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# Perceptions of the Body Haunted: An Analysis of Significant Pilot Study Findings on The Abuse and Harassment of Women with Disabilities Ho Chi Minh City, Vietnam

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Mingkwan, 2016

## **Perceptions of the Body Haunted**

**Perceptions of the Body Haunted:  
An Analysis of Significant Pilot Study Findings on  
The Abuse and Harassment of Women with Disabilities  
Ho Chi Minh City, Vietnam**

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An Honors Thesis Submitted to the International Studies Department at  
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## **Abstract**

This pilot study conducted with Disability Research and Capacity Development in Ho Chi Minh City, Vietnam, found that women with disabilities (WWD) reported significant experiences with abuse and harassment. Analysis of these findings revealed that the abuse and harassment of WWD is directly connected to the complex roles that gender and disability hold within Vietnamese society. Vietnam is a patriarchal society and WWD experienced abuse and harassment due to their roles as women; their expressions of gender and sexuality in connection with disability; and their desire for participation in processes such as sex, intimacy, and childbearing. Additionally, disabled bodies in Vietnam are associated with traumatic events from the past such as war, conflict, famine, and civil unrest. They are imagined as hauntings and are seen as disruptive to the state-sanctioned agenda of building a productive, healthy, and beautiful nation. Promoting WWD's rights, protections, and equality within Vietnam is dependent on establishing a better understanding of disability as a human condition and removing it from the realm of social evils and the supernatural.

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## **Introduction**

### ***Introduction to Disability***

Across the globe and throughout time, standards of beauty, normalcy, and functionality are centered on the idea of the whole, complete, and able body. Humans often regard difference as defect and deviations from the norm are met with fear, loathing, and misunderstanding. The disabled body is seen as inherently inferior even when the disability in question functions more as a label than it does as a limitation. The perception of disability is evident in the word itself: dis-ability, the prefix *dis* meaning “apart, asunder, away, or having a privative, negative, or reversing force” (Notre Dame). Difference in this case is marked by the perception of disabled bodies as being unable to exist in the ways able bodies do. And like so many other human responses to difference, the most common responses to the differences marked by disability are disrespect, discrimination, isolation and misunderstanding. Despite the perception of disability as a deviation from the norm, it is hardly a minor issue; as of September 2016, an estimated one billion people or 15 percent of the world’s population experienced some form of disability, defined as body function or structure impairments, activity limitations and participation restrictions (World Bank).

There are a number of other challenges that PWD face, in addition to the physical and/or intellectual disabilities they experience. Across the globe, disability is deeply connected to poverty and lower socio-economic outcomes on the basis of discrimination and lack of access (World Bank, p. 4). PWD are more likely to experience negative outcomes in areas such as access to education,



level of employment, health status and access to care, and access to public space (World Bank, pg. 4). Poverty and health are often deeply connected and create a cyclical trap in which the outcomes of one exacerbate the outcomes of the other. Poverty can function both as a cause of disability because of malnutrition, poor sanitation, and poor working conditions and also as an outcome of disability on the basis of lower education levels and job opportunities, lower pay, and the additional expenses and potentially catastrophic costs of living with and managing a disability (World Bank, p. 4).

Subsidized support and government benefits for disability care and expenses do exist, most notably in the form of disability benefits and incapacity benefits in countries such as Estonia and France (Guardian, 2015); however, they are more uncommon than not and PWD still face the prospect of having to absorb the elevated costs of their disabilities through out-of-pocket spending. Sadly, even the countries regarded as having the most robust disability services and support, such as the United Kingdom and Sweden, are still unable to meet the breadth of needs and protections that people with disabilities (PWD) require (Guardian, 2015). Additionally, these countries do not bear the majority of the global burden of disability (World Bank); developing countries have a much higher prevalence of disability than first world nations and have far fewer resources with which to address disability-related issues (World Bank). Many governments in both the developed and developing worlds have failed to introduce proper protections for PWD, such as protecting their rights and preventing discrimination (Human Rights Watch, p. 3). In many countries there

are significant barriers to PWD'Ss participation in society, which can include lack of transportation, inaccessible development and landscapes, and lack of services and support (World Bank, p. 3). Governments, such as that of Vietnam, are eager to promote the disability policies they have in place and tout their (often superficial) successes in providing PWD services. However, the reality of disability on a global level is that disability issues are distinctly undervalued and underfunded and that very little available data and research exist on the actual needs and challenges of PWD.

Global awareness of disability has increased somewhat in recent years, due to the 2006 introduction of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which aimed to promote the full integration of persons with disabilities in societies, and has since been ratified by 172 countries (World Bank, 2016). Additionally, there has been increasing awareness of national disability policies among aid donors, which has allowed for some resistance to discrimination through threats to funding streams by bilateral donors (World Bank, 2016). Additionally, seven of the targets in the Sustainable Development Goals refer to PWD.

However, the fact remains that the populations that are most distinctly affected by disability are also the most marginalized and underrepresented and most of this global policy and awareness is not reaching them. Disability has higher prevalence in developing countries and is more common among impoverished women, elderly, and young children (WHO, 2016). The compounding risk factors of poverty, disability, and low status result in many

PWD experiencing discrimination in areas such as health care and access to public space while also lacking the resources and social capital to be able to combat these issues (WHO, 2016). For these reasons and in support of basic human rights, it is critically important that governments regard disability as a serious issue and enact measures to increase PWD's participation in and access to, services, protections, and basic freedoms. Despite increasing visibility for disability issues on the global stage, disability advocacy on this level is not often realized on either the national or private level within individual countries. With these disparities in mind, it is crucial that the global community as well as individual governments invest in better research on disability issues and continue to seek new and innovative ways to combat such injustices. Improving disability rights and access has the potential to promote lifelong benefits by breaking the cycles of poverty and unachieved potential that so many PWD across the globe currently experience.

Vietnam provides a good case study of how issues relating to disability continue to be a challenge for public society and governments alike. The issues that PWD in Vietnam face are connected to the general lack of understanding, empathy, and knowledge that people have towards disabled bodies. Disability in Vietnam lacks attention, respect, and funding and PWD across the country experience deep-seated stigma. The issues in Vietnam are distinct but also, importantly, reflect some of the greater contemporary issues surrounding disability that exist on the global level. This paper explores some of the specific

issues that women with disabilities (WWD) in Vietnam face and what historical, cultural, and social factors have shaped the perception of disability in the country.

### ***Overview of Disability in Vietnam***

Vietnam is a rapidly developing country with one of the fastest growing economies in Southeast Asia and a population of roughly 89.7 million people (BBC, 2017). Vietnamese law formally classifies people with disabilities (PWD) as “those who have impairment of one or more parts of their body, or functional impairment, which are shown in different forms of disability, and may cause difficulties in work, daily life and learning” (DREDF, 2016). The United Nations Population Fund (UNFPA, 2011) census report of Vietnam from 2009 estimated that roughly 7.8 percent of people over the age of five, or 6.1 million people, registered a disability in one or more of the following four functioning domains (listed in order of prevalence): seeing, walking, cognition, and hearing (UNFPA, 2011). Additionally, as many as 49 percent of the 6.1 million PWD in Vietnam, or roughly three million people, are registered as having disabilities that fall into more than one of the four domains (UNFPA, 2011, p11). People with severe disabilities (PWSD) are those who register as being completely nonfunctional in one or more of the four domains, and account for 385,000 of the 6.1 million PWD in Vietnam, although this number is only representative of the PWSD who were registered as receiving care at the time of the census (UNFPA, 2011, p10). This 2009 UNFPA report is the most comprehensive report to date regarding disability in Vietnam, but is also only representative of data collected directly through self-reporting of a 15 percent sample from the housing and population census.

A few distinct demographic trends regarding PWD emerged from the 2009 UNFPA report. The report found that disability disproportionately affects women, has highest prevalence among the elderly, and is concentrated in rural areas (UNFPA, 2011, p13-19). Among males and females five years or older the prevalence of disability is 7.0 percent and 8.4 percent respectively (UNFPA, 2011, p13), and women experience higher rates of disability that range from moderate to severe classifications. The prevalence of disability is higher in rural areas than urban areas; roughly 75.7 percent of PWD live in rural areas (UNFPA, 2011, p19).

The majority of PWD and PWSD in Vietnam are people over the age of 60 at 54.6 percent (UNFPA, 2011, p15). This concentration of disability among the elderly is not surprising because difficulties within the four functioning domains can be associated with the aging process. No data that explored possible correlations between the high prevalence of disability among the elderly in Vietnam and historical events, such as war, famine, and disease prevalence, existed when this review was composed; therefore, high disability prevalence among the elderly can potentially be attributed to natural aging processes and/or other unknown causes of disability. The UNFPA report found that the onset of disability occurred most commonly at around 40 years old (UNFPA, 2011, p17) and that elderly females make up the greatest proportion of the population of PWD (UNFPA, 2011, p15). In general, the population of PWD is much older than PWOD, with median ages of 59 years and 30 years respectively (UNFPA, 2011, p18), suggesting that disability tends to be a more pressing issue for the elderly.

Caring for a large elderly and disabled population is challenging in any context. In Vietnam, the majority of the PWD are elderly and this results in specific challenges because PWD are statistically more likely than people without disabilities (PWOD) to live alone or in households with fewer persons (UNFPA, 2011, p17). This large population of elderly PWD in Vietnam, who potentially lack familial support and household care, likely results in the needs of many elderly PWD being unmet. This issue is just one example of the distinct incongruence between the need and reality of PWD care in Vietnam.

As previously mentioned, most disability issues across the globe have not been well researched or addressed and Vietnam is no exception to this trend. Very little research exists on disability in Vietnam and this failure to capture knowledge on such a distinct issue can be best attributed to the social discomfort and government controls on the discussion, acknowledgement, and exploration of something as sensitive as disability. The government of Vietnam (GoV) does not directly support disability research and provides very little funding for disability services, opting instead to ignore the presence of disability issues (UNFPA, 2011, pg. 18). Without this information it is hard for organizations, aid agencies, and the general public to even begin to understand the disabled experience, let alone provide the appropriate services and implement effective interventions for PWD'Ss needs.

The potential limitations of these data include that the most vulnerable populations of PWD may also be those who were not captured in the census data. Similarly, while census reports and others like it capture demographic

information regarding PWD and comparative outcomes for PWD and PWOD, they lack specific data about the experiences of PWD as well as the success or failure of existing policies to protect and serve PWD.

### ***Rationale***

The lack of research and attention paid to the plight of WWD in Vietnam is particularly important because of primary evidence of these issues. In the spring of 2016, a pilot study developed and conducted in connection with Disability Research and Capacity Development Vietnam (DRD) used focus groups on WWD's experiences with abuse and harassment in Ho Chi Minh City. The findings from this study revealed that WWD frequently experienced abuse and harassment and that the most common forms included street harassment, cyber abuse and harassment, a lack of resources and reporting culture, violations of sexual and reproductive rights, familial control, societal stigma, discomfort and lack of understanding of disability, and lack of empowerment. While the transcripts from the focus groups and the analysis of the findings proved important and influential for DRD and the plans for their future programming and interventions, identifying these issues does not explain their significance or the rationale behind their severity and frequency. The findings from the study shed light on what WWD were facing everyday but did not adequately address why such things were occurring.

