

# **DISABILITY, SEXUALITY, AND GENDER IN ASIA**

**INTERSECTIONALITY, HUMAN RIGHTS,  
AND THE LAW**

Edited by

Wanhong Zhang, Elisabeth Perioli Bjørnstøl, Peng Ding,  
Wei Gao, Hanxu Liu, and Yijun Liu



# Disability, Sexuality, and Gender in Asia

This book introduces experiential knowledge of the intersectionality of disability, sexuality, and gender equality issues. Scholars and disabled persons' organizations in different Asian countries such as China, Vietnam, Myanmar, Nepal, and Japan have contributed to the book. It is a preliminary introduction of the frontline practice of Asian disability activism and the experience of women and LGBTIQ people with disabilities. It presents the direct participation of disability advocates in mapping how both women with disabilities and LGBTIQ individuals with disabilities realize their rights such as identity, work rights, personal safety, and sexual rights. Studies presented here explore the experience of empowering diverse disability groups and advocating for equality and non-discrimination. It explains how to use the leverage of the Convention on the Rights of Persons with Disabilities (CRPD) for further human rights campaigns in a broader context for disadvantaged groups.

This collection is the product of a participatory research project, which aims to increase the capabilities of local disabled persons' organizations and NGOs in utilizing human rights laws and encourage dialogue and collaboration between academia, people with disabilities, and human rights advocates. It will be essential reading for academics, researchers, policy-makers, and campaign groups.

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# Contributors

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**Wanhong Zhang** earned his PhD in Law from Wuhan University School of Law, Wuhan, China, where he now holds the position of Professor of Jurisprudence. He studies and teaches in the legal areas related to human rights, public interest, and civil society. He is the pioneer of rights-based disability studies in China and founding editor-in-chief of *Disability Rights Studies in China*. He is also one of the drafters and evaluators of China's several National Human Rights Action Plans. He is the author and translator of a number of books, and has published articles in both international and Chinese journals. He is one of the founders and the Director of Wuhan University Institute for Human Rights Studies. As the Director of Wuhan University Public Interest and Development Law Institute, Professor Zhang and his colleagues are actively working in the field of protection and promotion of human rights in China. He also serves as advisor to several international and domestic organizations.

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# Introduction

The book *Disability, Sexuality, and Gender in Asia: Intersectionality, Human Rights, and the Law* is the result of a cooperation programme on “Disability and Intersectionality: Multiple Identities, Cumulative Discrimination” between the East Lake Institute for Social Advancement (EISA) in Wuhan, China, and the International Department at the Norwegian Centre for Human Rights (NCHR). The programme received funding from the Norwegian Ministry of Foreign Affairs.

The aim of the programme has been to increase the awareness of human rights and the intersectionality of discrimination among Asian civil society organizations working on disability issues. The programme was organized as a 3-year participatory research programme. Focus was on the exchange of experience and on capacity building workshops about disability and the intersectionality of discrimination particularly related to gender equality and to sexual orientation and gender identity (SOGI).

Intersectionality means that the various social categories such as class, race, disability, sex, SOGI, etc. that people belong to do not exist separately from each other but are interlinked and can therefore lead to other forms of discrimination for those with overlapping identities.

Intersectionality as a concept was first introduced by the black feminist scholar Kimberlé Crenshaw in 1989 and the concept intersectional discrimination is now used by many in the human rights field. The CEDAW (The Convention on the Elimination of All Forms of Discrimination against Women) Committee General Recommendation No.28 para.18 for example refers to intersectionality as a basic concept for understanding discrimination.

In our work we often see that a group-specific approach to discrimination and to human rights does not take full account of how different human rights issues and group identities intersect with each other. It is not always possible to neatly group people into categories like, for example, persons with disabilities, women, race, religious groups, ethnic minorities, LGBTIQ (Lesbian, Gay, Bisexual, Transgender, Intersex, and Questioning or Queer), etc. Many people belong to more than one of these groups, and the ways their identities intersect will vary greatly as will the many forms of discrimination that they

may encounter. Gay women with disabilities may experience other types of discrimination than heterosexual men with disabilities, for example.

By lifting the issue of intersectionality and discussing it, we hope to inspire both a better understanding of the complexities of discrimination of people with disabilities and how to more effectively counter discrimination. An approach to discrimination that does not take intersectionality into account could prioritize some group identities over others and thereby reinforce discriminatory practices.

People with disabilities are more than their disabilities and they are a very diverse group, yet they share some common experiences. In many settings, people with disabilities feel that their autonomy is taken away. Decisions are often made on their behalf and it is therefore more difficult for people with disabilities to enjoy their full rights and freedoms. The term “Nothing about us, without us!” was introduced in disability activism in the 1990s and highlights the challenges many people with disabilities face.

People with disabilities not only experience that they are treated as children when it comes to decision-making processes. Sex, family life, and the right to express your sexuality freely has also been unreachable for many. Many people with disabilities have also not received sexual education, they have not learned about safe sex or about abuse and how to deal with it. International research also shows that people with disabilities, and in particular women with disabilities, are at a much higher risk of becoming victims of domestic abuse and sexual violence than people without disabilities.

