to express themselves. That is, how could we create a community to be like the place wherein Hom Hinh desired to be?

The participants also shared how their knowledge was transformed through the training sections that they participated. During a discussion of a film, for example, one of the women with disabilities explained the impact of the project on women and girls with disabilities,

Just like when we have not gone to the training before, we have not understood much. However, when joining the training, although we have not understood much, we understand the problems when disabled people go out and communicate with others. Watching the disabled sisters playing in the film, I am so touched and sympathized. However, after training, now sisters have been trained and found that they should be confident to communicate, that’s in the movie while normally we only stay at home, never interact with society and community. That is a good knowledge.

Finally, the participants also wanted to spread the voices of girls and women with disabilities and amplify them. Discussing the next steps to promote the sustainability of the TDKRA project, one girl with a disability talked about maintaining and strengthening personal development as well as personal networks: “Uniting everyone, improving solidarity, making friends, and keeping in touch with one another. Then, using our confidence in our daily life, protecting ourselves, and encouraging other people with disabilities to be more confident.” (Moon, Reflection on community engagement, 2019).

It is important to interpret the confidence that the participants expressed through the transformation that they felt when engaged in the TDKRA project.



DISCUSSION

This study was conducted within the context of transnational human rights for people with disabilities, as outlined in the Convention on the Rights of Persons with Disabilities (CRPD) and related international conventions. During the legal reforms in Vietnam, the inclusion of people with disabilities into human rights paradigms could be seen as having different implications for social change: a reform process which recognizes people with disabilities as the subject of rights; a process of restructuring inclusion and exclusion with modern institutions through legal reforms; and the socio-political struggles of marginalized groups and individuals in re-claiming their space, power, and identities. Inclusion was engaged and mobilized by various vested interest groups, including the government's stakeholders, DPOs, and civil society organizations. Nevertheless, women and girls with disabilities have remained largely invisible as within the rights-based discourse currently applied by the government (VFD, 2020). The TDKRA project set a stage for the participants to develop their knowledge and activist skills through their engagement in various spaces and activities. We assert that it is important to see the findings as part of the process of negotiating and building relationships with the participants, partners, and local communities who are knowledge co-producers.

In recognizing the local communities and participants as knowledge co-producers, our research process sought to unsettle the boundaries between research and activism, and in so doing, redefined research relations in the contexts of working with women and girls with disabilities in the global South (Nguyen et al., 2019).

Internalized ableism and the desire to be 'Normal'

It is important to carefully interpret the perceptions of women and girls with disabilities in TDKRA. Many girls with disabilities did not grow up with people who share their experience of disability. Often, they were the only ones in their family who have a disability and so they did not have people around them to help them understand their experiences or to help shape their views about themselves as girls with disabilities. Ableism was found in many aspects of their lives, even in their families. Sometimes parents failed to accommodate their daughters at home, whether it was in the physical layout of the home, as was the case for Huong Duong, who had a mobility disability and could not reach kitchen tools because they were placed higher than where she could reach, or in a failure to create effective methods of communication when needed.

Clearly, not having other friends or family members with a disability can cause children with disabilities to want to be like everyone else around them, or to 'fit in.' It can be difficult to embrace having a disability when those around them do not understand or accept it. Some girls talked about being able to 'pass' as not having a disability and if the disability was caused by a health condition, the girls sometimes talked about wanting to be cured or wanting to work to earn money to be cured. One participant in Can Tho was direct in her desire to be cured and the impact her impairment had on her life. She said, "I could not see at the time I was born. When I was young, I wished we had had enough money for curing my eyes. But they cannot be cured now. I felt really disappointed because I couldn't take care of myself." (Interview with Be Cao in Can Tho, 2018).

It was common for the girls to focus on feeling unable to fit in or be accommodated. Here, their desire to be cured, or to eliminate their disability, was due to how they were being treated.