The purpose of this original study was to gain a better understanding of WWD issues from the viewpoint of the women who actually experience these things. The motivation for further exploring these results and their significance

stems from their deep influence on WWD health and wellbeing and the unique cultural context in which they are embedded. This paper explores what significance these findings hold in respect to cultural, historical, and societal factors and if the experiences of WWD in Vietnam are unique and culturally bound or if they fit into the greater global narrative of disability issues. It is important to understand the experiences of WWD as completely as possible, explaining not only what is happening to them but also why, and using this deeper understanding to promote lasting change. If the human potential and rights of PWD are recognized it will benefit individuals, families and the country as a whole. This paper will argue that the abuse and harassment that women with disabilities in Vietnam experience is directly connected to cultural, historical, and political forces that define and determine their status as women and as disabled bodies, and that understanding the context in which these issues are embedded will lead to the development of better and more effective intervention and empowerment strategies.



## **Literature Review**

### ***Introduction***

On the ground in Vietnam, the lack of comprehensive protections and acknowledgement of PWD suggest that disability and disability issues continue to be regarded with discomfort by the Vietnamese Government and much of the populace. As a result of this, there is little research on disability issues within Vietnam. The government does not allocate funds for federal research and investigation on the subject, and organizations that do work in support of disability advocacy and research do so with limited funding and resources and without major systemic support. This literature review has been constructed to include work, from within and beyond Vietnam, that contributes to the basic understandings of disability and disability issues, addresses valuable theoretical frameworks for analysis, and provides case-based studies for comparison. The selected literature has been included because it contributes to a better and more thorough understanding of how the harassment and abuse of women with disabilities in Vietnam can be located and analyzed through larger historical, cultural, and political frameworks pertaining to disability and gender. The intent is to establish what current research and theory exists regarding issues connected to the experiences of women with disabilities in Vietnam.

The literature included in this review is predominantly contemporary work that is classified as either theory-focused or a case-based study. Additionally, the abuse and harassment that women with disabilities experience is related to their status as women within the society and the cultural and political perception of disability and disabled bodies within the country. Therefore, the literature review

included has been organized as relating to gender or disability with some work that addresses these issues in connection with one another. The four key inclusion criteria for this review are as follows:

1. Contemporary work: Literature published no earlier than January 1st, 1996 and focusing on contemporary topics related to the subject.
2. Relevant content: Literature primarily focused on issues that pertain to systems of power and exclusion, gender roles and inequalities, and disability culture and issues.
3. Ethical research: Studies that have been conducted within ethical standards and with minimal risk to participants.
4. Unbiased information: Literature that provides factual information based on legitimate research that is not biased by external motivators such as government agendas or incentivized outcomes.

## ***Gender***

### *Historical and Political Constructions of Gender in Southeast Asia*

Women with disabilities (WWD) face the complex challenge of fighting discrimination and harassment on the basis of their gender, their status as a disabled body, and the convergence of both those identities. Exploring how gender is constructed within Vietnamese society is an integral part of understanding and locating the abuse and harassment that WWD experience. Through her work on gender, anthropologist Clara Sarmiento analyzes and emphasizes the importance of binaries in how gender is constructed in Southeast

Asia. She details how contrast is fundamental when establishing normalized gender roles within Southeast Asian cultures, such as strong male roles versus weak female roles and male prestige versus female stigma (Sarmiento, 2012, p. 441). Additionally, Sarmiento includes the historical regional development and notes that the marginalization of women is woven into the very fabric of nation-building in Southeast Asia, where the discourses and stories of national development that are valued are those in which men play dominant roles (Sarmiento, 2012, p. 450). In this way, nationalism and patriarchy have been deeply intertwined, with the roles left for women being those of respectability, maternity, and victim while the roles of men have been increasingly celebrated as they connect with cultural pride and national success (Sarmiento, 2012, p. 450).

In addition to the establishment of gender roles in domestic culture, memories of colonial control and modern globalization, both of which have brought foreigners in and stories out of Southeast Asia, have been central in perpetuating the stereotype of the Southeast Asian woman as an exotic and demure creature who exists in a land defined by pleasure and adventure (Sarmiento, 2012, p. 461). Historically, these gender roles for women were established based on colonial imaginings of exoticism and also as the result of the differentials of power that existed between colonizer and colonized; the behaviors of a woman who is being controlled will undoubtedly reflect the desires of the controller (Sarmiento, 2012, p. 462). Today, tourism in Southeast Asia continues to be a huge industry and visitors come searching for “romantic colonial narratives” with the hopes of discovering and participating in the Oriental

exoticism that has come to define the stereotypes of Asia (Sarmiento, 2012, p. 461). However, in lieu of protesting such simplifications and sexualization of complex and distinct cultures, many governments and people in Southeast Asian nations have worked to transform and perform culture in ways that are desirable for tourists, including the behavior, perception, and presentation of women, for the simple reason that performing culture in ways that meet Western desires is incredibly profitable (Sarmiento, 2012, p. 461). In her work, philosopher Simone de Beauvoir proposes woman as the Other based on the idea that society accepts man as the standard and norm and that any deviation from that is distant and of less value (1989). The new age of globalization has, if anything, further marginalized women in Southeast Asia, as the expectation for their performance of the lesser gender, or Other gender, has now expanded to involve not only their traditional and evolving cultural roles, but also their constructed roles on the global stage.

### *Sexual and Reproductive Rights*

There is very little current research on the sexual and reproductive rights of women in Vietnam, and none at all which includes the experiences of WWD. The data that do exist, such as a survey conducted by ActionAid in 2014, found that the prevalence of sexual harassment of women (not specifically WWD) in Vietnam is alarmingly high. A large-scale survey conducted by ActionAid in Hanoi and Ho Chi Minh City found that 87 percent of the 1500 female responders reported that they had experienced sexual harassment in a public space (Hoang, 2014, p. 11). The survey also found that 66 percent of female responders

reported that they would not report harassment or abuse for fear of retaliation or because they felt nothing would result from reporting it (Hoang, 2014, p. 5). The ActionAid survey also found that the most prevalent types of harassment in public spaces were whistling and teasing, inappropriate staring or suggestive looking, and being flirted with or followed continuously (Hoang, 2014, p. 12). The above findings are particularly concerning because they suggest that there is a certain normalization of sexual harassment behaviors in public space.

Additionally, although the ActionAid survey did not provide specific data on the experiences of WWD, the high prevalence of sexual harassment among able-bodied women strongly suggests that if these experiences extend to WWD, they may even be more severe based on the perception of WWD as vulnerable, easily manipulated and coerced.

Although there are no specific data on the experiences of Vietnamese WWD, exploring the challenges faced by WWD across the globe, such as violations of their sexual and reproductive rights, is useful in better understanding disability issues overall. In 2013 authors Frohmader and Ortoleva wrote an issues paper, titled *The Sexual and Reproductive Rights of Women and Girls with Disabilities*, which discusses global examples of the violations of WWD's sexual and reproductive rights (SRRs) and proposes key priority considerations for the future of WWD's SRRs policy and protections. Sexual and reproductive rights are recognized as fundamental human rights, and include self-determination and autonomy over one's body, sexuality, relationships, and reproductive decisions (Frohmader and Ortoleva, 2013).

WWD across the globe have been the victims of some of the most extreme and aggressive violations of sexual and reproductive rights. Violations tend to manifest in instances of extreme control and restriction, lack of access to services, and disability based discrimination. Frohmader and Ortoleva detail how forced sterilization and forced contraception are two very common violations of WWD's SRRs (Frohmader and Ortoleva, 2013, p. 4). Both practices are commonly performed under the guise of legitimate medical treatments but occur without the direct consent of the WWD (Frohmader and Ortoleva, 2013, p. 4). The International Federation of Gynecology and Obstetrics as well as the UN Special Rapporteur on Torture have declared that the forced sterilization of WWD "violates the absolute prohibition of torture and cruel, inhuman and degrading treatment" and that these practices are considered inhumane and torturous regardless of whether they are legalized and legitimized in their specific country settings (Frohmader and Ortoleva, 2013, p. 4). The concept that WWD have an active and expressive sexuality, like that of able-bodied women (Films Media Group, 2010), is a topic that generates discomfort. This likely stems from the dehumanizing view that many people have of PWD, and that attributing distinctly human experiences, such as sex and sexuality, with perceived "abnormal" bodies is a source of confusion and moral conflict (Films Media Group, 2010). WWD (especially those with intellectual disabilities) are much more likely than able-bodied women to be forcibly sterilized and to be administered long-acting contraceptive methods without their consent (Frohmader and Ortoleva, 2013, p. 5). The functions of forced contraception on WWD include sexual expression

repression, menstrual repression, eugenics-based population control, and pregnancy prevention (Frohman and Ortoleva, 2013, p. 5). In short, forced contraception is often used to prevent WWD from experiencing and participating in distinct processes that in many ways define womanhood and female sexuality. However, it is important to acknowledge that these contraceptive methods are sometimes given to WWD with intellectual disabilities as protection against pregnancy from sexual abuse. The ethics of prescribing contraception in these situations are complicated and illustrate the greater issue of the sexual abuse of WWD. There is evidence that WWD sexuality is not something that is homogeneous or well understood and that there is a tendency to suppress and ignore WWD sexuality, which demonstrates a failure to acknowledge their womanhood and often results in the violation of their human rights.

WWD are twice as likely to experience gender-based violence (GBV) as able-bodied women (Frohman and Ortoleva, 2013, p. 5). GBV is a serious issue for all women, but tends to manifest in more severe ways for WWD, occurring over longer periods of time and resulting in more serious physical and emotional damage (Frohman and Ortoleva, 2013, p. 5). This could be related to their status as PWD; they may be vulnerable because of mental or physical disabilities that make it challenging for them to defend and advocate for themselves. The other significant risk factor for WWD regarding GBV is that the perpetrators are often family members, caregivers, and people on whom the WWD are reliant for care and support (Frohman and Ortoleva, 2013, p. 5). This is particularly problematic because it may discourage WWD who are able to

report abuse from doing so on the basis of dependency or fear of retaliation, and leaves WWD who are unable to report abuse completely vulnerable to their abusers/providers. Related to this is the potential for WWD to experience difficulty in even recognizing abuse and violence and understanding how to go about reporting it and seeking help (Frohman and Ortoleva, 2013, p. 5).

The issue of GBV and WWD has not been documented in Vietnam. However, based on the global precedent of WWD'S experiences with GBV as described by Frohmader and Ortoleva, it is likely that GBV against WWD is a significant issue in Vietnam. It may even be further exacerbated by the general lack of visibility that WWD face and how deeply disability is stigmatized within the country. Additionally, the family unit is the legally and socially accepted caregiver for WWD in Vietnam. Without communities and outside resources and support, WWD face significant risk of experiencing GBV from within their private spheres, and typically lack the ability to protect themselves.