Talking about disability, gender, and SOGI in an Asian setting has brought out many similarities in experiences, but also some stark differences. While it is possible to live out your sexuality freely in some Asian countries, SOGI issues are taboo and treated as illegal in others. This cooperation programme has tried to create a space where these things can be discussed freely among disability advocates. Sharing issues and problems has promoted the development of solidarity among advocates across Asia and has already led to cooperation across borders.

The chapters in this book come from some of the participants of the workshops. The book introduces the experiential knowledge of the intersectionality of disability, sexuality, and gender equality issues. Scholars and disabled persons’ organizations (DPOs) in different Asian countries such as China, Vietnam, Myanmar, Nepal, and Japan have contributed to the book. Participants from many other Asian countries have contributed to the debates in the workshops.

The book is a preliminary introduction of the frontline practice of Asian disability activism and the experience of women and LGBTIQ people with disabilities. It presents the direct participation of disability advocates in mapping how both women with disabilities and LGBTIQ individuals with disabilities realize their rights such as identity, work rights, personal safety, and sexual rights.

This book could be the first book which presents evidence-based research on the rights situation of disability communities in Asia with a focus on the

intersectionality of sexuality and gender. Studies presented in this book explore the experience of empowering diverse disability groups and advocating for equality and non-discrimination. The book also explains how to use the leverage of the Convention on the Rights of Persons with Disabilities (CRPD) and other human rights standards to further human rights campaigns in a broader context for disadvantaged groups. Sociological, legal research, and comparative studies are applied in many of the chapters.

Issues surrounding the intersectionality of disability, gender equality, and/or SOGI are often overlooked. We hope that this book will help highlight the importance of both researching these issues in more detail and of developing effective strategies for working on these issues locally. These issues should be talked about more openly, not only in Asia but everywhere!

### **Part I: An overview on the situation of persons with disabilities in Asia**

When talking about the situation of persons with disabilities, researchers and DPOs across Asia face common challenges in accessing comprehensive and reliable data – both quantitative and qualitative. It is even more so when it comes to issues surrounding women with disabilities and sexual minorities with disabilities. In addition, most existing data still reflect the medical approach towards disability and fail to recognize the inherent dignity of persons with disabilities and see them as rights holders.

To address this challenge, our researchers have worked to present the situation of persons with disabilities in their respective countries by drawing on existing statistics or carrying out surveys. The surveys and analysis have adopted rights-based approaches that put the life experiences of persons with disabilities in the centre and look at how social barriers affect their enjoyments of human rights. Working with UNDP Vietnam, the Institute for Studies of Society, Economy and Environment (iSEE) conducted a study on persons with disabilities and their experience of stigma in Vietnam. This research is unique by examining both perceived stigma and self-stigma – namely how persons with disabilities feel in the face of society's discriminatory attitudes and even how people with disabilities internalize those attitudes.

Though looking at persons with disabilities in general, iSEE's study has identified gender differences in terms of the perceived stigma, in particular when it comes to intimate relationships and marriage where women with disabilities experience a higher level of self-stigma than men with disabilities. Luanjiao Hu's research echoes the experience of stigma by persons with disabilities in the Chinese context. By examining existing literature and statistics, Hu has brought to light experiences of women with disabilities that have been to a large extent invisible in China. Her research reveals compound discrimination against women with disabilities in areas of education and employment in particular, as well as violence against women with disabilities. Sarita

Lamichhane's research further zooms in and focuses on the employment situation of women with visual impairments in Nepal.

Wai Wai Aung's survey report has demonstrated the similar disadvantages faced by persons with disabilities and sexual minorities in Myanmar. What she noted in her research probably applies to most countries in Asia, namely that statistics on LGBTIQ individuals hardly exist, not to mention on LGBTIQ individuals with disabilities. Through Aung's survey, we can see parallel experiences of persons with disabilities and LGBTIQ individuals as both groups are subject to discriminatory attitudes and behaviours in school, in the workplace, and at home. While persons with disabilities and LGBTIQ individuals may experience different forms of discrimination and have different needs for inclusion, Aung has pointed out that the key is to change attitudes.

## **Part II: Intersectional identities**

This book goes further to present our researchers' attempts to unpack the intersecting identities and how the life experiences of marginalized communities deeply intertwine in a social structure favouring a "one size for all" normative framework.

Peng Yujiao's essay is a reflection of her activist experience and goes deep to explain how stigma works to affect the perception of women with disabilities towards their own identity. Through sharing life stories of women with disabilities, Peng focuses on the negativity attached to their body images and demonstrates how these "unique and almost invisible social challenges" that people with disabilities face profoundly affect their self-esteem, where they constantly think they are not "man" or "woman" enough.