Similarly, the effects of having other children treat them badly in school very strongly affected the girls' self-perception. Many girls described feeling ashamed or embarrassed when they were bullied. Given that girls and women with disabilities experienced ableism in their daily lives, the idea of wanting to be 'normal' is not surprising. One girl described worrying that other children would not play with her if they found out she had a disability. The notion of passing is very much tied to the desire to be viewed as 'normal.' Rather than seeing this from the medical model of disability, we suggest that internalized ableism, which is expressed in the desire to be 'normal,' is difficult to untangle because the girls described negative feeling about themselves due to how people treated them.

Internalized ableism is also reflected in the ways in which the girls felt about how they think they should perform well in order to change the ways other people think about them. For example, Moon felt that one way to change the way people viewed her was to succeed in conventional ways, meaning that if she was able to meet the 'standards' that come with a neoliberal ideology of success then she would be included and belong. She explained, "First of all, I have to study very well and then I will be successful in the future, and I think people won't look at me like this. Once we get success, they won't discuss but rather admire us because we have impairments, but we have to try." This shows how pervasive internalized ableism has become for girls and women with disabilities in a neoliberal economy. It also reveals competing ideologies in which women and girls with disabilities found themselves when attempting to reframe their disability and transform society's knowledge about them.

Finally, historical conditions such as war and violence have reinforced the participants' view of their own disability as an individual misfortune. While a few participants showed their consciousness of the impacts of imperialism on their bodies and communities, their perceptions of disability tended to be shaped by many factors, including the colonial/modernist constructions of disability as an illness, the bio-medical constructions of disability as a dysfunction or malformation, and the cultural prejudices against disability that are rooted in religious interpretations of individual's wrongdoing (Nguyen, 2015; 2019; Gammeltoft, 2014).

Making sense of intersectional oppressions

Despite legislation which claims to protect persons with disabilities against discrimination and ensure their rights to equal participation in social activities and related domains, the findings of this study show that women and girls with disabilities in the project are largely invisible within the current rights-based legislation. It affirms the observations from the CRPD's independent report that the Law on Persons with Disabilities (SRV, 2010) has not recognized the rights of women and girls with disabilities (VFD, 2020). Specifically, the findings from TDKRA show that these girls and women are denied of their basic needs such as livelihoods, employment, access to education, health care, and social services. They are subject to discrimination and violence on a large scale compared to others. While the degrees to which participants experienced violence, marginalization, and discrimination varied, they all experienced some forms of exclusion, which deprived them from equal opportunities to participate in schools, families, communities, and employment. There are multiple layers of discrimination which women and girls with disabilities faced, including ableism, racism (in the case of ethnic women and girls with disabilities), adultism (in the case of girls/children with disabilities), and male patriarchy. The intersections between and among these layers of oppression perpetuated their invisible social positions.

Intersectionality helps us understand structures that produce inequalities by unveiling intersecting forms of power that impact the women and girls. For example, ethnic minority girls and women with disabilities seemed to have experienced more structural inequalities than nonethnic minority girls and women with disabilities. Discrimination against ethnic minority girls and women occurred at a much larger scale than with ethnic majority girls and women. Participants' narratives of poverty and exclusion reflected ableist and racist perspectives on their disability and ethnicity. In many other cases, the intersection between ableism, racism, and gender discrimination perpetuated their exclusion. Adultism played out in the research process when parents tended to make decisions for their children to participate in the project or to answer on their behalf during the interviews. In other cases, it continued to linger in spaces where adult participants tended to lead the conversation and make decision on behalf of the girls.

We must interpret the experiences, silences, and relationships between the women and girls within the context of the global South, where women and girls with disabilities have been multiply marginalized by their class, gender, disability, age, ethnicity, caste, and religions (Meehotra, 2013). While the study does not show evidence of the impacts of caste and religions in the lives of girls and women in Vietnam, their experiences with ableism, racism, and male patriarchy were evident. This finding highlights the need to recognize multiple layers of oppressions which deprived women and girls with disabilities from exercising their rights. Furthermore, due to the lack of access to basic needs to sustain their lives, the women and girls did not see rights as important as their family's livelihoods, health care, and employment opportunities. While it may be argued that these are basic human rights guaranteed by the CRPD, the lack of access to knowledge about their rights, as well as the ways in which rights-based discourse has been largely abstract and lack concrete significations for participants in the global South, seemed to put the conversations about rights at odds with the participants' need for livelihoods to sustain their lives.