The same disabilities that leave WWD susceptible to abuse also result in powerful medical and social pressures to deny WWD maternity and parental rights (Frohman and Ortoleva, 2013, p. 5). WWD are often perceived as unable to engage in self-care, autonomous decision-making, and general independence (Frohman and Ortoleva, 2013, p. 6). These perceptions fuel the stereotype of WWD as unfit to be mothers (Frohman and Ortoleva, 2013, p. 6). This perception is fueled by the assumption that disability reduces a person's humanity in some way, making them ineligible to participate in human life processes such as childbearing and rearing. Expression of WWD'S sexuality is



perceived as inappropriate or irresponsible and they are seen as being unfit to be mothers on the basis that they would not be able to care for their children and/or that children they would bear would also be disabled and be a continuation of “unfit” genetic lines (Frohman and Ortoleva, 2013, p. 6). These societal stigmas and unfounded fears result in many WWD being prevented from having children, and WWD with children have a significantly higher risk than able-bodied women of having their children forcibly removed from their care (Frohman and Ortoleva, 2013, p. 8). WWD are much more likely to lose their parental rights during divorce than able-bodied women because their disability dominates the arguments about their parenting abilities, rather than their actual capacity, skill, and parenting behaviors (Frohman and Ortoleva, 2013, p. 6).

The issues of GBV, forced sterilization and contraception, and denial of maternity for WWD are exacerbated further by the fact that WWD have much more limited access to reproductive health services and education than able-bodied women (Frohman and Ortoleva, 2013, p. 7). This includes provider discrimination towards WWD and a lack of access to fundamental services such as prenatal care, cervical and breast cancer screenings and information and education on reproductive health and family planning (Frohman and Ortoleva, 2013, p. 6-7). This lack of access can be associated with a fundamental lack of providers in areas where WWD live, but is more often due to discrimination against WWD and lack of accommodating services that make care accessible for them, such as transportation, disability equipment, exclusionary policies, and the

stigma or incorrect assumptions of health care providers regarding WWD's health and reproductive rights (Frohman and Ortoleva, 2013, p. 7).

Ortoleva and Frohman's work describes some of the issues faced by WWD across the globe. In Vietnam, the current knowledge on disability is that it is highly stigmatized in the country, that WWD experience low accessibility to public spaces, and that disabled bodies have low visibility in society (Gammeltoft, 2014). With these things in mind, it is highly likely that the issues mentioned in Ortoleva and Frohman's briefing are also issues for WWD in Vietnam and may even be exacerbated by country-specific challenges such as familial structure, stigma, economic development, and culture. Ortoleva and Frohman's work is important for establishing an understanding of these challenges, and in light of the lack of specific research on the topic, it helps to provide insight into what WWD in Vietnam are likely experiencing.

A French documentary film titled "Disability and Sexuality: Exploring the Intimacy Option," produced in France in 2010, chronicles the personal stories of people with disabilities and their journeys with sex and intimacy. Many of the participants who were interviewed throughout the film express that the literal need for physical intimacy and connections stems from not sexual needs, but human ones. Disabled bodies are often not seen or acknowledged as human in the same way as able bodies; they are not expected or anticipated to need physical interaction, crave intimacy and sexuality, or be acknowledged or described as beautiful. The issue with these limited perceptions of disabled bodies is that, in fact, many people with disabilities desire the same level of

human interaction as able-bodied people. Because disability, physical or mental, is seen as a deviation from the norm, the prospect of disabled sexuality and intimacy sparks great discomfort among able-bodied people. Marcel Nuss, a man who was born with severe disabilities, states that sexuality for anyone is defined by kindness, human warmth, sincerity, and courage. Throughout the film, the participants experience the same challenges that are related to the confinement and forbidden nature of the expressions of their sexuality. These taboos and discomfort are perpetuated by the opinions and decision making of the caretakers and care institutions of which the PWD are a part (Films Media Group, 2010). Interviews with the staff members in a care home in Lille reveal that they are conflicted by the ethics of sexuality among disabled people and that it is difficult not to conflate a person's physical disabilities with their mental capacity (Films Media Group, 2010).

Another barrier addressed during the film was the challenge in supporting PWD'Ss sexuality when they required physical assistance in order to engage in intimacy and sexual acts (Films Media Group, 2010). Interview participants expressed their shame and embarrassment at their bodies' involuntary responses to physical interaction from caretakers and stated that they felt their distinct deprivation from intimate contact and human closeness was to blame (Films Media Group, 2010). This brings into question what qualifies as a distinct human right and need. Marcel Nuss, who had been married twice to able-bodied women and enjoyed an active sex life with severe physical disabilities, described sex as a method of expressing joy (Films Media Group, 2010). His circumstances

were different from those of most of the other participants because he had an able-bodied partner; the challenge for PWD with disabled partners was that even if they desired physical intimacy, they would need physical assistance in order to make that possible (Films Media Group, 2010). A private center in Hanover, Germany offers sexual seminars and retreats for people with disabilities each month where they can engage in normalized conversations about sex and sexuality and have the opportunity to work with sex assistants in what is described as a chance for people with disabilities to spend time “reflecting and discovering their bodies and their own sexuality” (Films Media Group, 2010). The center in Hanover is an exception to the general rule of sexuality and intimacy being inaccessible to people with disabilities that inhibit their independent movement. Although France is a highly developed and predominantly socially liberal country, conversations and services surrounding disability and sexuality are still deeply stigmatized and there is no existing infrastructure or policy in place to influence these issues.

A salient theme in the film was the policing of disabled bodies’ access to intimacy and reproductive rights based on their dependency and disabled status. A young couple, both severely disabled, detailed their story of struggling to find a care home that would accept both of them as a couple and even in doing so, the director and staff refused to acknowledge their partnership and refused to facilitate any cohabitation, physical contact, or intimacy (Films Media Group, 2010). Their situation emphasized the distinct lack of existing options and

solutions for people with disabilities who want to engage in intimacy and maintain relationships.

Perceptions of disability can invalidate an individual's gender, sexuality, and reproductive rights. A distinct example of this from the film was a couple in Northern France who both used wheelchairs and were the parents to a young boy (Films Media Group, 2010). They described the pushback they had experienced from doctors when they were trying to get pregnant and that many physicians had refused to help them, stating that it was unethical or impossible. Their "wanting to have a child upset the establishment" and even when they got pregnant, they experienced distinct discrimination from health care providers (Films Media Group, 2010). The woman shared that having a child was important to her, a reaffirmation of her womanhood, and that "handicapped women were not associated with female qualities and beauty" (Films Media Group, 2010). Much like many of the Vietnamese women within the focus groups, she detailed how expressions of sexuality or attempts to participate in distinctly feminine rituals were met with hostility and distinct discomfort from able-bodied people.

France is a vastly different social landscape from Vietnam, but the discomfort surrounding the sexuality of PWD is, in many ways, parallel. This is discouraging in some sense because it suggests that despite improved disability infrastructure, a robust health care system, and more rights and recognition for PWD, France has not developed a more open-minded or comprehensive approach to acknowledging PWD as humans with the same needs, rights, and desires as able-bodied people. However, the continued discomfort surrounding

PWD sexuality in France further supports the idea that accepting PWD as normalized members of society is a question of culture change and cannot simply be influenced by policy and infrastructure development. The global conversation about PWD'S body rights and the ethics of denying their human sexuality and desires is one that is still emerging. WWD in Vietnam reported being met with discrimination and harassment when they expressed their sexuality and gender. Many of the complex issues present in France are also reflected in the experiences of WWD in Vietnam. The policing of disabled bodies and denial of sexual and reproductive rights seem, sadly, to be universal experiences for WWD across the globe. The discomfort that able-bodied people and policy makers feel is related to the vision of the disabled body as deviant, and this perceived deviance denies disabled bodies access to normalized aspects of human life, culture, and society.

#### *Gendered Familial Structure in Vietnam*

Understanding the basic familial structure in Vietnam is useful when considering issues of disability and how they are connected to family, community, and cultural life. Article 8 in the Vietnamese *Law on Persons with Disabilities* states that families are legally obligated to “protect, nurse and take care of persons with disabilities.” This legal obligation for families to care for PWD has implications for family dynamics, including how power and control function for PWD. Family structure in Vietnam has changed significantly in the last 40 years due to the influences of war and conflict, economic reform, political change, and social upheaval (Knodel et al, 2005). However, despite the many evolutions that

familial structure and function in Vietnam have undergone, there remain distinct differences in the gendered roles and expectations present within most families and these differences are important to note when considering the roles that WWD hold within their family units.

Data from a 2005 study on gender roles within the Vietnamese family suggests that women and men are increasingly equally employed, and while women still possess the majority responsibility for domestic work, they also have significant decision making power in regards to familial finances, childbearing, and children's education (Knodel et al, 2005, p. 5). Historically, Vietnamese family structure was based on the Confucian model, which emphasized patriarchal power and women's dependency on men, but observations from as far back as the French Colonial period suggest that Vietnamese women have always held strong positions in the household in comparison to their female counterparts in surrounding Asian countries (Knodel et al, 2005, p. 2). Aspects of the patriarchal system are still present today, most evidently in the patrilineal kinship and inheritance pathways and the post-matrimony patrilocal residence, although the nuclear family household is still the most common living arrangement (Knodel et al, 2005, p. 5). Vietnamese women are more likely to be directly involved in childrearing, especially during infant through preschool years, and have limited but existent influence over household budget decision making (Knodel et al, 2005, p. 12). In the past decade, governmental control over family life has eased significantly and there is some speculation that people's increased autonomy over their family life has actually resulted in the re-adoption of

Confucian values and a shifting of expectations towards more traditional gender roles, which can lead to women being increasingly disempowered within the familial sphere (Knodel et al, 2005, p. 13).

When considering WWD'S roles within the family, it is important to note the historical significance of familial units. A survey on family structure in Vietnam, conducted by Hirschman and Loi in 1996, states that "families are the core social unit in society...Children are socialized to societal norms and values, in large measure, through family interactions" (Hirschman, 1996, p. 229). This is significant when considering how WWD see themselves in relation to society, and how they perceive the shame and stigma of disability. These perceptions are likely directly linked to how they have been socialized and the roles they play in their own families; the experiences WWD have within their private spheres deeply influence their confidence in the public sphere. Honoring the family unit and ancestors, providing for aging parents, continuing the familial line through marriage and reproduction, and performing gendered roles are expectations that are often difficult or impossible for WWD to fulfill.

#### *Family based interventions*

The close-knit family units within Vietnamese society provides both benefits and risks to WWD, who are more likely than their able-bodied peers to be dependent on their families for physical and financial support. As previously discussed, this level of dependency can be of concern because any abuse or harassment from within the family unit can leave the WWD in an extremely vulnerable position. However, the commonality of direct family investment in



WWD health and well being also has potential as a valuable intervention point. As much as insular familial environments can pose a risk to WWD, they can also be the forefront of allyship and be an active part of empowering WWD. A study conducted in Bangalore, India, in 2012 assessed the efficacy of a new intervention that aimed to empower mother-in-law/daughter-in-law dyads and improve their health outcomes as well as reduce domestic violence (Krishnan et al, 2012). Marriage and fertility are greatly valued within South Indian culture and married women face extreme pressure to produce children and are susceptible to domestic violence (Krishnan et al, 2012, p. 2). The role of domestic violence in Bangalore mirrors that of disability discrimination in Vietnam in that it is highly normalized within society and considered a part of the private domestic sphere and therefore women are unlikely to reach outside of their families for support (Krishnan et al, 2012, p. 3). The intervention was called the DILMIL project; DILMIL is an acronym for Daughter-in-law, Mother-in-law and the word also translates to “hearts together” in Hindi. Participants in the DILMIL project were recruited through community health centers where young pregnant woman went to receive antenatal services (Krishnan et al, 2012, p. 1). The young woman would be asked to join the study and her mother-in-law would be recruited through her if eligible and willing (Krishnan et al, 2012, p. 1). The goal of the study was to build relationships between the DILs and MILs in an effort to empower them both and establish the MIL as an advocate for the DIL, and protect the DIL from domestic violence perpetrated by her husband (Krishnan et al, 2012, p. 1). At the beginning of the study, DILs reported that MILs were often

involved in instigating violence against them but that they also had significant power to prevent it because their sons (husbands of the DILs) were unlikely to challenge their mothers (Krishnan et al, 2012, p. 3). The intervention took the form of six guided sessions, the first three with DILs and MILs separately, the latter three with them in combined groupings, as well as two post-intervention assessments and an in-depth exit interview (Krishnan et al, 2012, p. 4). The sessions were led by trained healthcare professionals experienced in domestic violence prevention and covered topics ranging from antenatal health care to empowerment to domestic violence prevention (Krishnan et al, 2012, p. 4).