Naoko Kawaguchi's research echoes Peng's findings. Through 12 interviews, Kawaguchi explores experiences of women with disabilities regarding their love life, marriage, and reproduction. One quote serves as a perfect example of how repeated denials of femininity and sexual existence of women with disabilities affect their sense of identity:

*When human beings are divided into categories such as men and women, I do not feel I belong to these categories. From my perspective, human beings are categorised into men/women/disabled.*

Our researchers and activists have gone beyond to explore possibilities to positively construct one's identity. Peng then shares her experience working at the community level to empower women with disabilities through providing social work services. Through innovative programmes such as theatrical performance, inclusive dance, and audio and video self-narrating, women with disabilities can gradually change their perceptions of their body images.

Xu Yue, Shen Chengqing, Guo Jiani, and Tong Wei's action research on the construction of disability identity through social media among women with disabilities also provides an encouraging illustration on the power of

community. All four authors belong to the online group *Minority Voice*, which shares blog posts about disability issues. Their research analyzes the process of disability identity development along the development of *Minority Voice* and presents an effective approach to engage women with disabilities through social media and collective disability activism. It is illuminating to see how the internal discussion of the group has created a space for women with disabilities to share stories of their experiences that are often ignored in their other social interactions. Through the process of de-isolation and de-stigmatization, group members collectively build a sense of disability pride.

Besides the intricating identities above, another identity often overlooked is caregivers of persons with disabilities, usually the mothers. As the primary bearers of family care for children with disabilities, mothers in many cases have a hard time balancing work and family and constantly face the dilemma between continuing to work and returning to home. Li Xuehui, Huang Shixin, Hu Luanjiao, and Dong Dong have conducted 22 months of participant observations at a special education centre located in Shanghai. Based on in-depth interviews with eight mothers of children with autism and textual analysis of parent auto/biographies, they explain mothers' decision-making process on quitting their jobs, the challenges faced when returning to home, and their coping strategies. Though this research is not a typical identity analysis, by including it here we hope to draw attention to the situation of caregivers of persons with disabilities as well. As illustrated in the research, how women manage their various identities as workers, mothers, wives, caregivers, and "experts" on autism is no less challenging.

### **Part III: Sexuality, body autonomy, and gender-based violence**

As shown above, sexuality and body autonomy occupy a significant place in the discussion of the situation of women with disabilities and LGBTIQ individuals with disabilities. The last section of the book looks at concrete challenges that persons with disabilities face in exercising sexual rights and body autonomy as well as the rights framework around such issues.

Through analysis of written testimonies of disabled people about their experience using voluntary sex services provided by *Hand Angels*, Carmen Yau guides us towards a nuanced understanding of the lived experiences of disabled people in accessing sex. *Hand Angels* is a Taiwanese non-governmental organization that advocates for the sexual rights of disabled people through providing free voluntary sex services for disabled people regardless of their body conditions and sexual orientation. Yau argues that social work practices in this field should support the "intimate citizenship" of disabled people that enables them to take control of their bodies, emotions, and relationships.

In the report submitted by 13 disability rights groups across Nepal to the Committee on the Rights of Persons with Disabilities, Rama Dhakal introduces the current situation of the sexual and reproductive health and rights (SRHR) of women with disabilities in Nepal under the international human



rights framework. The report has identified a series of SRHR issues concerning women with disabilities in Nepal including but not limited to forced sex, forced contraception, and lack of access to sexual and reproductive information and services, based on which policy recommendations are suggested.

Gender-based violence is severe violation of one's body autonomy. Women with disabilities face a higher prevalence of domestic and interpersonal violence. Both Carmen Yau's studies and Feng Yuan and Hao Yang's studies particularly investigate gender-based violence against women with disabilities and have identified some common challenges. For example, gender stereotype and biases against disability usually lead to violence in the name of love; unequal relationships within families and high dependency on caregivers prevent women with disabilities from escaping abusive relationships; the lack of social support that accommodates the needs of women with disabilities leaves them with no options when encountering violence. Both studies have identified inadequacies in social services and Feng Yuan and Hao Yang's research additionally addresses the aspect of lack of access to justice.

## **Annex**

The annex provided by River Hustad gives readers an overview on relevant international human rights instruments related to equality, prohibition of discrimination, and intersectionality.

Part I

**An overview on the  
situation of persons with  
disabilities in Asia**



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# 1 Stigma faced by people with disabilities in Vietnam<sup>1</sup>

*Institute for Studies of Society, Economy and Environment (iSEE)*

## 1.1 Introduction<sup>1</sup>

The study focused on analyzing stigma from the perspective of people with disabilities with the aim to strengthen the voice of people with disabilities. The study was conducted in five cities in Vietnam from August to November 2017, with the participation of individuals with different disabilities such as visual, hearing, mobility, communicative, and cognitive disabilities. The findings of the research showed that perceived stigma was still prevalent, with 43% of the participants experiencing perceived stigma, and was related to gender, age, type of disability, and the individual's multiple disabilities status. The findings of the research reveal the need for: (i) further research and/or review at institutional and systematic levels, focusing on assessing current policies and programmes in Vietnam on eliminating or causing stigma and discrimination towards people with disabilities, paying attention to factors such as age, gender, type of disability, and one's multiple disabilities status in these policies and programmes; and (ii) simultaneous review of efforts at institutional and systematic levels to reduce stigma and/or discrimination, to find out which practices work. Based on the outcomes from (i) and (ii), measures can be mapped out to eliminate disability-related stigma at the institutional level.