Furthermore, the ways in which rights-based discourse did not resonate with the lives of the women and girls in these contexts requires us to engage more critically with research as an act of decolonization. That is: who benefits from research? In whose interest does the research serve? How can research benefit the communities and participants? How can we resist the colonial practices in exploiting and objectifying participants?

Struggles for inclusion

This study reveals the struggles for inclusion from different aspects: the cultural struggles to reclaim the existence and representation of girls and women with disabilities; the material struggles to claim one's access to schools, health care, and social services in the face of poverty and exclusion; and discursive and political struggles to resist forms of violence and discrimination which have marked these girls and women invisible. The use of participatory methods enabled participants to reclaim their difference in more positive ways. Through all these forms of struggles, we found that the majority of participants formed their collective networks as a transformative approach to the art of re-building their local and translocal movements.

As we mentioned in the research findings, there was a clear sense of transformation, expressed in the participants' feeling of 'confidence' in their capacities to speak up, to amplify their voices, to resist violence, and to build their networks with other girls and women. Here, the transformative approach to inclusion is expressed in a shift in an individual's perception of their difference towards the end of the project. This is coupled with a sense of belonging to their peer networks, their communities, and their disability organizations. The project's interventions, which combined the individual and collective dimensions of participation, created more positive impacts on the participants to shape a sense of relational agency that promotes inclusion within themselves and in their communities. For example, their affirmation of strengths and leadership was fostered through some of the final stages of the project, suggesting their potential to open new possibilities for radical change through their collective activism and engagement.

Another dimension of inclusion of the TDKRA project could be observed through the decolonial struggles to reclaim the existence of non-Western knowledges on disability by involving women and girls with disabilities as knowledge co-producers. The use of decolonial PVM opened up the possibilities for dialogue and conversations about participants' issues and concerns through visual art making (Mitchell, De Lange, and Moletsane, 2017). It created alternative spaces for reclaiming participants' perspectives, identities, and existence in the context of the global South. The use of decolonial PVM unsettled the power of the researchers from the global North to conduct research about people with disabilities in the global South (Nguyen, 2020). Instead, participatory methods such as drawing, photovoice, and cellfilms gave participants immediate access to their self-expression and helped them to think about action, in so doing acquiring agency and empowerment. In so doing, it made visible the invisible experiences of girls with disabilities from their own perspectives.

However, we caution against the need to celebrate ‘inclusion’ in the absence of understandings of structural and political exclusions which constitute the realities of women and girls with disabilities in the Global South. Most participants in TDKRA experienced different forms of exclusion which have been structurally constituted such as the lack of access to education, health care, and social services. They also experienced disability and gender-based violence and marginalization from and within their school and public space. These exclusions were structured and reinforced by the impacts of colonial and neo-liberal ideologies where disability is deemed unproductive and therefore “unfit” for the neoliberal economy (Stienstra & Nguyen, 2020). This study affirms a need to further investigate different manifestations of exclusion as a precondition for inclusion research and practice (Slee, 2011).

The politics of engagement

The politics of engagement in the context of TDKRA refers to the ways in which girls and women with disabilities in the Global South engaged in the creation of knowledge that has been historically absent (Nguyen, 2016; Stienstra & Nguyen, 2020). The engagement of women with disabilities as mentors, facilitators, research assistants, and researchers in TDKRA provided examples of what is possible for this politics of engagement. It also gave the women valued roles and chances to strengthen their skills with meaningful participation. This process also enabled the girls to shape their own voices and relationships with one another. They had a chance to share their stories with their wider communities, thus resisting the frequent invisibility that many girls and women with disabilities experienced.