This study suggests that the intervention allied dyads against domestic violence, empowered both parties and improved health outcomes for the DIL (Krishnan et al, 2012, p. 11). Measurable outcomes included increased social support of DILs by MILs, increased knowledge of domestic violence, increased decision making power for DILs, increased safety, improved perception of quality of life, and improved communication within the dyads (Krishnan et al, 2012, p. 10). A large part of the intervention programming involved educating the dyads on issues of health and domestic violence, but the aspect of the intervention that was most associated with measurable outcomes was the effort that was put into bonding the pairs and helping them form supportive relationships (Krishnan et al, 2012, p. 10). The intervention design included trying to remind MILs of when they themselves were young brides and mothers, and the scrutiny they faced from their husbands' families (Krishnan et al, 2012, p. 11). Building relationships within

the dyads based on their shared experiences and struggles as women within the family sphere empowered the members as allies (Krishnan et al, 2012, p. 13).

This intervention is valuable because it speaks to the potential of opportunistic intervention through existing health infrastructure and to the power of family-based empowerment and ally building. Combating the abuse and harassment of WWD by family members may be extraordinarily difficult because of the level of isolation and dependency WWD experience. However, the DILMIL project demonstrates that a familial-based intervention system, focused on empowerment and the fostering of mutual understanding and empathy, might be valuable.

## ***Disability***

### *Social, Cultural and Political History and Disability*

The conception of disability in Vietnam is integrally connected to the sociopolitical history of the country, and it carries symbolic and memory-bound meanings that extend beyond mild discomfort of deviance. Vietnam is a rapidly developing country defined by massive economic growth following its recent history of violent conflicts, political instability, famine, and poverty. Although Vietnam today seems in many ways to have transcended its challenging past, much of its societal structure, culture, and policy still reflect the fears and memories of those recent traumas. Perhaps the most distinct—and certainly the most recent—of these traumas is the Vietnam War and its aftermath. Although Saigon fell in 1975, many hauntings of the war and its effects on the country are

still present today. One of the most distinct and painful legacies of the war is the lingering memories and effects of Agent Orange. Agent Orange was mixture of powerful herbicides and chemical defoliants that was developed by the U.S. with the goal of defoliating the forests where the National Liberation Front (NLF) troops might be hiding and destroying the crops and livelihoods of the Vietnamese people (Beaulieu and Fessele, 2003). Over a nine-year period, roughly 20 million gallons of this toxic herbicide was dropped over southern Vietnam, and American troops, the NLF army, and many Vietnamese civilians were exposed (Beaulieu and Fessele, 2003). Roughly twenty years after the war ended, the U.S. government began investigating the health consequences of herbicide exposure following the emergence of a baffling and severe array of illnesses appearing in a large number of U.S. veterans who had been exposed (Beaulieu and Fessele, 2003). Continuing investigations have revealed that exposure to Agent Orange and other herbicides can be directly connected to a number of poor health outcomes such as cancer and severe skin damage; however, there is still much contested between scientists and the U.S. and Vietnamese governments about the potential consequences of Agent Orange exposure and how severe they are. Some researchers argue that the effects of Agent Orange on the human body can be seen in birth defects and fertility reduction in up to four generations after direct exposure (Beaulieu and Fessele, 2003). In Vietnam, memories of the war are present in structured memorials across the country, but also present in the form of human lives. In addition to the postwar challenges of an unstable government and significant famine, families

who were exposed to Agent Orange during the conflict faced the prospect of managing the extensive consequences of chemical exposure. Although specific mechanisms have not been determined, many people in Vietnam, and indeed across the globe, feel that there is distinct evidence that links Agent Orange exposure to birth defects and disabilities across generations (Beaulieu and Fessele, 2003).

Tine M. Gammeltoft has written extensively on reproduction and body politics in Vietnam and in 2014 wrote an article on selective abortion due to malformations detected in the fetus and how the increasing use of this technology is linked to the anthropology of the imaginary and constructions of disability for the Vietnamese. This article is significant for two predominant reasons: it provides an ethnographic glimpse of how disability is perceived among families, health professionals, and policy makers, and it provides an important framework for considering the fear and stigma of disability within the context of the constructed imaginary. The subject of Gammeltoft's piece is the increasing use of ultrasound and scans during pregnancy to determine, during pregnancy, if the fetus is likely to have abnormalities and disabilities. If abnormalities are detected, the most common response on the part of the mothers and families—and the recommended course of action from health care professionals and the government—is abortion (Gammeltoft, 2014). The emphasis on abortion for fetuses with abnormalities stems from the government of Vietnam's (GoV) goal of increasing "population quality" (Gammeltoft, 2014, p. 155). Having already slowed fertility rates and encouraged a two-child policy

inspired by China, the GoV saw “quality” as creating a Vietnamese population that was comprised of healthy and productive individuals with whole, complete, normal, and attractive bodies (Gammeltoft, 2014, p. 155). This push towards increased quality of the population was introduced by the Minister of Health in 2005 and has influenced pregnancies and prenatal care from that point forward (Gammeltoft, 2014, p. 156). However, the implications of this policy extended far beyond pregnancies at the time; the push towards a quality population that did not include disability meant that people currently living with disabilities were established as socially and politically unwanted. The moral question of aborting fetuses suspected to have abnormalities is beyond the scope of this argument; what remains immediately problematic with the increased use of screening during pregnancy is how these practices are associated with overall societal values and goals and how PWD are excluded from that vision. In Gammeltoft’s earlier 2008 work, she emphasizes that the increased screenings resulted in “the disabled child becoming a political figure” (571) because disability came to represent far more than physical outcomes and extended to pain, suffering, value, justice, and responsibility (Gammeltoft, 2008).

The deep-seated fear and stigma that is associated with disability exists within the broader systemic and policy levels and extends all the way down to individual fears and perceptions. In Gammeltoft’s work, the most common rhetoric used to describe PWD were as burdens to the family and to society, as creatures that were less than human (Gammeltoft, 2014). Dr. Nga, an OB/GYN who was a direct employee of the state, counseled women on when to abort their

pregnancies based on how she imagined the lives of their future disabled children, saying “If you do not intervene, the child will become a burden for society...They will bring pain for their parents and other people too. If you know for sure that a child will be disabled, there is absolutely no point in keeping it.” (Gammeltoft, 2014, p. 154). The imagined lives for disabled children: sad, burdensome and less than human, were visions that were shared by mothers and health care providers alike and contributed greatly to the success of the GoV’s goal of improving the ‘quality’ of the population. The collective vision and imaginings were of PWD as mistakes and burdens, less than human occurrences that could and should be prevented. In this way, the fears that people had of being seen as a deviation from the norm through and because of their disabled child and the government’s goal of building a society full of “desirable citizens” (Gammeltoft, 2014, p.165) converged to act as a powerful influence on the choices that expectant mothers made. The GoV’s discriminatory policy against PWD and the active condemnation of PWD as bad for families, for the state and responsible for the slowing of development and influx of poverty (Gammeltoft, 2014) added to the citizen’s human fear of being seen as deviant from the norm. For Mai, a young mother who opted for an abortion after seeing abnormalities in her fetus, extensive imaginings of how hard her life would be should she have chosen to bring her pregnancy to term influenced her decision. She felt that “if this child had been born...this would have stigmatized her family and confronted her and her husband with impossible care-giving tasks” (Gammeltoft, 2014, p. 163). Although there are distinct challenges related to PWD’Ss lives and the lives

of their families, the completely bleak and hopeless imagings of PWD lives are inevitably influenced by more than just perceived realities. The inclusion of people's experiences and imaginings in Gammeltoft's work establish the current realities for PWD in Vietnam based on how they are perceived by society and the GoV. Equally important is Gammeltoft's theory of how the imaginary influences present realities in Vietnam and how these imaginary outcomes are constructed.

In imagining the life of a disabled infant, Dr. Nga says, "it will not be able to become a human being. Or it is not clear if it is a human being. It lacks mental capacities, people who lack mental capacities are not people" (Gammeltoft, 2014, p. 156). The future that she has imagined for the disabled child is one that is doomed. Although there are distinct challenges regarding disability, such a unified collective imaginary of PWD as burdens and non-human is grounded in other collective experiences, realities and fears. Gammeltoft places an "emphasis on the creative imaginary capacities that we possess as human beings, while also recognizing how these capacities, rather than reflecting a free consciousness, are always shaped through politically inflected structures of signification that extend our conscious awareness of self, stimulating our imagination yet operating at more subdued levels of life." (159). In the case of the collective imaginings of disability in Vietnam, one of the most significant influences is the country's recent experience with conflict.

When considering disability in Vietnam, a large part of disability causation, memories and exposures are associated with violent conflict, war-related injury and the effects of Agent Orange exposure. Gammeltoft emphasizes that a



collective imaginary is not coincidental; it is constructed based on collective histories and fears. And in Vietnam, many of those fears and memories are still strongly associated with the war and its aftermath. The imagining of future lives for fetuses was defined by “two starkly different kinds of images [that] seemed to compete for attention: images of chubby healthy-looking babies figuring in commercial advertisements for formula milk, baby lotion, or washing powder found their ghostly counterpoints in pictures of the grossly disfigured offspring of Agent Orange victims” (Gammeltoft, 2014, p. 165). Because of the collective memories of this trauma, women’s fears during scans and their imaginings of disability were directly connected to the circulation of images of Agent Orange victims and the aftermath of exposure. Disability was imagined as a threat to the family but also to society in the same way that the violence of the past was. Understanding the collective imaginary as it has been constructed by past trauma is fundamental in understanding how disability functions within Vietnam because it establishes disability as an undesirable deviation from the norm and presents it as a visitation or haunting from a violent past and an obstacle to recovery.

If the imaginings of disability are founded in shared experiences, it is important to consider what cultural practices and beliefs shape those experiences. In her book, *Consoling Ghosts: Stories of medicine and mourning from southeast Asians in exile*, Jean M. Langford explores the role that haunting plays in the lives of Southeast Asians who experienced trauma and violence during the Vietnam war and related conflicts. She establishes that death by

violence results in haunting that permeates not only the realm of dreams but also has the power to disrupt and alter daily life (Langford, 2013, p. 26). Deaths as a result of violence are seen as unnatural and are classified as 'bad deaths', which are mostly likely to result in restless, dangerous and wandering souls who inhabit the world of the living (Langford, 2013). Incomplete and damaged bodies result in restless spirits; the souls of the deceased will continue to wander searching for their lost limbs or bodies that were lost in battles or seeking vengeance (Langford, 2013). Death should be a natural end to the processes of life, with bodies being laid to rest where they lived and in complete and whole physical and spiritual form (Langford, 2013). Conflicts, like those in the Vietnam War, leave great potential for haunting because of the sheer number of disruptions and bad deaths that occurred.

