Empowerment Through Participation in Vietnam: A Personal Experience of Taking Back the Pride of Disability

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Abstract

This paper presents my experiences as a young woman with disabilities engaging with a research project, “Transforming Disability Knowledge, Research, and Activism” (TDKRA) - a collaborative project that aims to tackle the challenges of disability research and activism in Vietnam. It illustrates the lessons I learned about disability knowledge, activism, and the experiences of other girls and women with disabilities in Vietnam through my participation in TDKRA. From my own perspective, I assess the effectiveness of participatory visual methodologies and arts-based research in exploring the perspectives of girls and women with disabilities and in fostering girls and women with disabilities to get out of a silent zone to speak out their unheard stories.

Key words: girls and women with disabilities, empowerment, participation, Vietnam

Positionality

I am an undergraduate student at the Hanoi Law University and a research assistant for the Transforming Disability Knowledge, Research, and Activism (TDKRA) project. I live with my parents and my older brother in Hanoi, the capital of Vietnam. My father was a serviceman for two years – starting one year after the Vietnam war ended. He had served in the military in Quang Tri, an area deeply affected by Agent Orange. Then he worked at a bike manufacturing company. My mother was a prosecutor at People's Procuracy in a district in Hanoi. When I was born, there was a lot of discussion about "Why do I have disabilities?" Some people believed that I might have been a victim of Agent Orange. Others thought it was because my mother gave birth to me when she was too old (I was born when my mother was 42). Still others believed that it was because I had to pay the price for my previous life, whatever that might be... The question has been asked by many strangers. And my answer has always been, "I have had disabilities since I was born. That is all."

Since I was small, I have never thought that I was more "special" than other people. I remember when I was at a kindergarten, my friends and I counted on fingers together. All of them said they had 10 fingers but I said I had 6. They said, "Why does your left hand have one finger?" I said, "Because not everyone is alike." This was one of my experiences when I went to school. I think my parents let me engage in an inclusive environment to play and study together with non-disabled friends, which made me think, "I am different from my friends, but it does not mean I cannot do as they can. I can do in my own way, which is different from theirs." Having been in an inclusive education system, I can see the barriers and opportunities it brings for personal development for girls with disabilities. Therefore, I really want to remove the barriers to ensure all people with disabilities can participate in society fully and equally.

As a young woman with disabilities, I engage with the TDKRA project as a way of building knowledge and activism around areas of disability rights and media productions. Before engaging with the TDKRA, I was a volunteer as a media manager and an editor at Dom Dom Studio, a media project about people with disabilities and their issues, founded by people with disabilities working in the media. As a member of Dom Dom Studio, I had a chance to have the experience of using media as a tool for people with disabilities to raise their voices in ways that highlighted how they want to be known. We created videos of a talkshow, with an interview

format to let people with disabilities tell their stories. In addition, due to lack of funding, we chose to re-write newspaper articles on people with disabilities from mainstream media as a means to express our perspectives. Also, the able-bodied volunteers were trained about how they should interact with and write about people with disabilities. Furthermore, in 2018, I took part in a program named "Training on Developing Campaigns and Communications for Developing The Rights of People with Disabilities." Through this program, I and other individuals with disabilities in my team created a film based on my story (including others' perspectives) to make a narrative with the collective stories of all members. The name of the film is *When you believe you can, you can* and it is about the internal conflict of a young girl with disabilities. Disability made her feel shy and feel wary of what she could do. But deep down inside she always wanted to express herself. She had been living with regrets because she thought that she could not express herself. The film includes other characters: a woman with visual impairment and a deaf man, both of whom had succeeded on their own terms, and who helped the young girl to figure out what she really wanted to do. Having another opportunity to do what she had not ever done yet, and with the encouragement of other friends with disabilities, the girl shone as she wanted to be. The message of the film is very straightforward: people with disabilities are not people needing special treatment; we can have our own success by ourselves if we have equal access to opportunities.

The story was based on my old story from my years in high school. At the time I was afraid of what I perceived to be the strange attention to my disabilities. I was the only one who did not join in my class's 'live show' although deep inside my heart I really wanted to be included in this activity. Looking at how all my friends were celebrating and taking photos together without me when the show ended, I felt excluded, and it hurt me badly. This was not the first time I had that feeling but this was the first time I could not endure it and I burst into tears in a crowd. I was always trying to prevent myself from doing that and it worked well for a long time. However, this time it seemed impossible for me to stop crying. After that, I had a period of time living with regrets; I was wondering, what if I had been a part of the liveshow, or whether anyone had remembered me. However, all of those things came to make me stronger, and I convinced myself that I should try to do everything I wanted to do no matter what it was. Successful or not, at least I already tried my best and there is nothing to regret. Most importantly, through my experiences, I came to believe that the participation of girls and women with

disabilities could play a crucial role in the family, school, and community. It is irrefutable that participation ensures the full development of individuals, but it still seems unachievable when the opportunities of participating do not open equally.