## 1.2 Background information

### 1.2.1 Definition

According to Article 2 of Vietnam's Law on Persons with Disabilities (National Assembly 2010), people with disabilities are those who have deficiencies in one or more organs or functionality, which are manifested in the form of disabilities that cause difficulties to work, live, and learn. Compared to the

1 This article is adapted from the report produced by the Institute for Studies of Society, Economy and Environment (iSEE) with the support of the United Nations Development Programme (UNDP) in Vietnam. The full report can be accessed at [https://www.undp.org/sites/g/files/zskgke326/files/migration/vn/Xoa-bo-ky-thi-eng-sua\\_13.4.18.pdf](https://www.undp.org/sites/g/files/zskgke326/files/migration/vn/Xoa-bo-ky-thi-eng-sua_13.4.18.pdf).

Convention on the Rights of Persons with Disabilities (CRPD), Vietnam's terminology is still attached to the old approach of focusing on medical deficiencies and forgoing physical or social barriers faced by people with disabilities in accessing public services and social activities.

### *1.2.2 Data and statistics*

In Vietnam, statistics on the number of people with disabilities are not consistent due to differences in classifying disabilities and determining which types of disability are included in surveys (see Institute for Social Development Studies [ISDS] 2013; International Labour Organization [ILO] 2013). According to the 2009 population census, Vietnam has more than 6 million people with disabilities aged five and above (approximately 7.8% of the total population), of which 8.4% are women and 7% are men (Ministry of Labour, Invalids and Social Affairs [MOLISA] 2017a). However, according to ILO (2013), if measuring the number of people with disabilities in Vietnam using the International Classification of Functioning, Disability and Health (ICF) Framework, 15% of the Vietnamese population have disabilities. It should also be noted that 75% of people with disabilities in Vietnam currently live in rural areas (ILO 2013) and 58% have multiple disabilities (ISDS 2013).

Compared to the national poverty rate of 14%, 16% of people with disabilities live in poverty (ILO 2013). At least 70% and 65% of people with disabilities in urban areas and in rural areas, respectively, live solely with the support of their families (see Le Bach Duong et al. 2008).

According to a study conducted in six economic zones in Vietnam plus Hanoi and Ho Chi Minh City (see ILO 2013), 25% of respondents with disabilities do not have health insurance and 20% of people with disabilities aged between 18 and 60 are unemployed, mainly due to their poor health. In the same study, it found that 76% of people with disabilities are illiterate, compared to 5% of illiterate people without disabilities (ILO 2013).

### *1.2.3 Legal framework*

The government of Vietnam has taken extensive measures to protect the rights of people with disabilities and enable them to take part in socio-economic activities. The first important step in legalizing the rights of people with disabilities was manifested in the 1992 Revised Constitution, which recognized the rights of “handicapped” children to be supported in formal education and vocational training (Article 59), and the right to assistance from government and society for disabled people without any support (Article 67). The 2001 Revised Constitution changed the term “handicap” to “disability” (Article 59), which demonstrated a new approach to people with disabilities.

Vietnam also has regulations ensuring access to public buildings and facilities for people with disabilities. The Ministry of Construction issued Decision No. 01/2002/QD-BXD (Ministry of Construction 2002) on Construction

Standards to ensure that people with disabilities could access and use public places. The 2014 Law on Vocational Education (National Assembly 2014) encouraged vocational training for disabled people by introducing tax breaks for training providers.

An outstanding achievement in ensuring the rights of people with disabilities in Vietnam was the adoption of the 2010 Law on Persons with Disabilities (National Assembly 2010), which was the first comprehensive legal document to ensure the rights of persons with disabilities. In the Law on Persons with Disabilities, the term “handicapped people” was replaced throughout by “disabled people,” marking a shift approach towards people with disabilities in Vietnam. Article 4 of the law states that people with disabilities are entitled to receive healthcare, rehabilitation, education, vocational training, employment, legal aid, access to public places, means of transport, information technology, cultural services, sports, tourism, and other services by the types and levels of disability. In addition, people with disabilities are entitled to social protection, such as a monthly disability stipend, or health insurance free of charge for poor households (Article 12).

The government issued Decree 28/2012/ND-CP detailing and guiding the implementation of several articles of the Law on People with Disabilities. However, it did not include regulations that specify the eligibility criteria for legal aid in terms of types and levels of disability. This leads to confusion and conflicting instructions from relevant government agencies. For these reasons, the right to legal aid for people with disabilities is not effectively enforced by law enforcement agencies.

### **1.3 Definitions of stigma**

In a study by the National Assembly’s Social Affairs Committee, 13% of respondents in Hanoi, Da Nang, and Ho Chi Minh City said that they were not well treated by their community. Stigma against people with disabilities varies depending on the type of disability, age, gender, and education. People with intellectual, communicative, and self-care disabilities face stigma more often than those with other disabilities. Young people encounter stigma more often than older people. People with higher education seem less likely to be stigmatized (ISDS 2013).