Langford establishes that for many Southeast Asians, ghosts very much exist in the realm of the living and are not confined to the imaginary and that "haunting is less an interior state than a relationship both with the dead and with an ambience of terror surrounding violent death. It is also an aftershock in which the tremors of violent histories are kept rolling by a structural violence in the present" (Langford, 2013, p. 26). Although memories and haunting exist in different spaces, both are present in relation to modern Vietnam and its history of violence. There is still a generation in Vietnam that can remember the wars, and people that can recall the challenges that followed. Perhaps as a reminder of progress or simply out of respect for the past, Vietnam, through its infrastructure and society, has very much kept memories of the war alive. The War Remnants

Museum (formerly the War Crimes Museum) in Ho Chi Minh City has an entire floor dedicated to Agent Orange, with large and graphic depictions of people who were exposed and their disabled children. The violence of the past is hardly forgotten; if anything, the lingering memories, hauntings, and reminders of that recent history are overwhelmingly present. If Gammeltoft's theory of the collective imaginary and Langford's work on haunting from violent deaths are put into conversation with one another, they provide important insights into how disability has come to be imagined. The collective imaginary that Vietnamese people have for disability is rooted in their shared experiences and memories of the outcomes of violence and chemical exposure. The grandmother of a woman who had an abortion saw the fetus as non-human and feared the haunting of such a spirit saying, "this was a monstrous fetus, so it was best to leave it there so that it did not come back. After abortions, fetuses very often return" (Gammeltoft, 2014, p. 162). The potential for disability in fetuses "embodied the destroyed and damaged bodies that people did not want to talk about or remember, reminding them of experiences that were too frightening to keep in mind" (Gammeltoft, 2014, p. 168). Disabled bodies can therefore be imagined as the violence and destruction of the past and as the physical manifestation of the haunting bad deaths from that violence.

Because the past is so deeply connected to the present, disability can be interpreted through "karmic terms" (Gammeltoft, 2014, p. 162) where the transgressions and violence of the past are manifested in a fetus. The fear of haunting and of violent pasts is projected onto disabled bodies as they come to

represent old fears that seep into the modern world; people “characterized the imaginary defective fetus as a ghost (ma), devil (quĩ), or monster (qu’ai vật), thereby categorizing it with other kinds of uncanny beings which haunt people in Vietnam, threatening to disturb or destroy everyday lives” (Gammeltoft, 2014, p. 168). PWD in Vietnam are conceptualized as defective and incomplete in a postwar society that is working collectively to move away from the memories and hauntings of the past and therefore are a threat to the state and the dream of security and stability. The “ideas and imaginaries regarding what it means to be human, complete, or valuable come into expression in everyday lives” (Gammeltoft, 2014, p. 157) and bodies that are seen as physical reminders of painful pasts are not expected to be included in the modern Vietnamese reality. PWD are consistently defined as non-human and incomplete. The definition of the Vietnamese word used to describe completeness extends beyond physical and literal completeness and includes being intact, good and possessing moral integrity (Gammeltoft, 2014, p. 165). PWD in Vietnam are not granted the human rights and respect that are afforded to able-bodied people because their very existence has been established by cultural and spiritual norms and by government policy and propaganda as less than human and as a manifestation of past evils.

### *Shame in Asian Cultures*

Many of the descriptions in scholarly work of PWD in Vietnam use rhetoric that is centered on shame and embarrassment. These feelings towards disability are widely uniform even in the different contexts from which they emerge. The common use of specific terms like this suggests that these words are imbued

with distinct meanings that are connected to the societies and cultures in which they are embedded. Sociologist Francis Inki Ha's work discusses both the quantitative and qualitative methods that have been used to assess shame and its poignancy for people in Asian cultures. Ha notes that scholars such as Goffman (1967) and Harrington (1992) defined shame as an unacceptable emotion in Western cultures whereas in contrast, in many Asian cultures, expressing shame at certain times is considered appropriate and even virtuous (Ha, 2012). Additionally, Ha details how shame is often hyper cognized in Asian cultures and plays a distinct role in everyday life (Ha, 2012). Shame is an important factor to consider when investigating the roles WWD in Vietnam hold within their families and in society. Ha includes a section in her work dedicated to exploring how shame and relationships function together and how they are interconnected.

Ha argues that the experience of shame is shaped by the values of the culture and that in Asian cultures there is a distinct emphasis on respect and approval within relationships (Ha, 2012, p. 1116). Additionally, she includes speculation that people within collectivist cultures, such as that of Vietnam and other Asian countries are more concerned with gaining in-group approval and when it is withheld, shame is the dominant emotion that is felt (Ha, 2012, p. 1117). The contrast to shame in some cases is pride that is borne from dependency; a person's feelings of shame emerge when approval and pride are not gained from people with whom they are in close or dependent relationships (Ha, 2012, p.1118). The distinct understanding of shame that is felt by Asian

cultures is related to the largely collectivist culture that exists within them, in comparison to the more individualist approach of the West. The collectivist culture places an increased focus on in-group attachment and harmony and not achieving such inclusion is cause for shame. Exclusion from the in-group is made even more painful for an individual in a collectivist culture because they are taught to value intimate and long-term relationships and are wary and unwilling to enter new groups (Ha, 2012, 1119). This basic understanding of shame in Asian cultures helps to explain a large part of the experiences of WWD in Vietnam. Social exclusion and discrimination that WWD experience is a way of shaming them and preventing them from entering the greater collective in-group of society.

The abnormal and the Other, including PWD, are not considered to have a place in the order of Vietnamese society and are unfortunate reminders of realities that modern idealism is working so hard to forget. In her work, Nina Hein attempts to uncover the things that are considered the “not-beautiful” in Vietnam and delves into how denial of imperfections comes to exist. Her work is based on the unspoken rules that are applied to the production of images in Vietnam; photographs should show beauty, pride and optimism even at the expense of depicting reality (Hein, 2013). The value lies in portraying an idealized reality, and that capturing images of Vietnam should display what Vietnam could be or is striving towards (Hein, 2013, p. 2). Hein describes how capturing images of despair, poverty, and disability were considered to expose Vietnam in a bad light and were destroyed because they depicted a threatening reality (Hein, 2013, p.

3). The idea that anything imagined can be real is much too threatening in Vietnam, and so poor projections and images of the country are seen as bad omens and contributors to bad outcomes (Hein, 2013). It is better to depict an idealized scene in the hopes that what the image shows will also be what reality reveals.

The exclusion of WWD from public space and the discrimination that they encounter in the public sphere can be explained in part by how Hein describes the Vietnamese aversion to images that deviate from the idealized reality. In her work, Hein covers the condemnation that accompanies the Vietnamese word *xấu*, which most simply translates to “ugly” (Hein, 2013). But the depths of the meaning of *xấu* are what actually matter; it can also mean “bad”, “shameful” and “poor in quality” (Hein, 2013). These extended meanings are important because they help establish the extended meanings given to ugliness; that it lacks value and is undesirable and should be kept out of sight (Hein, 2013, p. 2). Hein describes how the main reason to show (or show off) something in Vietnam is to show its beauty and that calling something or someone *xấu* is deeply offensive and damaging to them and their image (Hein, 2013). The preferred way to approach the “not-beautiful” (Hein, 2013, p. 3) is to simply omit it from the public eye by leaving it out of photographs and other memories. The classic Vietnamese phrase that Hein includes is “Show the beautiful, hide the ugly and bad” (Hein, 2013, pg. 3). The messaging is clear; visibility and memory should be reserved for the beautiful, the things that capture and display Vietnam as it ought to be, that depict a bright future. The ugly, incomplete, different or deviant things

are better left tucked away out of fear that displaying them would prompt that reality to come to the surface. Something as visible as a deviant body, different from the norm and beyond basic understanding, is a visible threat to the projection and idealization of a beautiful society. The disabled body visible in public space is an uncovering of a reality that extends beyond the constructed that is captured in images.

### *Laws and Policy on Disability in Vietnam*

In addition and in connection to the power that historical and cultural roles have, the official legal frameworks surrounding disability within Vietnam deeply influence the perception of disabled bodies. *The Law on Persons with Disabilities* contains 12 articles and places its primary focus on establishing classification for disability and an emphasis on disability equality. The law formally classifies PWD as “those who have impairment of one or more parts of their body, or functional impairment, which are shown in different forms of disability, and may cause difficulties in work, daily life and learning” (DREDF, 2016). The interesting aspect of this classification is that it remains the prerogative of government officials to determine how an individual’s disabilities are classified and therefore what support systems they qualify for (DREDF, 2016). So despite personal experience or outside medical opinion, the PWD may only be eligible to receive support for the disabilities that they have formally been classified as possessing. Although multiple articles within this law are focused on establishing that PWD are equal and possessing both state and human rights, the reality of PWD lives



within Vietnam demonstrate that this legal rhetoric is not effective in terms of actual outcomes and enforcement.

Discussion of this legal document have been included in this review with the intention of affirming which aspects of the existing law are most valuable and could be used as the basis for future interventions. With this in mind, the articles and excerpts from the Law that are most valuable are those that address issues of PWD discrimination, abuse, rights and state sponsored support and are not currently being enforced or utilized in many ways. For example, *Article 4: Rights and Duties of Persons with Disabilities* states that PWD have the right to live independently while still being included in their communities (DREDF, 2016). This article should actively apply to PWD who are classified as being capable of living independently but PWD who require assisted living are the legal responsibility of their family (DREDF, 2016) and the inclusion or exclusion of PWD under familial care is much harder to regulate. Additionally, Article 4 details how the state and GoV should provide health care and employment, vocational training, legal assistance, public transportation, and technology for PWD (DREDF, 2016). These two articles with direct statements about the level of independence and support that PWD are legally entitled to receive stand in stark contrast to the reality of what PWD have access to.

Article 14 of the Law addresses issues of abuse, harassment and discrimination. The article explicitly states that it is forbidden to discriminate against persons with disabilities (DREDF, 2016). While this explicit and clear statement is valuable from a policy perspective, the fact that it has no literal and

social traction makes it obsolete. The law includes a clause about how violations and infringements to PWD rights are the responsibility of the state (DREDF, 2016). However, the fundamental issue with the protections of the law is that the enforcement authorities, such as the police, health professionals and other civil servants, are themselves deeply biased and discriminatory towards PWD. For this reason and due to general social stigma, PWD cannot find solace in knowing their legal rights because they lack the power and support to translate this law into protection. Article 14 states that physical abuse of any kind as well as abuse to PWD'Ss belongings, dignity, or rights are forbidden (DREDF, 2016), but despite this strong claim, the experiences of PWD in Vietnam suggest that social law far outweighs legal decrees.