The Context

According to the National Survey on People with Disabilities 2016, there are around 6.2 million people with disabilities in Vietnam, of which 671,659 are children aged 2-17. The prevalence rate for rural areas in the country is almost 1.5 times higher than in urban areas. The survey indicates:

Accessible opportunities to schools for children with disabilities are much lower than for non-disabled children. Primary net enrollment rate for children with disabilities is 88.7%, while the rate for non-disabled children is 96.1%. The gap of this rate among children with disabilities and non-disabilities increases at higher education levels. At the upper secondary level, only 1/3 of children with disabilities go to school at the right age (33.6%), compared with 2/3 of nondisabled children (88.6%). (General Statistics Office, 2016, p. 19)

In terms of legal frameworks, Vietnam has implemented various laws, policies, and standards pertaining to people with disabilities. On January 1st, 2011, the Laws on People with Disabilities came into effect. This replaced the 1998 Ordinance on Disabled People, which officially used the notion of "People with Disabilities" (người khuyết tật) in place of the concept of "Disabled People" (người tàn tật), following the general recognition of world-wide trends on disability. The promulgation of the Laws on People with disabilities had a significant impact on the disability legal framework. In 2014, Vietnam ratified the Convention on the Rights of the Persons with Disabilities (CRPD), United Nations, 2006), which was a landmark commitment to work on promoting an inclusive society, and to ensure persons with disabilities are able to participate fully in all aspects of social, political, economic, and cultural life. However, the exclusion of women and girls with disabilities, in social and educational participation, has been ignored by the developing programs and initiatives, on assistance to people with disabilities, to engage in socio-economic, legal, and educational activities (Monitoring Educational Rights for Girls with Disabilities project [MRGD], 2016). Nguyen and Mitchell (2014) opine that in

legislative terms, the equality approach is believed that men and women, boys and girls, must have equal opportunity to participate, guaranteed by the law. Nonetheless, this approach does not attend to the intersection between disability and gender in human rights provisions (MRGD, 2016, p.11). Moreover, Stienstra and Nguyen (2019) argue that deliberative democracy, as theorized and practiced in the global [?] North, has limited capacity to explain the engagement of disabled girls and women in Vietnam.

In “Disability, Girlhood, and Vulnerability in Transitional Context,” Erevelles and Nguyen (2016) argue that through engaging with hierarchies of power in diverse contexts, the conversation created by connecting the stories of disabled girls within and across geographical borders is key. It also has the potential to negate forms of domination. Coming out of this work, TDKRA is a collaborative research project funded by the Social Sciences and Humanities Research Council of Canada (2016-2020), with the aim of engaging women and girls with disabilities in three disadvantaged communities in Vietnam- Bac Tu Liem, an urbanized area of the North; A Luoi, a mountainous district of the North Central Coast; and Binh Thuy and Ninh Kieu, two communities of the South - in a process of knowledge production based on their perspectives. The TDKRA project has three key objectives: (1) to document the situation of girls with disabilities in school in three geographic areas of Vietnam; (2) to develop interdisciplinary, community-engaged, and participatory methods for obtaining in-depth knowledge on the educational rights of girls with disabilities; (3) to build capacity for women and girls with disabilities, including graduate and undergraduate students and practitioners, by providing training on participatory methods (Nguyen, Miron, Rahim, Dang & Mitchell, 2019). As I highlight below in my personal account of participating in this project, this is a particularly generative study for learning and reflection.

My Engagement with the TDKRA Project

In the summer in 2017, as a second-year law student and a volunteer on a media project about people with disabilities, I was looking for a job that would help me gain more knowledge and improve my soft skills. On searching through a number of recruitment advertisements I found that the requirement of “having a good appearance without disability” was a barrier to my goal. A project for girls and women with disabilities was recruiting an assistant, but I felt extremely nervous because a research project was big and new for me. From my own experience,