This project brought together collective engagement among the girls and women with disabilities in ways that prepared them for activism. For example, TDKRA enabled the girls and women to mobilize their voices through arts-making. The exhibitions in three communities offered the audiences access to the participants’ ways of seeing themselves as leaders of their communities. These exhibitions served as spaces for change by allowing the girls to make themselves visible and connect their voices within and across the translocal communities where the project was implemented. In mobilizing their knowledge through arts-making, the participants showed their desire for representing themselves to fight for their self-determination. As a participant said, “Well, we want to be the representatives to bring the voices of the girls and women in this room to everyone outside the community” (fieldwork in Can Tho, July 2019).

Furthermore, engagement of and with DPOs as partners in this project not only provided local expertise and connections, but also ensured the project had links to activist networks within the communities in Vietnam, which have gradually grown through the translocal and transnational networks. The engagement of DPOs and collaborative relationships with these organizations showed that long-term, trustful, and decolonial relationships can help transform the research process and outcomes through mutual learning and respects with the partners.

Finally, this study provided some convincing evidence on how participatory and decolonizing research can unsettle the traditional power relations between researchers in the Global North and participants in the Global South by shifting away from the ways in which knowledge was historically produced by researchers in the global North. In TDKRA, the participation and engagement of girls and women with disabilities, as well as of the local DPOs, were key to the accomplishments of this project. This decolonial approach unsettled the relationships between research and activism by deploying a variety of forms, content, and participatory approaches, such as film and art making, community engagement, and knowledge mobilization activities. Interestingly, while the discourse of activism may not have been officially recognized by Vietnamese authorities, the participants were able to use arts-based research as a creative tool for mobilizing their knowledge and activism without direct confrontation with the state's political agenda.

At the same time, as the discourse of activism for disability rights have traveled transnationally, it is possible to observe some impacts of this discourse on the political context of disability rights in Vietnam. Current discourses of disability activism in Vietnam have created some inclusive spaces for disability activists and practitioners to engage in the development agenda. However, there are implications for inclusion and exclusion within this transnational framework of disability and development. This can be demonstrated within the design and implementation of disability programs which claimed to promote disability inclusion. On the one hand, internationally funded programs that focus on aspects of disability rights such as accessibility, leadership, legal rights assistance for disabled people, employment, and inclusive education may have been more inclusive of disability^{iv}. This rights-based approach to development can be important for redressing systemic exclusion of disability within Vietnamese social and political spaces.

On the other hand, these programs may have fostered DPOs and NGOs' dependency on donor's investment, where resources tend to be invested within DPOs and NGOs deemed to have better professional capacities and 'reputation' to successfully implement these projects. This approach can result in sustained inequities in terms of funding and capacities among disability and civil society organizations, in so doing reinforcing neo-colonial structures of power within the transnational disability rights agenda (see also Nguyen, 2015).

As a global North funded project, TDKRA has not been able to transform these sustained colonial practices; however, the lessons learned from this project showed that disability studies must engage with the local knowledges as a decolonial practice that allowed us to re-imagine disability justice differently. By engaging women and girls with disabilities and their communities in more inclusive dialogues that recognize their values and ways of seeing, this approach created participatory spaces for decolonizing the knowledge practices and privileges assumed by global North researchers, in so doing re-centering perspectives of women and girls with disabilities from the global South.

Silences and omissions

While the transformative aspects of the TDKRA was encouraging, we also recognized silences and omissions in the process of engagement with the participants. In their interviews, there were several instances where the girls kept silent when being asked various questions. Some of the participants remained largely quiet and only answered questions that required a 'yes' or 'no' response. Some girls, during the interviews, were reluctant, or perhaps unable to answer questions that require details. Some girls with intellectual disabilities appeared to remain silent when encountering questions that required them to explain their thoughts verbally or in writing. However, they participated well in various spaces but offered minimal verbal expressions. This suggests the challenges of traditional methods such as interviews in working with participants with different abilities and ways of understanding. It also reflected the power imbalance among the group where some girls with intellectual disabilities were more disadvantaged by traditional research methods such as interviews and focus groups.