Lastly, Vietnam's official (if not actual) commitment to improving and protecting the lives of PWD was presented on the global scale when the GoV signed the *Proclamation on the Full Participation Equality of People with Disabilities in the Asia and Pacific Region* in 1992. As of 2001, 41 countries had signed the proclamation, which is a seven part policy that recognizes that the number of people with disabilities is rising globally due to environmental hazards, disease and accidents of human error, and that advances in the medical field have resulted in PWD having longer life expectancies (DINF, 2003). By signing the proclamation, the GoV agreed to continue to proportionally increase the budget for PWD services as per GDP growth in acknowledgement of the fact that PWD are marginalized and should receive a level of service and support that is proportional to the country's wealth and resources (DINF, 2003). However,

Vietnam has grown rapidly in the past two decades, emerging as one of Asia's fastest growing economies and demographic measurements such as life expectancy and quality of life have improved significantly for the general population. Despite this growth, marginalized populations, such as PWD, continue to suffer from social and systemic discrimination. There have not been tangible global consequences for the GoV's failure to improve PWD status PWD services in Vietnam and research and programming continue to be significantly underfunded, undervalued and mismanaged.

## **Overview of Pilot Study: Methods and Findings**

This paper was created in response to the need for greater analysis and explanation of the findings from a pilot study, conducted with the approval of Macalester College's Institutional Review Board, on the experiences of women with disabilities with abuse and harassment in Ho Chi Minh City, Vietnam. I designed and implemented this study in partnership with another student on behalf of Disability Research and Capacity Development Vietnam (DRD); an NGO that provides a number of valuable services and resources for PWD in Vietnam. DRD had the intention of expanding the programming to include services specifically for WWD and wanted to assess what the most distinct and immediate needs of that population were. As previously discussed, government limitations, cultural stigmatization and social norms have severely limited knowledge and research pertaining to disability issues in Vietnam, As such there were almost no data available as to what the needs of WWD might be and what programs and services DRD should expand or offer. The director of DRD as well as many of the female staff members with disabilities had informal evidence of and experience with the abuse and harassment of WWD and collectively they felt that those issues might be the most pressing and important to address in pursuit of specifically improving the lives of WWD in Vietnam.



*DRD Research Team, Spring 2016 (Mingkwan, 2016).*

The goal of the study was to begin to assess how WWD in Vietnam experience abuse and harassment and what potential exists for the implementation of programs or interventions to combat such issues. DRD had limited funding and recognized that the depth of these issues would likely call for extensive and longitudinal research in the future and so opted to instead launch a pilot study as a basic starting point for understanding these issues. The pilot

study used a focus group model in order to collect data on the experiences of WWD. The participants in the focus groups were members of the Club of Women with Disabilities in HCMC with whom DRD had some familiarity. This was a limited population but due to the challenges with recruiting WWD in Vietnam, the Club represented the most accessible and lowest risk (for participants and researchers) participant pool from which to draw. 46 women from the Club participated in the focus groups. It is important to note that the investigators did not define disability or use any definition as inclusion criteria for the study. The women who participated self-identified as having a disability and did not disclose what disabilities they possessed any point. The lack of a rigid definition for disability prior to recruitment and participation in the focus groups was intentional; first to protect the privacy of the participants, and second because without distinctly defining disability, the Club already self-identified as a community with shared experiences.

Disability is defined throughout this paper based on existing academic and legal definitions but was not rigidly defined for the study. The specific definitions of disabilities that have been proposed by researchers and lawmakers are important in the theoretical realm in order to establish limitations and inclusion criteria for academia and policy creation. However, in actual practice, such as in the focus groups, creating a rigid definition for disability was much more difficult and, in large part, unnecessary. The goal of the study was the better understand how WWD felt they were experiencing abuse and harassment, and how their disabilities were categorized by international agencies and the government did

not influence their personal experiences. Capturing how the women felt about their own experiences based on how they saw themselves as disabled bodies was far more important than the formal classifications and categorizations that exist to define their bodies and abilities.

The focus groups were conducted over the course of two and half hours following a meeting of the Club of Women with Disabilities in HCMC. The goal of the groups was to investigate the following major questions:

1. What do women with disabilities feel are their greatest challenges and disadvantages?
2. What kinds of abuse and harassment have women with disabilities experienced?
3. How do women with disabilities react and respond to abuse and harassment?

The focus groups were entirely voluntary and began with the distribution of disclosure forms followed by an explanation of the verbal consent that outlined the risks, benefits, and goals of the group. Participants were asked to carefully read (or have read to them) the disclosure form, a copy of which they were given to keep, and then verbally consent to participating in the focus groups. Verbal consent was used in an effort to protect confidentiality by not collecting any names of participants in the form of signatures. The investigators also requested that all participants made an effort to minimize breaches in confidentiality by not sharing the information discussed within the group with anyone or any party outside of the session. The investigators broke the group into two smaller groups

and conducted a guided conversation. A DRD staff member, a principal investigator and a translator facilitated each smaller group. The staff member asked the questions and helped generate conversation while the translator related everything to the principal investigator taking notes in English and recording the session. Both sessions were recorded using audiotaping. Following the completion of the focus groups, the audio was translated and partially transcribed and the information was then categorized into major findings.

The major findings from the focus groups are listed below. These six categories are those in which WWD in Ho Chi Minh City reported as the most significant in connection to their experience of abuse and harassment:

- Street Harassment
- Lack of Resources and Reporting Culture
- Violations of Sexual and Reproductive Rights
- Familial Control
- Societal Stigma, Discomfort and Lack of Understanding of Disability
- Lack of Empowerment

Based on these findings and an extensive literature review on these issues, the investigators concluded that programs and intervention implementations for WWD should include new models for support groups, familial involvement, reproductive health and sex education trainings, media campaigns, an online resource library, and a referral network and support system to improve reporting culture. The investigators also recommended that future researchers hoping to better understand the abuse and harassment of WWD in Vietnam conduct



research with populations that are more inclusive of urban and rural localities and a broad range of socioeconomic statuses, and also narrow the focus of the research to address specific issues and needs within the greater issue. Lastly, the findings were analyzed and used to inform preliminary best practice recommendations for these issues in the case specific setting of Vietnam.

There were a number of limitations to the study. The primary and most significant limitation was the small and limited sample size. The focus group participants were recruited from the Club of Women with Disabilities in Ho Chi Minh City because DRD had an existing relationship with the Club and recruiting WWD is incredibly difficult in Vietnam. This is due in part to the lack of visibility that WWD have; they are not often captured in census data and do not have access to social spaces and communities from which they might have been recruited. The staff at DRD felt that recruiting through the Club increased the likelihood that the women participating would not be put at significant risk by the study because they were already able to engage in conversations, move outside their homes and share their opinions as part of their existing participation in a community like the Club. This is because the women who belong to the Club are already inherently privileged in that they have access to transportation, membership in a community and some level of support or permission from their families for participation in discussion and social spaces. These privileges made it possible for them to be enrolled in the focus groups but also present significant limitations. Because membership in the club involves a distinct level of privilege, the information that the women in the focus groups shared is only representative

of the experiences of some of the most privileged WWD in Vietnam. The focus groups did not include any of the most vulnerable WWD, such those with low socioeconomic status, severe familial control, and limited access to mobility and public space because recruiting these populations is far more complicated and difficult. As such, it should be acknowledged that the experiences of the women in these focus groups is only representative to a small and privileged population of WWD and cannot be generalized and assumed to apply to all WWD in Vietnam.

## **Analysis and Discussion**

The goal of this paper is to further explore the findings from the DRD pilot study in an attempt to establish how the experiences of WWD and the public perception of disability is grounded in historical, cultural and social factors. The focus groups revealed that the abuse and harassment that WWD experienced could be best categorized into six major themes: Street Harassment, Lack of Resources and Reporting Culture, Violations of Sexual and Reproductive Rights, Familial Control, Societal Stigma, Discomfort and Lack of Understanding of Disability, and Lack of Empowerment. Although there are very little existing data in Vietnam that explore disability issues and the challenges that WWD face, it is possible to draw connections and make inferences about the significance of the focus group findings by investigating the pertinent historical, cultural and social forces that have and continue to influence life in Vietnam. The literature reviewed in this paper was selected based on its thematic relevance to issues of gender and disability in Vietnam and the convergence of the two. Analyzing those works and putting them into conversation with some of the most significant findings from the pilot study helps to establish a more complete understanding of the abuse and harassment of WWD in Vietnam.

Further analysis and a better understanding of the findings and how they fit into the larger cultural and historical framework of the country is valuable because it establishes a more distinct explanation for the data. Possessing this deeper level of comprehension is critically important in the development of potential interventions and empowerment programs for WWD. The raw findings from the focus groups are indicative of the fundamental issues that WWD face

but provide less information about the most effective and successful ways to combat these challenges. Preventing the abuse and harassment of WWD in Vietnam will require the introduction of interventions and programming that is based on best practice recommendations from previous research and that is culturally sensitive and specific. With that in mind, the goal of this discussion is to interpret the findings from the pilot study within the cultural, social and historical frameworks that are characterized in the literature. This analysis of the focus group findings is intended to extend knowledge about the abuse and harassment of WWD into evidence-based understanding of these issues.

Much of the abuse and harassment that the WWD reported was related to being overtly sexualized, touched and groped, and harassed in public space. However, these experiences are sadly relevant to almost all women (Hoang, 2014) and therefore it is unclear as to whether the WWD experienced harassment simply on the basis of their gender with lower status as women or if it they were specifically targeted on the basis of their disability. One distinction that was made by the women involved in the focus groups was that the disrespectful behaviors, threats and challenges that women face regarding sexual harassment was worse for WWD because they were perceived to be easy targets. The marginalized status that WWD hold within their domestic spheres, as well as in public spaces, is connected to the fundamental gendered roles that women play within the context of Southeast Asian nations. The abuse and harassment that WWD experience is best explained through the social and historical

constructions of gender and sexuality within Vietnam and comparatively low status of women that continues to exist there in some forms.

In her work, Dr. Clara Saramento, a specialist in gender studies, works to establish a concrete image of how the low status of women has come to exist within Asian cultural frameworks. The foundations of Asian nation building are based on the celebration of masculine success and power and women have been relegated to being remembered only in supporting roles. Additionally, historic colonization and recent globalization have introduced an arguably more destructive narrative of Asian women as highly sexualized and exotic creatures which has acted to further marginalize them within the public sphere. Saramento argues that the tourism industry's search for romantic colonial narratives is incredibly destructive in establishing the legitimacy of Asian women's personhood, but is also highly profitable. In these ways, when contemporary Asian women are disempowered, it can be associated with both historical and modern influences that have tried to relegate them to secondary citizens and overtly sexualized creatures.

Based on these problematic constructions of gender, it is of little surprise that many WWD experience the level of harassment that they reported. They face the compounding challenges of discrimination on the basis of both their gender identity and their disabilities. Considering the evidence that there is historical precedent in addition to modern constructions of woman as lesser to man, it is predictable that a woman who inhabits a body that is already seen as less than human or less than complete would face extraordinary challenges in

terms of garnering respect in social space. Many of the WWD in the focus groups reported that they felt they were often targeted for sexual harassment, such as groping or flashing, because the perpetrators perceived them to be easy targets: dually disempowered by their status as a woman and as a disabled body. If all PWD in Vietnam face forms of abuse and harassment, WWD's experiences with such things are likely to be the most damaging and frequent because the identities that they embody are symbolic of weakness and low status and value. In the gender binary that Saramento and Beauvoir discuss, the female role as one of stigma, shame and weakness stands as a distinct categorization for WWD. Combating the stereotypes, ascribed status and expressions of disrespect that WWD experience would require the implementation of robust programming in addition to an overall shift in cultural perception of disability and gender. With this in mind, any efforts that work towards gender equity will also benefit WWD in Vietnam. Additionally, the focus groups revealed that despite the vast cultural forces that were working against them, WWD were not complacent in their oppression and persecution. In an effort to resist the projections of weakness and docility that were placed upon her, one WWD in the focus group proudly shared that when a man harassed her in public she would take one of her crutches, a distinct marker of her disabled status, and hit the man with it. The assumed inclusion of weakness and docility in the Asian female identity need not define the identities and actions that WWD claim for themselves.