I know girls and women with disabilities in Vietnam have faced many challenges accessing our rights, such as basic and higher education, getting a job, and so on. Therefore, I thought it would be great if I could have an opportunity to engage in advocating for the educational rights and social inclusion of girls with disabilities in Vietnam. Before having an interview with the Principal Investigator, I just thought I should give myself a try. I knew that I would regret not following my dream, though I could not imagine that I would actually be hired. Once I was involved in the project, I realized that my disability was not considered a problem in assessing who I am or what can I do. This helped strengthen my determination and eradicated my negative thinking toward disability; it had always scared me when being stared at because of my disability or becoming a “topic” of conversation. I realized that the reason it made me uncomfortable was not my disability, it was the way some people were treating me. When my disability is respected, I am self-confident in front of a crowd. In addition, I had never confided my stories about what I had been through in terms of my disabilities to anyone, including my beloved family members and my best friends. I was extremely stressed when being teased in secondary school and by my neighbours, but I just kept this as my secret. I used drawing as a way to unburden and cheer myself up (see Image 1). However, since engaging with TDKRA, I understand the importance of speaking out in claiming our rights. Indeed, that was what allowed me to decide to tell my confidential story in the film, *When You Believe You Can, You Can*.

Image 1: My drawing with a cheering-up message, “Linh, hang in there!”

Through my journey in the TDKRA project, I understand more deeply the situation of girls and women with disabilities in three different locations in Vietnam through their own narratives. While working with other girls and women with disabilities, I found a part of myself in them. I think the similarities enhance the relationship between girls and women and help us can communicate openly with each other. Nonetheless, it took some time and effort to get close to and gain the trust of the girls and women. Furthermore, as a research assistant and young woman engaging in TDKRA, each task, each stage of the fieldwork, has been truly an eye-opening learning experience for me.

First of all, I broadened my horizons on disability knowledge and rights. Now I realize that before I engaged in TDKRA, all I had was shallow knowledge about what the law stipulates about the rights of people with disabilities, what benefits they get from the policies. Learning from and working with the TDKRA team has helped me figure out why the previous approaches were inappropriate. It is undeniable that the rights of individuals with disabilities are human rights, not preferential rights. Disability cannot be considered in terms of people wanting special treatment, or to be 'cured' or to live in a specialized care center. Everyone should be equally treated and respected no matter what their circumstances are. We have the right to access all aspects of life as a member of society. We can not alter our disabilities to adapt ourselves to a society that is designed for and by non-disabled people. The responsibility of society is to create an inclusive community for all members. Opening up opportunities for access and inclusion is essential for each individual to develop their maximum ability and devote themselves to the community as an independent member.

Second, I managed to step-by-step get out of my non-critical approach. Assisting the team in coordinating the fieldwork helped open my mind to the myriad of issues involved and explore them more deeply. For instance, before engaging in this project, when watching a media production about people with disabilities, I just received information from it. The project has helped me think more insightfully and critically. I have started responding to the information I get. For example, I realize most people know about people with disabilities through mainstream media. However, the stories typically selected are not shared by all people with disabilities because they must be touching or inspiring enough to attract viewers. That [forms] creates the image of people with disabilities as either 'miserable' or 'extraordinary.' Viewers see persons

with disabilities either treated as objects of pity, who have a range of difficulties and rely on charity, or presented as superheroes who overcome a disabling condition to achieve great things, so as to inspire the non-disabled. These stereotypes draw audiences into the model in which people with disabilities are viewed through their impairment. That pushes us to the edge of being discriminated against. It is irrefutable that the stereotypes will continue if people with disabilities do not raise their voices. It is essential that people with disabilities use media as an instrument in raising awareness, countering discrimination, and altering societal misconceptions from their perspectives.

Lastly, TDKRA uses a range of research methodologies, such as interviews, arts-based research, and a participatory research paradigm. As a research assistant and a woman with disabilities involved in the project, in my view, the participatory research methods are an effective means to encourage girls and women to share their stories, and to speak out. As I describe below, these methods help them to tell their stories from their perspective instead of being “spoken for” by others. Each activity with different approach methods plays a crucial role in not only strengthening the engagement of girls and women but also encouraging their unheard stories to be told. The voices of girls and women play vital roles in creating dialogue on what is true inclusion and generating changes to the legal framework to achieve a fully inclusive society. Therefore, the voices must be listened to, reflected on, and responded to by policy makers and community members.

Image 2: A photovoice and land-based activity of women and girls with disabilities in Bac Tu Liem, Hanoi. Fieldwork July 2018. TDKRA website

Visual Learning

Photovoice: Photovoice is one of the arts-based research methodologies used to represent the voices of the girls and women with disabilities in the TDKRA Project. The participants used cameras to create their own ways of seeing, re-imagining their own stories through the photovoice component of the project (see Image 2). Each photo is accompanied by a short caption or story related to what they went through and/or face in their daily life. Then each of the groups created their own stories about the collection of photographs and put them together on posters with a prompt, “Places where we belong and do not belong.” The photovoice posters were decorated with insightful stories and messages they wanted to share. Not only telling their experiences but talking about the photos is a way to help the girls and women express their feelings and thoughts on being excluded and included. It provides access to the worlds of girls and women with disabilities and generates a better understanding of how they felt and what they went through (see Image 3).