The participation of parents and family members in the interviews may have had some impacts for the children's responses and silences. In some cases, the presence of parents was helpful as they translated the questions into their daily language, thus making the methods more accessible. They also helped to maintain trust for their children to participate in the process. In other instances, the presence of parents seemed to have shifted the focus of the interviews from the girls to the parents and silenced their children's voices. In one case, a mother answered because she said the daughter was 'sick' and could not understand everything. In the second case, a father was called in when the interviewer had trouble understanding an answer. The father explained the question to the daughter without giving the answer for her, but eventually the interviewer asked questions directly of the father instead of the daughter. In these instances, then, ableism intersects with adultism in rendering the perspectives of girls with disabilities silenced. Critically, then, if we had focused only on the participants' voices through the interviews and did not pay attention to the power dynamics with their family members, we would have run the risk of misinterpreting the participants' perspectives due to their silences, and potentially reinforcing ableism through the research process.

Finally, we wish to draw attention to a broader context of silence - the tendency to silence the voices and perspectives of participants through the assumption that they are victims. The overarching assumption of women and girls with disabilities as victims has been largely assumed within existing human rights paradigms (e.g., United Nations, 2012) and related social science disciplines.

As researchers, we caution against the tendency to speak on behalf of these girls and women and assume transparency in the process of translation or interpretation. Rather, silences signal oppressive structures in which the research process is situated which makes the idea of giving voices largely unimaginable. As postcolonial theorist Gayatri Spivak (2010) reminds us, the idea of giving voice to those who have been systemically excluded by colonial and imperialist practices is extremely challenging. We should take silences as a way of expressing oneself to resist the culture of audism, and in so doing, re-defining research ethics of engagement by respectfully valuing different ways of understanding and being.

LIMITATIONS AND OPPORTUNITIES WITH THE METHODOLOGIES

The use of different research methods generated different sources of information. It could be seen that approaches such as participatory visual methods offered the participants with more creative and fun opportunities to participate in the project, thereby generating more meaningful information about their own experiences and representations. This approach is thus more effective than traditional research methods such as interviews and focus groups in the TDKRA project, where the participants required more accessible and engaging methods in order to produce meaningful data. We noticed that sometimes the girls did not respond extensively during the interviews. When the girls answered only with yes or no answers, they did not give detail about some of their answers. For example, JellyMy was a deaf participant who did not learn Sign Language. As a result, despite her mother's assistance, her interview did not generate a lot of data. However, she was able to elaborate on concepts in creative and meaningful ways through visual methods. In fact, the use of participatory visual methodologies such as cellphlms, drawings, and photovoice allowed most of the participants to express themselves in non-verbal ways and perhaps provided more meaningful conversations about their ways of viewing. This helped some of the girls articulate their experiences, hopes and desires in distinctive ways that they could not or did not want to express through the interviews.

However, we encountered some challenges in the translation process. We were able to hire a local translator to translate the interview transcripts in ethnic languages into English. In other instances, our research assistants helped with the translation. In the process of data analysis, we re-visited the original language to ensure that the translation correctly conveyed what has been originally articulated. However, rather than assuming transparency in the translation process, we highlight the need to view data as being constructed through different processes, including the process of translation because meaning tends to get re-interpreted, omitted, lost, or changed through the translation.

Critically, despite its many promising outcomes, this study had some limitations regarding the decolonizing methodologies which it had set out to tackle. Due to the colonial legacies inherent within the research process, the researchers were constrained by the financial procedures and regulations pre-determined by funding bodies in the global North. One particular example of this colonial legacy was the ways in which funding is structured, which disallowed the collaborators to use research funds when participating in research practices. The collaborators who represented their DPOs could not use the funds to conduct independent research. This reduced their autonomy in decision-making and further jeopardizes our decolonizing ethos.

Furthermore, as the financial reporting procedures required the partners to be competent in language (English) and computing skills in order to follow appropriate financial procedures, the partners without such skills became dependent on our team members to provide such technical assistance. Barriers in terms of language, Western ethical standards, as well as rigid funding structures limited our efforts to exercise inclusive, respectful, and collaborative relationships in the research process (Nguyen, 2020; Nguyen et al., 2019).