Ortoleva and Frohmader's work clearly demonstrate that issues surrounding WWD sexuality are not isolated to Vietnam and that many WWD

across the globe share these experiences. Many of the issues discussed in their work pertain to specific examples of sexual abuse and harassment to which WWD are vulnerable. Direct and personal examples of sexual abuse and harassment were not shared during the focus groups because of the deep sensitivity of the subject, the nature of the discussions and the shame associated with such issues. Some WWD described stories that had happened to other women and there was a group consensus that issues of WWD sexual abuse were significant although they do not receive appropriate attention due to the deeply personal and shameful nature of such things. However, many WWD involved in the focus groups did provide specific examples of discrimination that they experienced, especially regarding the public opinion and misunderstandings about WWD sexuality, reproductive rights and intimacy. The focus groups revealed that opportunistic perpetrators (strangers mainly) saw WWD on the streets, especially those with mobility related disabilities, as easy targets for harassment. Perpetrators targeted WWD because of their limited or low mobility and because they reportedly made assumptions that WWD would 'appreciate' any sexual encounter they received. This assumption is deeply grounded in the perception that WWD are not capable of experiencing sex and intimacy and that therefore any sexual encounter, even those without consent, is a gift to them. Additionally, the WWD reported facing extreme backlash when they attempted to express themselves as women, engage in relationships, get married, and have children. This societal discomfort of WWD engagement in women's activities and fulfilling women's traditional roles suggests that WWD are not yet seen as

women in society and therefore their participation is deemed inappropriate and unacceptable. The reports of the WWD involved in the focus groups strongly suggest that there is no existing discourse on WWD sexual and reproductive rights in Vietnam. This is connected to the more general misconceptions that surround PWD in Vietnam as lacking in any identities beyond the label of disability and the long-standing stigma that is associated with that role.

Ortoleva and Frohmader's work support the findings in the focus groups in that the experiences shared by the WWD within our focus groups mirrored closely those of the WWD that were included in the 2013 issues paper. Stigma and discrimination are in part responsible for the discrimination and denial of WWD's sexual and reproductive rights, however the root cause of these things is still directly connected to the profound discomfort and lack of understanding that surrounds WWD sexuality. Acknowledging WWD sexuality raises a lot of ethical questions and pushes caregivers and medical providers to consider WWD bodies and desires as equal to those of able bodied people. The distinct Otherness that is associated with disabled bodies makes this simple acknowledgement extremely difficult and results in the denial or prevention of WWD expressions of womanhood and sexuality. Much like the experiences of the PWD in the documentary film on sexuality and disability, the WWD in the focus groups reported that they often felt that people did not know how to respond to their engagements in sexuality, gender expression and maternity and so reverted to the basic stereotypical understandings of PWD; as childlike and dependent,



unable to care for themselves and separate from distinct human processes such as the desire, affection, and sexuality experienced by 'complete' or able bodies.

In Vietnam and across the globe there is a general misconception that disabled bodies cannot be sexual, attractive and productive bodies. Many of the WWD in the focus groups reported experiencing harassment and disapproval from family members and the general public when they took time to engage in self-care and expression through beautification. One woman said that when WWD dress nicely and wear makeup and accessories, able-bodied people are uncomfortable and say they should not do that and draw attention to them. Another woman said she went to get her nails done and was harassed by the entire family of the salon owner, who shamed her and said because she was disabled she should not be thinking about her beauty and self expression. These interactions reinforce the idea that the prevailing opinion of dominant Vietnamese society is that WWD should not inhabit intersectional identities and that their status as a disabled body is perceived as their sole and defining characteristic. In her work, Nina Hein emphasizes that the predominant reason to display or show off something in Vietnam is to tout its beauty and value (Hein, 2013). WWD who engage in self-expression through cosmetics, fashion or other forms of beautification are perceived as violating the standard that Hein suggests. She describes how the appropriate way to handle the "not-beautiful" (Hein, 2013, p. 3) is to eliminate it entirely from the public eye. Through their self-expression, the WWD were seen as bringing further attention to their disabled bodies instead of quietly omitting themselves from public attention. Displays and celebrations of

deviance, such as those found in the disabled body, come into conflict with idealized Vietnamese society in which only the beautiful and perfection are intended to be on display.

The perception that WWD only occupy a disabled identity contributes to the distinct discomfort that people feel towards WWD as mothers. As Hirschman and Loi described, the family is the locus of Vietnamese society and is therefore imbued with sacred qualities. The women in the focus groups reported that able-bodied people most often greeted WWD who were mothers with disgust and anger. This response is likely related to the overall discomfort that able bodied people experience when forced to consider the prospect of disabled bodies engaging in human processes such as partnership and sex. However, within the specific context of Vietnam, this response is also very likely connected to the sanctity that motherhood and familial units possess within society. The response that able bodied people have to WWD as mothers is grounded in both a physical discomfort with disabled bodies and also the feeling that deep-seated cultural norms are being violated and trespassed upon. With familial units as the locus of Vietnamese society, deviations from the standard model of the 'good family' are cause for alarm and a source of disruption. In many ways the rhetoric used in describing WWD engagement in life processes, such as sex and parenting, has the same discriminatory tone as prejudices leveled against other non-traditional family structures like single parents or same sex couples. This strong aversion to WWD participation in parenting, sexuality and gender expression can only be mitigated if there are changes and an evolution in the traditional perceptions of

what elements constitute a family and if PWD are recognized as equal members of society with the same rights and access as their able bodied peers.

The WWD in the focus groups reported that unwillingness to cooperate, professional exclusion, and lack of support services were the top three ways in which they experienced discrimination. Many reported being harassed for being present in public spaces, including using transportation. The specific examples of discrimination that the WWD provided were when riding and trying to park their three wheeled motorbikes, riding public transportation, and while trying to participate in normalized activities in society. The severe reaction and stigma fueled responses to their presence in public space suggests that disability and the participation of PWD in public life have yet to be normalized and accepted in Vietnam. The reactions that WWD elicit extend beyond able bodied discomfort with Otherness or deviant bodies - they are symbolic of the greater socio-political forces that have come to shape the unique ways disability is perceived in Vietnam. WWD movements and visibility in public spaces forces the acknowledgement of the disabled body and this participation in seemingly exclusive able bodied processes prompts both external and internal disruption for the Vietnamese public.

On the external level, the imperfections and lack of normalcy that many people see within disabled bodies is in direct conflict with the state sanctioned values that Vietnamese people are meant to embody. The government of Vietnam has emphasized the need for population quality; a citizen who possesses quality is one who is whole, complete, normal, productive and

attractive. Because this open and aggressive move towards building a 'good population' (Hein, 2013), bodies that do not fit within these government determined quality standards are intended to be left out of the national image and narrative. The responses that WWD encounter when they are in public space are not just based on people's discomfort but also on their civic disapproval; the public presence and visibility of WWD in Vietnam is seen as a mark on the face of a country aspiring towards a high quality future.

Gammeltoft's work details how disabled bodies are perceived as disruptions to positive national growth by corrupting its quality population. This is something that is actively discouraged in the public realm; health providers encourage abortion in the case of fetuses that show signs of abnormalities in an effort to prevent incomplete or damaged bodies from being born. In Vietnam, disabled bodies are perceived as a disruption in society because they represent physical manifestations of violent pasts. Many argue that disabilities in Vietnam are literal products of past violence because of the continued effects of Agent Orange exposure. Whether literal or imaginary, the function of disability as a modern link to past trauma results in lives of PWD being defined by stigma, fear and discrimination. In Gammeltoft's work, fetal screening can be seen as a tool for remedying the lingering effects of war and as a political tool to animate people's memories and fears (Gammeltoft, 2014, p. 157). A large part of these fears is connected to cultural beliefs of haunting and the spiritual realm. The conflation of haunting and the imaginary contributes to perceptions of PWD as non-human that fall closer to monsters than kin.

The abortion narrative that Gammeltoft captures further reinforces the idea that disability is seen as a disruption on the external level; it does not solely belong to the individual or the family but instead becomes the concern of the state. The disabled body does not belong only to the individual but inevitably becomes a burden of the state as it represents in physical form the atrocities of the past and their continued consequences for the future of a thriving and 'quality' Vietnam. After years of war, famine and unrest, the new and emerging Vietnam is something to be celebrated and the public display of disabled bodies is seen as damaging to the idealized society toward which the country is striving. However, this emerging nation has an underbelly constructed from the very real masses of the poor, the disabled, the criminal and the sick, and the vision of the quality population and the idyllic nation can be preserved only as long as these people are kept in the shadows. The collective imaginary of Vietnam is focused on narratives of an emerging nation that is disconnected from the traumas of the past. Gammeltoft's work emphasizes that this collective imaginary has been constructed by the memories, fears and goals that the population possesses. After disruptions, such as the Vietnam War, famine and civil unrest, the collective imaginary has developed a distinct commitment to imagining and building a future that excludes any memory of these past challenges. Disability is therefore perceived as a threat to society because of the resemblance it bears to the violence of the past. The collective imaginary that has been constructed by shared experiences of past trauma has established disability as disruptive to the process of recovery and nation building.

People feel internal disruptions and discomfort when they encounter disabled bodies in public space because the visual presentation of imperfections and damage conjure up specters and reminders of the past. These internal disruptions and their foundations in past traumas help explain some of the complicated relationships that WWD have with their families and caregivers. In the focus groups WWD reported that their relationships with their families were complex and that the people closest to them often acted as both a support network and also as perpetrators of abuse and harassment. WWD reported that their families were often the people who most heavily policed their movements and decisions. They expressed that their families considered them inferior to their able bodied counterparts and felt they were unable to make decisions for themselves. This level of abusive control is related to the dependency that WWD have on their families, and also the family's legal responsibility to care for WWD. The strong, traditional family values that are inherent in Vietnamese culture, in combination with the deep stigma that is still attached to disability, results in a level of protective shame that is expressed by families exercising control over WWD in an effort to both hide and protect them from society. WWD are disempowered within their family settings and this adds to the existing barriers that prevent their full participation and visibility within society.

Many of WWD in the focus groups actively described their hyper-cognition of the shame their families experienced and their descriptions were congruent to those in Ha's work on shame in Asian cultures. This familial shame towards disability is distinctly connected to the meanings and representations possessed

by disability in the recent past. Vietnam has experienced a number of significant challenges in its recent history that range from violent conflicts and wars, famine, civil unrest and a lack of governmental stability. These challenges resulted in traumatic outcomes and extraordinary hardships for the general populace, evidence of which is still present in Vietnam today. However, the country has experienced significant growth in a very short period of time and the memories of past atrocities are beginning to fade into the folds of history. However, Gammeltoft argues that the motivation in Vietnam to move beyond the violent past is so distinct it results in the active elimination and condemnation of anything or anyone that is perceived to be in conflict with the goal of creating an idyllic national narrative. Fear is a powerful motivator and this aggressive promotion of the new Vietnam is as much grounded in visions of the futures as it is in fears of the past. In her work, Langford establishes the riveting fear that is associated with haunting due to bad and violent deaths. The collective imaginary that Gammeltoft suggests extends beyond imaginings of the future and also includes memories from the past.