From cultural perspectives, people with disabilities are discriminated against because their disabilities are considered as punishment for sins committed by their family in the current generation or grandparents in their previous incarnations. This kind of stigma is imposed immediately on a disabled new-born and even puts the life of the child at risk by causing the parents to hide and/or neglect him/her (ISDS 2013; Burr 2015).

Recognizing the need to improve understanding of stigma through perceptions of people with disabilities, iSEE, with financial support from United Nations Development Programme (UNDP) Vietnam, conducted this research from August to December 2017. The study focused on the current state of



the stigma that people with disabilities in Vietnam perceived and experienced. Unlike other studies, this research examined stigma through the lenses of people with disabilities. With this approach, iSEE wished to promote the voices of people with disabilities so that the outside world can learn about their perspectives on stigma. In doing so, people with disabilities can contribute to abolishing stigma against them.

Stigma is a complicated concept that has multiple definitions and different measuring scales<sup>2</sup> (Link and Phelan 2001; Alonso et al. 2011). Studies on stigma against people with disabilities have been strongly influenced by the work of Gofman (1963), with its strong focus on both social and medical cognition to understand how people categorize other people and treat other people accordingly (Link and Phelan 2001).

### *1.3.1 Public stigma (stigma)*

There are several types of stigma that this report will refer to; thus, definitions of different types of stigma are provided here. Public stigma (hereafter called stigma) is a (negative) reaction by society towards stigmatized individuals. The reaction is based on attitudes or beliefs towards the stigmatized individuals (Corrigan and Shapiro 2010). Sharing the views of Link and Phelan (2001), Hing et al. (2015) argued that the reaction is shown when certain groups of people in a society exclude people with undesirable attributes by the standard of the former. In other words, stigma is the result of social classification of people who do and do not have what is seen as being normal. These attributes can originate from differences in gender, social classes, or ethnicity. Stigma can be reflected in the views and/or behaviours of one or more individuals or organizations. Discrimination based on disability is a form of stigma.

### *1.3.2 Perceived stigma*

Perceived stigma, in the context of this research, is the belief by people with disabilities that the society holds negative attitudes towards them (Corrigan and Watson 2002). Effects of perceived stigma on persons with disabilities are expressed in different ways, including anger, ignorance, embarrassment, or self-stigma (Corrigan and Watson 2002; Corrian et al. 2006; Alonso et al. 2011).

### *1.3.3 Self-stigma*

Self-stigma, again in the context of this research, is the process where people with disabilities internalize prejudices against them and apply the

2 The fact that the concept of stigma is applied in a variety of fields such as health, politics, psychology, and society which have their own specificities of understanding and applying the concept of stigma is the reason for various concepts and approaches in research on stigma.

negative conceptions to themselves. Self-stigma can lead to a lack of confidence and lowered self-esteem (Corrigan and Watson 2002). Self-stigma may be manifested in forms of hiding conditions and difficulties related to disability, non-involvement in social activities, refusal to access disability services, or keeping a distance from stigmatized people (see Hing et al. 2015).

## **1.4 Objectives and methodology**

### *1.4.1 Research goal and objectives*

The main purpose of this research is to strengthen the voices of people with disabilities in Vietnam to abolish stigma against themselves. In doing so, the research seeks to work with people with disabilities, their organizations, and networks to identify and discuss stigma, which is at the same time an empowering process. Findings of the research can provide policymakers and organizations that support people with disabilities with information necessary to make sound decisions.

To realize this goal, the research has four objectives:

- To collect evidence of stigma against people with disabilities.
- To analyze the social settings where stigma is present.
- To find out the impacts of stigma on the lives of people with disabilities.
- To make recommendations for policy advocacy to reduce stigma.

### *1.4.2 Scope of the research*

Participants of the research include people who have difficulties carrying out one or more of the following functions, according to the Disability Measurement Scale:

- Vision.
- Hearing.
- Mobility.
- Self-care.
- Cognition (in Vietnam, functional difficulties related to cognition can refer variously to mental disabilities, mental retardation, intellectual developmental delay, Down syndrome, and autism).
- Communication.

This research focuses on the stigma that people with disabilities feel and experience in the following three areas:

- Education.
- Employment.
- Mental wellbeing.

The age range of research participants is 18 years old and above so that they could share feelings related to stigma directly and in depth. In the case of people with cognitive disabilities, participants under the age of 18 were also included and researchers carried out the survey through explaining the research to the participants or through consulting their family members or caretakers. In this case, the research team also sought to include participants coming from different economic backgrounds.

### *1.4.3 Research approach*

#### *1.4.3.1 Research framework*

The research is based on three theoretical strands. The first one is the social model of disability. According to this model, it is the way society is organized rather than individual impairments that cause exclusion and limitations in participation and development of people with disabilities (Davis 2016). As a result, advocates for this model seek solutions to remove barriers that restrict the choices of people with disabilities, so that they can participate in society independently and equally.