Furthermore, the rigorous process of data collection was at times compromised by the growing culture of institutional policing in Vietnam, including surveillance of our project activities by police. In some instances, the presence of police disrupted our engagement with the participants. In a knowledge mobilization event, we were required to remove a visual artefact produced by the participants due to the authority's interpretation about its "political" (read as 'anti-government') implications. We were then required to hand in our power point presentation to the authorities to verify the appropriateness of the content. In another instance, we were required to remove the term "socio-political" in association with the concept of disability due to what may be seen as 'sensitive' implications. Within the context of state policing, the research process and outcomes have been constrained within this colonial and authoritarian structure of power. This rendered struggles for the researchers, partners, and participants in our efforts to decolonize and democratize the research process.



RECOMMENDATIONS

As part of the research process, we endeavored to gather the insights of the women and girls with disabilities on meaningful ways forward to improve inclusion and equality as promoted by their collective engagement. This projective gave the participants space to imagine a better future for other women and girls with disabilities. They offered several recommendations during the community engagement workshops as well as through the focus group discussions.

From girls with disabilities

1. **Awareness raising:** Raise awareness about disability in the community to tackle discrimination against people with disabilities and enhance respect for them.
2. **Enacting media-based activism:** Engage media to mobilize awareness about the situation of women and girls with disabilities and improve community understanding of people with disabilities.
3. **Building an inclusive education system:** More accommodations for people with disabilities should be provided in schools and in public places. Install ramps where there are stairs, and have teachers use Sign Language.
4. **Developing inclusive policies:** Community, society, and government officials should develop more inclusive policies in support of people with disabilities and improve the awareness of people with disabilities about their rights.
5. **Creating equal opportunities:** Create more equal conditions and support for people with disabilities to participate in recreational activities, studying, and employment. Provide programs such as vocational training to help them obtain a job and earn a living.
6. **Monitoring stakeholders' actions:** Ensure that policymakers and community leaders are accountable for their words and actions.
7. **Organizing outreach activities:** Reach out to donors and grantors to sustain the program. Future projects should include outdoor activities such as field trips and training on leadership skills.



From women with disabilities

1. **Mobilizing the project results:** Provide multiple ways to disseminate the results of the project to the broader community and society. Social media, live stream, and other platforms should convey messages about disability. Disseminate the films and communication products of the project in university settings. Organize meetings with girls and women with disabilities who are film actresses so that students can understand more about their work.
2. **Organizing disability activism:** Engage women with disabilities in community activities as role models. Provide examples of successful families and children so society will understand them better. Share project products with girls and women with disabilities who were not involved.
3. **Ensuring accessible information:** Make communication materials in public places and on TV accessible to everyone regardless of their ability status. Notification screens at public places and TV should have subtitles or Sign Language.
4. **Reframing the image of people with disabilities:** Reframe and share images of people with disabilities who have strength and capacity to do things like non-disabled people because non-disabled journalists and media usually show emotional and tragic images of people with disabilities.
5. **Expanding and diversifying the scope of the project:** The TDKRA model can be expanded in other locations of the country where girls and women with disabilities did not have the opportunity to participate in this project. To sustain the impacts of the project, create more projects in the future that include more girls and women with disabilities from other rural areas. Invite more male representatives from the community and government to attend the exchange activities so that they can know more about people with disabilities and gender balance. Maintain the network and connections among women and girls after the project ends.
6. **Strengthening policy advocacy:** Engage community leaders and government's departments and amplify the voices of people of disabilities. Make a call to government officials, policy makers, and local and international NGOs to ensure that their future projects support the inclusion of people with physical and mental disabilities. Include community leaders in propaganda activities so that community leaders will propose legislations that support their inclusion.
7. **Providing financial support:** Low-income families should receive financial support so that parents can take their child with disabilities to school out of town to study at higher levels if there is no school in the area. When children with disabilities can go out and participate in activities like the TDKRA project, their children can learn more and build their confidence.