For many Vietnamese people, images of disabled bodies in the modern world conjure up frightening memories, collective or personal, of a violent past in which damaged and incomplete bodies died bad deaths. The presence of disabled bodies acts as an anchor to the violent deaths of the past and the sadness and despair that accompanied them. The damaged and destroyed bodies that people do not want to remember are thrust back into the realm of the living in the form of disabled bodies. The restless and wandering souls of the

thousands of people who died bad deaths strike fear into a nation that is trying so actively to become more than its past. The continued birth of disabled children and visibility of disabled bodies in public space reaffirm for many Vietnamese the fear of haunting. Despite so many efforts towards development and bright futures devoid of past atrocities, witnessing the disabled body, something less than whole like so many of the victims of the past, forces the populace to acknowledge again the violence in the history of their nation. This history is not how Vietnam wants to be remembered nor is it in line with the bright future it is striving so desperately to achieve.

These fears of haunting are what influence medical providers to encourage abortions of potentially abnormal fetuses and drive families to shield their disabled kin from the outside world and vice versa. Haunting is also believed to be karmic; the birth of a disabled child or occurrence of a disabling injury or illness can be perceived as the vengeance of ancestors who died bad deaths or were never properly laid to rest. The fear of haunting and violent pasts is projected onto disabled bodies; PWD represent historic atrocities seeping into the modern world. Conjuring the dead and reviving the pain of the past is counterproductive to the national agenda of prosperity and growth. The “in group” in this case, as Ha describes it, are the able bodied citizens who are participating in building the future of the country. The control that families exercise over WWD is a defense against shame; disabled bodies are not sources of pride and approval.



The social and cultural factors that define disability in Vietnam have created significant barriers for WWD attempting to participate in society. The abuse and harassment of WWD is perpetuated by fear and misunderstanding which are embedded in specific cultural frameworks. Because of this, combating disability related issues is incredibly difficult; promoting PWD equity and protections involves programmatic, cultural and systemic change. The focus groups demonstrated that reporting culture on the abuse and harassment of WWD was significantly under supported. WWD expressed that they often would not report abuse or harassment because they didn't feel it was serious enough or because they did not have appropriate reporting outlets. Additionally, many of the participants recounted that when they had reported their abuse, the response they received from law enforcement or other officials was abusive as well. They felt as if reporting served no purpose and that it often increased risk because the response could be one of further abuse, harassment or judgment and scorn. The WWD felt that law enforcement and social services invest little to no effort into PWD concerns and safety and this lack of response only further perpetuates and normalizes abusive behaviors and harassment. Much of this disregard can be attributed to corruption within the government and social service sector that leads to low functionality of the system overall. However, the specific disregard for WWD safety is also related to the stigma, shame and misunderstanding of disability issues. The lack of action taken on behalf of WWD safety extends beyond the realm of disrespect and can be seen as a lack of acknowledgement. Reporting abuse and harassment is an expression of agency, a protest against

mistreatment and effort to participate in the systemic protections that are provided for citizens. However, when WWD attempt to participate and engage with the system, they are met with scorn and disregarded or shamed for their actions. When WWD attempt to defend their well being, or express themselves through their appearance or behavior, it is perceived as a disruption to society because their active and visible engagement in the system is a direct acknowledgement of their participation in it; society cannot ignore and exclude disabled bodies from the idealized national narrative if they gain visibility through participation.

The focus groups provided evidence that suggests that WWD are not regarded as active, valuable, and equal members of the family or of society. WWD were often perceived as being unable to make decisions or care for themselves in regards to issues related to personal choice and autonomy, self-expression, and intimacy. However, in situations where WWD did need support, such as on public transportation or official and systemic protection from abuse, family members and the general population were unwilling to help. The contradictions in these findings strongly suggest that the most common approach to disability is a lack of acknowledgement of WWD personhood, womanhood and membership in society. The presence of disabled bodies induces a complex feeling of discomfort in people that is bound by cultural norms, national history and social traditions and customs.

The disabled body does not belong to the individual; it captures the attention of the greater public because the meaning it carries is collective in

nature. The chaos and trauma that has filled Vietnam's recent history has prompted the emergence of controls on bodies that resemble those times of crisis. Hughes and Lock describe in their work the concept of the Body Politic; when threatened it tends to increase its power and control over individual bodies (1987). The resemblance that disabled bodies have to traumas of past is threat to the Vietnamese Body Politic and is therefore seen as something that needs to be policed in order to protect the society. However, despite efforts to relegate WWD to being only disabled and imperfect bodies, they have come to inhabit a full range of intersectional identities. The presence of WWD within Vietnamese society serves as a contradiction to many of the value systems that have been established; they are meant to embody the submissive roles of women but also denied expression of their womanhood. They are bound to filial piety but deeply shameful to and separate from their families. They embody visions of the past within a nation that is committed to outgrowing its history. The fundamental flaw in the attempt to omit WWD from the national narrative is that the women themselves refuse to be erased. They continue to negotiate the different expectations and discrimination that is thrust upon them and often remain defiant in the face of a society that is determined to move forward without them. Women with disabilities in Vietnam have consistently been associated with the past and excluded from the future. Promoting the equal, rightful and safe participation of WWD in Vietnamese society will require reclaiming disability from the realm of monsters and ghosts and establishing it firmly as a truly *human* condition.

Women with disabilities are a part of modern Vietnam and the country's future progress rests on developing a narrative that is inclusive of all its citizens.

## Bibliography

- BBC (2017, January 13). Vietnam country profile. BBC Asia. Retrieved from <http://www.bbc.com/news/world-asia-pacific-16567315>
- Beaulieu, A., & Fessele, K. (2003). Agent orange: Management of patients exposed in Vietnam. *Clinical Journal of Oncology Nursing*, 7(3), 320–323. doi:10.1188/03.cjon.320-323
- Beauvoir, Simone de. (1989, c1952) *The second sex* /New York, Vintage Books
- Brown H. Safeguarding Adults and Children with Disabilities Against Abuse. (2003). *Council of Europe*. Available at: [http://www.coe.int/t/e/social\\_cohesion/soc-sp/abuse\\_e\\_in\\_color.pdf](http://www.coe.int/t/e/social_cohesion/soc-sp/abuse_e_in_color.pdf). Accessed May 18, 2016
- Disability Information Resources. (2003). Proclamation on the full participation and equality of people with disabilities in the Asian and pacific region. Retrieved March 2, 2017, from DINF, <http://www.dinf.ne.jp/doc/english/intl/apddp/9.html>
- Disability rights education & defense fund. (2016, December 16). The National Assembly of Vietnam. The Law On Persons with Disabilities 1992. Retrieved March 2, 2017, from DREDF, <https://dredf.org/>
- Facts and Figures: Ending Violence Against Women. *UN Women* 2016. (2016). Available at: <http://www.unwomen.org/en/what-we-do/ending-violence-against-women/facts-and-figures>. Accessed May 18, 2016.
- Films for the Humanities & Sciences (Firm), Films Media Group, & System TV (Firm). (2010). *Disability and Sexuality : Exploring the Intimacy Option* (Films on Demand; Films on Demand). New York, N.Y.: Films Media Group. <http://digital.films.com/PortalPlaylists.aspx?aid=8751&xtid=41389>
- Frohman, C., Ortoleva S. (2013). *The Sexual and Reproductive Rights of Women and Girls with Disabilities* 2013.
- GAMMELTOFT, T. M. (2008). Figures of transversality: State power and prenatal screening in contemporary Vietnam. *American Ethnologist*, 35(4), 570–587. doi:10.1111/j.1548-1425.2008.00099.x
- Gammeltoft, T. M. (2014). Toward an anthropology of the imaginary: Specters of disability in Vietnam. *Ethos*, 42(2), 153–174. doi:10.1111/etho.12046
- HA, F. I. (1995). Shame in Asian and western cultures. *American Behavioral Scientist*, 38(8), 1114–1131. doi:10.1177/0002764295038008007

Hein, N. (2013). The good, the bad and the not beautiful: In the street and on the ground in Vietnam. *Local Culture/Global Photography*, 3(2)

Hirschman C, Loi VM. Family and Household Structure in Vietnam: Some Glimpses From a Recent Survey. (1996). *Pacific Affairs*. 69(2):229. doi:10.2307/2760726.

Hoang PT., ed. (2014). For Women and Girls: Can Dreams Come True. Actionaid Available at: [http://www.actionaid.org/sites/files/actionaid/aav-bc\\_tp\\_an\\_toan-en-trang-24-11-2014\\_1.pdf](http://www.actionaid.org/sites/files/actionaid/aav-bc_tp_an_toan-en-trang-24-11-2014_1.pdf).

Knodel, John, Vu Manh Loi, Rukmalie Jayakody, and Vu Tuan Huy. (2005). "Gender Roles In The Family." *Asian Population Studies*. 4: 69-92.

Krishnan, Suneeta, Kalyani Subbiah, Prabha Chandra, and Krishnamachari Srinivasan. "Minimizing Risks and Monitoring Safety of an Antenatal Care Intervention to Mitigate Domestic Violence among Young Indian Women: The Dil Mil Trial." (2012). *BMC Public Health*, 12.1: 943.

Langford, J. M. (2013). *Consoling ghosts: Stories of medicine and mourning from Southeast Asians in exile*. Minneapolis: : University of Minnesota Press.

Mingkwan, Pia (2016). *Original Photography from Vietnam*. Unpublished.

Notre Dame Archives. Retrieved March 2, 2017, from <http://archives.nd.edu/cgi-bin/lookup.pl?stem=dis&ending=ability>

Penketh, A., Connolly, K., Kirchgassner, S., McDonald, H., McCurry, J., Crouch, D., ... Bawden, A. (2017, February 17). Which are the best countries in the world to live in if you are unemployed or disabled? *The Guardian*. Retrieved from <https://www.theguardian.com/politics/2015/apr/15/which-best-countries-live-unemployed-disabled-benefits>

People with Disabilities in Vietnam: Evidence from the 2009 Census. (2011). Retrieved March 2, 2017, from United Nations Population Fund UNFPA, [http://web.unfpa.org/webdav/site/vietnam/shared/disability\\_eng.pdf](http://web.unfpa.org/webdav/site/vietnam/shared/disability_eng.pdf)

Sarmiento, C. (2012). Culture, politics and identity: Critical readings on gender in Southeast Asia. *Indian Journal of Gender Studies*, 19(3), 437–467. doi:10.1177/097152151201900305

Scheper-Hughes, N. and Lock, M. (1987). The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology. *Medical Anthropology Quarterly*, 1(1), pp.6-41.

Watch, H. R. (2014). One Billion Forgotten: Protecting the Human Rights of People with Disabilities. Retrieved from [https://www.hrw.org/sites/default/files/related\\_material/2014%20disabilities\\_program\\_low.pdf](https://www.hrw.org/sites/default/files/related_material/2014%20disabilities_program_low.pdf)

WHO Fact Files: Disability Facts. Retrieved March 2, 2017, from World Health Organization,

<http://WHOhttp://www.who.int/features/factfiles/disability/facts/en/index1.html>

World Bank. (2016, September 21). World Bank: Disability overview. Retrieved March 2, 2017, from <http://www.worldbank.org/en/topic/disability/overview>