The second theoretical strand for this study is to approach disability-related stigma from a social perspective rather than a medical one. According to the theory of social stigma (see Link and Phelan 2001), stigma is formed through continuous and integral interactions among labelling, stereotyping, and separating/social distancing, which leads to status loss and discrimination (see Hing et al. 2015). Social stigma theory helped the authors of this report to analyze factors that constituted stigma and how they affected the lives of people with disabilities.

The third theoretical strand, complementing the above two, is a framework composed of four scales, namely Disability Measurement Scale, Perceived Stigma Scale, Mental Health Scale, and Job Satisfaction Scale. There are two to six questions in each scale, and each question has four or five options to measure disability, stigma, job satisfaction, and mental health. These scales were translated and localized with suitable terms to ensure the relevance of the scales and the comprehensibility of the language used in the scales in the Vietnamese context. This was done in consultation with people with disabilities who were research collaborators and experts in the field, and through consulting reports on similar topics in Vietnamese.

#### *1.4.3.2 Research tools*

The study sites were selected in two ways. First, the research team referred to previous studies to identify areas that were under-researched and/or with a high incidence of disability. Second, the team consulted the research collaborators and experts to determine where the team could receive support from local networks to recruit participants for this study.

Quantitative data were collected through online and paper questionnaires in Hanoi, Thai Nguyen, Da Nang, and Ho Chi Minh City from people with

disabilities aged 18 and above. In total, there were 578 responses, and 516 were valid.

Qualitative research was conducted to complement quantitative research. For this reason, qualitative research used questions from the questionnaire as a basis. Qualitative research was conducted with two major tools: in-depth interviews and group discussions.

#### *1.4.3.3 Difficulties encountered during the research*

Questionnaires can provide a great amount of information. However, there were some challenges. In addition to a low response rate to the online questionnaire, other challenges also appeared beyond the control of the research team. For example, appointments with organizations, associations, and groups of people with disabilities to reach more participants were reliant on the timing of their monthly or annual activities. Also, approaching people with disabilities through associations sponsored by or established under the permission of the state was often delayed due to administrative procedures required by these associations' management boards before agreeing to facilitate meetings. Appointments with associations and groups of people with disabilities usually took two to four weeks.

As for qualitative research, access to people with disabilities in provinces was challenging. The biggest obstacle of approaching people with disabilities in provinces outside cities to participate in interviews was actually the suspicion by people with disabilities themselves, given their limited contact with strangers. In Nghe An province, for example, many interviews were cancelled or declined, especially by people in older age groups. As for Hanoi and Ho Chi Minh City, one challenge was participants' fear of boredom, since they had been invited to many interviews by government offices, associations of people with disabilities, and non-governmental organizations (NGOs) during the previous two years.

To cope with the challenge of reaching out to participants in person, the researchers used the networks of the collaborators to contact suitable participants in the provinces. The involvement of clubs for persons with disabilities, such as in the case of clubs for deaf people in the targeted provinces, helped to build bridges and create a trust relationship with potential participants.

A few other limitations of the research are noticed here. The authors were aware that friends and relatives of people with disabilities might also experience stigma related to the disabilities of those they take care of or are related to. However, this study did not concentrate on this aspect of stigma. Instead, it only focused on the stigma that people with disabilities perceived and factors that caused this to happen. In addition, this study did not aim to be a representative evaluation of the stigma perceived by all people with disabilities in Vietnam. Rather, it should only be considered as a quick assessment to meet the information needs of organizations and policymakers working with people with disabilities and for people with disabilities to have a quick

but sufficiently in-depth knowledge of issues of importance to people with disabilities.

The final limitation of this study relates to the nature of it. Quantitative research is based on surveys with requested information filled in by persons with disabilities. Answers may, therefore, be limited or biased by perceptions or experiences of the persons with disabilities being studied. In the qualitative study, the research team tried to minimize the impact of this factor through discussions to understand the information and views that interviewees gave in response to the questions (extracted from the survey). In doing so, the authors wished to explore the causes or environments that may affect the information or views given in the questionnaires.

#### *1.4.3.4 Ethical considerations*

Researchers in this research took measures to ensure compliance with research ethics.

First, before each interview, the research team spent time explaining to the interviewees what the research was about and how the collected information from the interview would be used. The researchers also provided their contact information in case the interviewees had any questions.

Second, the non-disclosure principle was communicated with the participants. When data were collected, the names of participants and their locations were encoded into letters and numbers.

Third, the interviewees were counselled and the voluntary nature of the research was communicated. It was made clear to interviewees that they could withdraw from the interview if they wanted. The use of audio recorders was also checked with the interviewees and they could either agree or decline to participate. If they wanted to stop the audio recording at any point, the researchers would stop.

Fourth, during the interviews, the interviewers always explained the questions to the interviewees. If interviewees did not want to answer any of the questions, they were not obliged to.