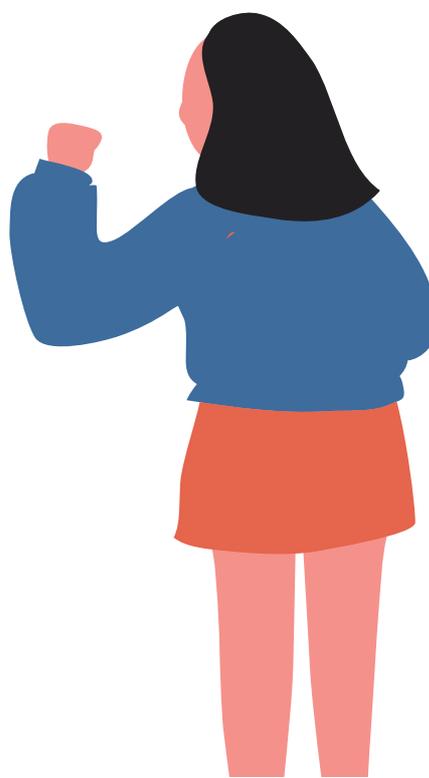
From DPOs

1. **Supporting children with disabilities through training:** Organize training courses for children in communities to increase their knowledge and access to the community and society.
2. **Mobilizing the project's knowledge:** The TDKRA films should be broadcast on the television central channels. The project outcomes should be submitted to the central government to be included in their annual report on people with disabilities.
3. **Enhancing collaboration to support Agent Orange survivors:** Work with individuals, family, society, and businesses to develop more long-term projects to support people with disabilities since the consequence of Agent Orange will continue to last for decades.
4. **Creating jobs and financial support:** Create jobs and provide financial support for women and children with disabilities so that they can expand the model and create jobs for themselves.
5. **Fostering collaborations among global and local stakeholders:** DPOs should associate and collaborate with other organizations such as Women's Union, the Agent Orange Association, the Networks for the Rights of Women and Girls with Disabilities, and international NGOs to promote the inclusion of girls and women with disabilities.



From communities

1. **Raising awareness:** Raise awareness on disability at all levels of government and community through training, workshops, national and international seminars, and conferences in order to mobilize awareness and resources.
2. **Ensuring access and accessibility:** Implement changes for disability inclusion such as modifying the infrastructure to make it more accessible. Create jobs for people with disabilities.
3. **Mobilizing knowledge:** Disseminate the project's products at schools and universities during the new academic year ceremony. In addition, share information about the program and its impacts on building capacity for girls and women with disabilities with their families, community, and society.
4. **Expanding the scope of the project:** Expand the TDKRA model to other areas of the country in order to help more girls and women with disabilities gain knowledge and engage more in changing society's awareness of people with disabilities.
5. **Creating employment opportunities:** Invest in the community by creating jobs for people with disabilities to get their own income. Support women with disabilities to develop their own business so that that can help other women in their networks. Organize career orientation sections in ways that tailor to the capacity and health of girls and women with disabilities.
6. **Building inclusive schools:** Encourage cooperation among family, school, and society for successfully facilitating inclusion in education for children with disabilities. Mobilize resources to support the child in an inclusive environment. Organize volunteer networks to support inclusive schools.
7. **Building inclusive and respectful communities:** Mobilize inclusion support from families, teachers, friends, schools, and communities. Showing respect and encouragement for people with disabilities. Community and society should develop specific actions to support the inclusion of people with disabilities into their community.