Image 3: A group of girls with disabilities had a presentation about their photovoice poster, Fieldwork July 2019, Can Tho, Vietnam.

Image 4: A group of girls and women with disabilities was making a cellphilm, Fieldwork May 2018, A Luoi, Thua Thien Hue, Vietnam.

Cellphilm

Most media productions of people with disabilities have been made, narrated, and acted by non-disabled people, so that participatory film-making methodologies (in this case cellphilm) are useful for reflecting the perspectives of girls and women with disabilities about their own images and stories in the media. Moreover, making a cellphilm is a reflective approach for them to express themselves in the way they want and to decide what stories they want to tell (see Image 4). In their cellphilms, girls and women with disabilities acted out their stories and shared their reflections on addressing challenges, such as a dream about going to school, difficulty with accessibility, the daily life of being discriminated against, and so on. The cellphilms provided visual proof of the intersection of disability and other stigmatizing characteristics, including poverty, ethnicity, and gender. Furthermore, the film-making process stimulated more dialogue about how to represent images of girls and women with disabilities in public. Also, the cellphilms led to conversations on the barriers that they face in different contexts.

Image 5: A girl introduced a cellphilm of her group in community engagement, Fieldwork July 2017, Can Tho, Vietnam.

Image 6: A group made their community map in a Community Asset Mapping activity, Fieldwork July 2018, Bac Tu Liem, Hanoi, Vietnam.

Community Asset Mapping

A third approach was to use community mapping. A community map or a Community Asset Mapping activity involves identifying and distinguishing areas of exclusion and inclusion

in society. Working on their community maps, the girls and women traced their ways to school, soccer fields, health care facilities, and community centres (see Image 6). This approach enabled them to reimagine their social positionings by envisioning and re-envisioning accessible spaces where they belong or want to belong. (Nguyen, Stienstra, Gonick, Do, Huynh, 2019). Therefore, Community Asset Mapping helped the girls and women with disabilities identify their participation in each place, to assess their engagement within their community in a more exact and comprehensive way (see Image 7). Moreover, it encourages the girls and women to use their abilities to build and change the community. Not only did this method raise awareness about individual values, it also evoked community connections. Connecting women and girls with disabilities is an effective way to create and improve collective empowerment, to inspire them to speak out, claim their rights, make changes, and lead their communities to be inclusive for all.

Image 7: One group identified their local community through a Community Asset Mapping activity, fieldwork July 2018, Can Tho, Vietnam. (TDKRA website).

Conclusion

It cannot be denied that everyone, including girls and women with disabilities, has the right to live to their full potential. However, the rights of girls and women with disabilities, which should not be viewed as preferential treatments, are agents of change for their own individual and collective empowerment. Our voices need to be included officially in making policy to ensure the rights are implemented in the reality. Doing research is also critical for the effective implementation of rights to find and remove barriers so girls and women can fully participate in society. Participatory visual methodologies and arts-based research create a space that encourages them to get out of a silent zone and makes them feel comfortable when sharing their unheard stories. The methods approach the worlds of girls and women with disabilities naturally, instead of forcing them to speak. When they engage in the activities, they stand together in solidarity, express their perspectives, and exercise their voices to transform awareness of disability. It is a way to empower them to advocate for their rights, make changes, and contribute to an effective and fully inclusive society.

What I have experienced and learned in 2 years of participating in TDKRA has paved the way for me to get back to myself. I was self-confident about my disability when I was a child. I did not care why people were always looking at me really strangely, I enjoyed my ordinary everyday life. Then, over time, my self-confidence seemed to disappear. Being teased and bullied was a terrifying experience. I was too scared to look at other people and even myself. However, throughout my journey in TDKRA, I realized it was not up to me, it was up to other people and how they treat me and my disability. That is why I think society must change its attitude and behavior toward people with disabilities, yet all I knew was just my experiences. It is clear that if I want to fight for the rights of girls and women with disabilities, I will have to listen and understand their stories clearly. Furthermore, having a deeper understanding of girls and women with disabilities in Vietnam motivated me to do my first research paper, "Educational Laws on Children with disabilities in Vietnam - Reality and Suggestions," which was awarded second prize in the "Research Contest for Students 2019" at Hanoi Law University. This is just to say then that I was silent and suffered, and a lot of other girls and women with disabilities did too. But now, we are transforming suffering into strength, to raise our voices to foster inclusion and social change.

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