## **1.5 Research results**

### *1.5.1 General information of research participants*

As mentioned above, this research included participants with six types of functional difficulties or disabilities, categorized in the Disability Measurement Scale developed by the Washington Group (WG). Experts in the Washington Group on Disability Statistics (WG 2009) defined disability as interactions between a person's functionality and his/her surrounding environments. Those environments include their bodies, their culture, and policies affecting their lives. With this approach, the WG endorsed the principle that the CRPD wants to promote, namely addressing disability beyond the traditional medical

approach. Disability is dealt with by removing obstacles that stop disabled people from completing basic tasks and taking part in society.

With the above-mentioned point of view of disability and based on the International Classification of Functioning, Disability and Health (ICF), WG developed the six-questions questionnaire to describe and measure the level of difficulty that one individual has in carrying out the six functions of vision, hearing, mobility, cognition, self-care, and communication (see WG 2009). The questionnaire was translated into Vietnamese and can be found in Table 1.1.

This questionnaire was selected because it had been approved by the World Health Organization (WHO) to assess disability. This framework is recognized and used by all WHO member countries. Using this questionnaire, the results of this study could be compared with other studies using the same framework. In addition, the questionnaire has been tested for its relevance, so using it ensures greater reliability for the results of the study.

In the following sections, “difficulties” to carry out the six functions are used interchangeably as types of disabilities, as follows:

- Difficulty related to vision = visual impairment (still have some ability to see) or blind.
- Difficulty related to hearing = hearing impairment (still have some ability to hear) or deaf.

*Table 1.1* Disability measurement scale

	<i>No difficulty</i>	<i>Some difficulties</i>	<i>A lot of difficulties</i>	<i>Unable to perform</i>
How much difficulty do you have in looking, even when wearing glasses?				
How much difficulty do you have in hearing, even when using hearing aids?				
How much difficulty do you have in walking or climbing up and downstairs?				
How much difficulty do you have in remembering or concentrating on something?				
How much difficulty do you have in taking care of yourself, such as taking a bath or dressing?				
Using common language, how much difficulty do you have in communicating with other people? (For example, to understand and to be understood by others.)				



- Difficulty related to mobility = mobility impairment.
- Difficulty related to cognitive function = cognitive impairment.
- Difficulty related to self-care = self-care impairment.
- Difficulty related to communication = communication impairment.

Among the 516 respondents (with valid responses) to the questionnaire, 269 (52%) were male, 237 (46%) were female, and 6 people (aged 18–38) identified themselves with “Other” gender. The majority of participants were from 18 to 38 years old (67% of total participants). People between 39 and 58 years old made up 17% and the rest were above 59, excluding four respondents who did not provide age information (see Chart 1.1). Unmarried people accounted for 49%, married 38%, divorced 6%, and 7% did not provide information on marital status.

As assessed by the Disability Measurement Scale, among the respondents, 36% were people with visual impairments, followed by people with mobility impairments (34%). People with hearing, self-care, and communication difficulties had similar participation rates (around 13%). People with cognitive disabilities had the lowest participation rate (9%) (see Chart 1.2).

Regarding levels of difficulty, having “some difficulties” was chosen by the greatest number of participants in the quantitative study. “Unable to perform” had the highest rate among the participants with visual impairments, followed by the group with mobility impairments (see Chart 1.3). According to the

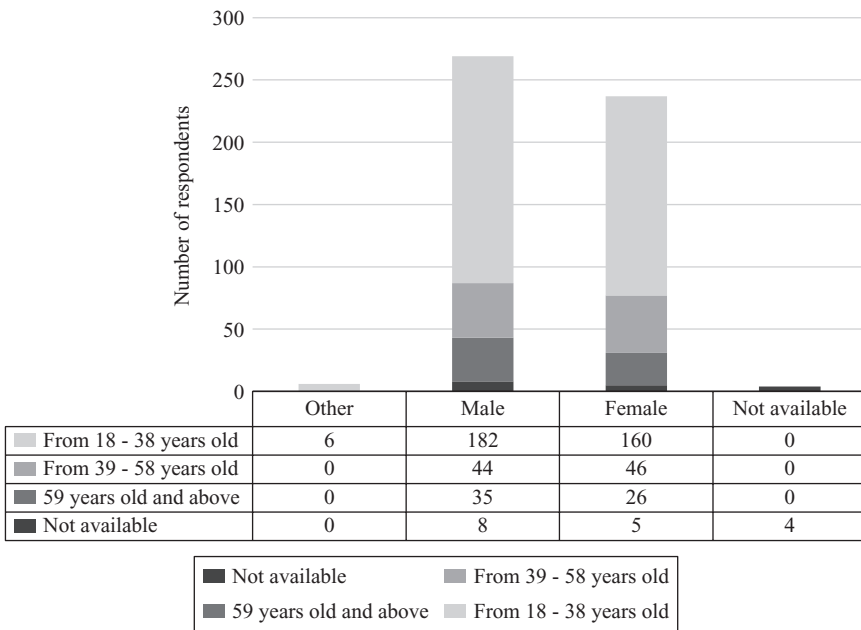


Chart 1.1 Number of participants by gender and age. Data by the author.