TDKRA Policy Recommendations

1. Creating multiple spaces for girls and women with disabilities to develop their knowledge, skills, networks, and to enhance their actions in relation to access and inclusion. This could be accomplished through promoting inclusive education, community outreach, and expanding on the project's participatory approach so that more women and girls with disabilities from more regions can be involved.
2. Developing training and mentoring programs to build leaderships, advocacy skills, and to foster civic engagement with girls and women with disabilities.
3. Awareness raising and disability advocacy – Mobilizing more positive representations of disability in the media and public discourses. The products from the project can be used to help improve the understanding of women and girls with disabilities themselves about their rights and value as individuals. Utilize the tools and products produced by girls and women with disabilities (e.g., films, drawings, photo voice, and other social media tools) to improve public awareness on their rights, capacities, and voices.
4. Understanding the importance of local contexts when developing disability policies for women and girls with disabilities.
5. Including girls and women with disabilities in public policy by ensuring that these girls and women are consulted in relation to issues concerning them.
6. Developing a substantive approach to disability inclusion to tackle systemic forms of discrimination against girls and women with disabilities in relation to their disability, gender, ethnicity, and socio-economic class. Involve government officials in developing more inclusive policies and ensure that community leaders are accountable for what they produce during community engagement events.
7. Developing a holistic approach to inclusive education to ensure that girls with disabilities can meaningfully participate in education and social institutions. Use the products from this project as part of outreach to universities and the broader community to improve understandings about disabilities so that more people with disabilities can access these institutions.
8. Developing protective measures to tackle different forms of violence against girls with disabilities, including girls with intellectual disabilities, in schools and domestic contexts.
9. Developing sustainable partnerships with DPOs and their communities to enhance their leadership on disability-related matters.
10. Developing meaningful collaboration among research institutions, DPOs, civil society organizations, the United Nations agencies, and the government's policymakers in support of women and girls with disabilities in Vietnam and the global South.

CONCLUSION

The TDKRA project is unique in the extent to which it utilized multiple ways of researching with women and girls with disabilities in three distinct communities in Vietnam. Through the use of decolonial and participatory research methods, TDKRA aimed to resist the confluence of colonial and imperialist contexts by engaging girls and women with disabilities, creating spaces for their inclusion, fostering their voices, leadership, and activism within their respective communities, and involving girls and women with disabilities in forging strong relations with communities in the global South. There are ongoing challenges with sustainable livelihoods, inclusive education, promoting positive perceptions of disability, resisting exclusion and discrimination in all areas of life and the resulting internalized ableism the girls and women described. At the same time, experiences were nuanced by instances of inclusion, feelings of belonging and the surfacing of activism, empowerment, and opportunities for transformation. We know that lived experience of disability is complex and shaped by intersectional oppression and privileges. Importantly, women and girls with disabilities can experience privilege in some aspects of life and oppression or discrimination in other areas of life at the same time. What is important is the space we provided for the participants to share about those experiences and to work together to propose ways forward that support their inclusion and wellbeing. The outcomes of this project show potential for women and girls with disabilities to engage in local and transnational activism. We have further pushed against traditional research methods and sought to implement decolonial methodologies by way of epistemological engagement with Global South representations. To this end we have centered the experience of women and girls in the Global South and worked with them to produce their desired outcomes while also respecting their agency and supporting their feelings of empowerment throughout the research process.



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[i] Due to specific local conditions, some DPOs requested expanding the age range of the girls from 18 to 20 to allow for access to some girls in their communities. We received approval from the university's ethics board to expand the age range.

[ii] Here we only used the perspectives of participants in the project where their blindness was seen as a medical issue. We do not attempt to theorize blindness from social theorists' perspective (e.g., Michalko, 2011) but rather drew on the participants' discourses and practices. There is room for further theorizing blindness from a decolonial perspective. However, this is not within the scope of the TDKRA study.

[iii] There was no distinction between disability and impairment from the participants' epistemological standpoint. When the participants talked about "disability," they referred to part/parts of their bodies that do not function in an able-bodied manner. The term "impairment" was not often used in the participants' contexts and languages. In the translation, however, we used "impairment" to signal the bodily conditions that the participants referred to.

[iv] Currently, there are many internationally funded programs focusing on inclusion of people with disabilities in Vietnam. These include such programs as Raising Voices, Creating Opportunities project, funded by the US Agency for International Development in Vietnam between 2018-2021, and Increasing the integration of persons with disabilities (PWDs) into society: "We can", funded by ChildFund Vietnam between 2018-2019. These programs are run by the Action to Community Development Center/Institute in Vietnam. See other program websites more information relating to disability programs such as Inclusion of People with Disabilities, funded by Norwegian Mission Alliance in Vietnam, and Promotion of inclusion of persons with disabilities (PWD) and persons living with HIVs/AIDs, funded by Caritas.