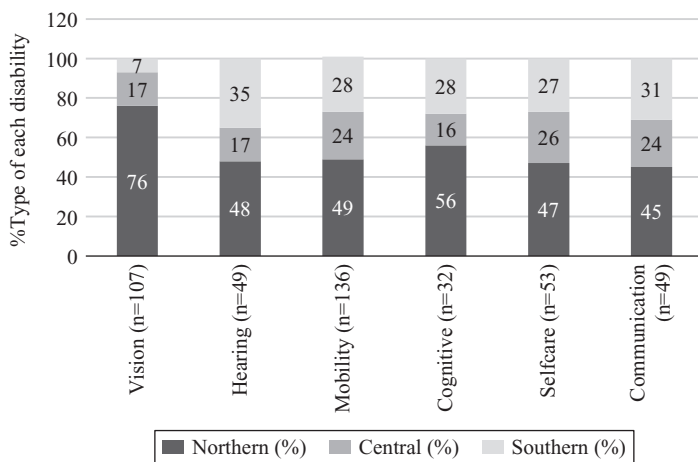


Chart 1.2 Percentage of participants by region and type of disability (n = total number of people in that group). Data by the author.

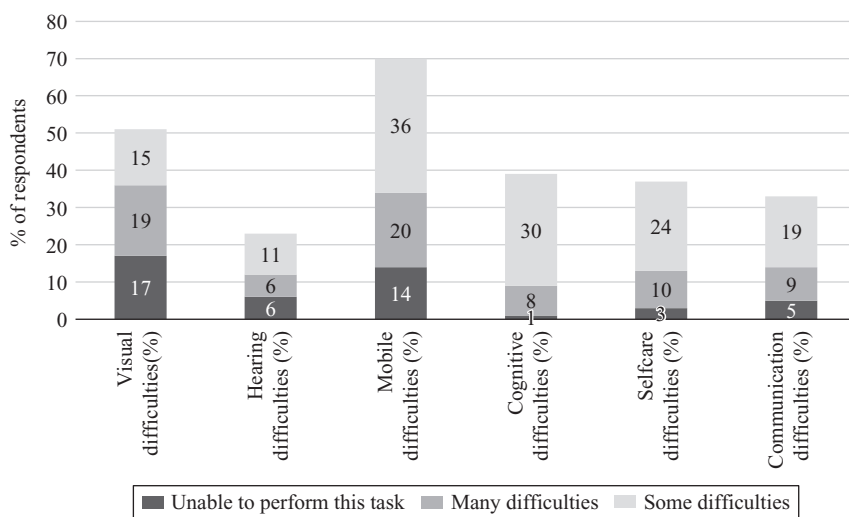


Chart 1.3 Levels of difficulty in performing six basic functions. Data by the author.

survey result, 73% (n = 448)<sup>3</sup> of the respondents had at least two types of disabilities, and 7% indicated no functional difficulties, which was likely because they were respondents with dwarfism caused by low growth hormone.

3 Among the 516 valid questionnaires, not all respondents have responded to all the questions. Therefore, “n” here refers to the number of respondents who answered that particular question. The same applies to the rest of the paper.

*Table 1.2* Educational level of participants (n = 425)

<i>Highest academic level</i>	<i>n</i>	<i>%</i>
Never been to school/not completed primary school	43	10
Primary school	69	16
Middle school	101	24
High school	100	24
Vocational college	52	12
Undergraduate, graduate education	60	14

A total of 50% of the participants had completed high school and above, while 10% had not had the opportunity to attend a school or had not finished primary school (see Table 1.2).

Participants with self-care difficulties had the highest rate (22%) of not going to school or not finishing primary school. Participants with visual disabilities had the highest percentage (14%) among those who received undergraduate and graduate education, followed by participants with mobility disabilities (8%) (see Table 1.3).

From a gender perspective, more female participants have received undergraduate and graduate education than male participants. At other levels of education, the difference was insignificant (see Chart 1.4).

There were 58 participants in the qualitative study: 29 men, 28 women, and one identifying as other gender. There were 44 participants between the age of 18 and 38. The highest number of participants came from the hearing disability group (17). Among the respondents, 69% were unmarried and 15% were married, while the rest did not answer this question (see Chart 1.5).

*Table 1.3* Number of participants by type of disability and education level

	<i>Visual</i>		<i>Hearing</i>		<i>Mobility</i>		<i>Cognition</i>		<i>Self-care</i>		<i>Communication</i>	
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>
Never been to/ not completed primary school	16	11	1	2	23	16	5	13	12	22	6	11
Completed primary school	19	13	13	27	27	19	11	29	10	19	13	25
Completed middle school	31	21	21	43	26	18	5	13	5	9	21	40
Completed high school	39	27	3	6	29	20	9	24	12	22	9	17
Completed vocational college	21	14	7	14	26	18	6	16	10	19	4	8
Completed tertiary education	21	14	4	8	11	8	2	5	5	9	0	0

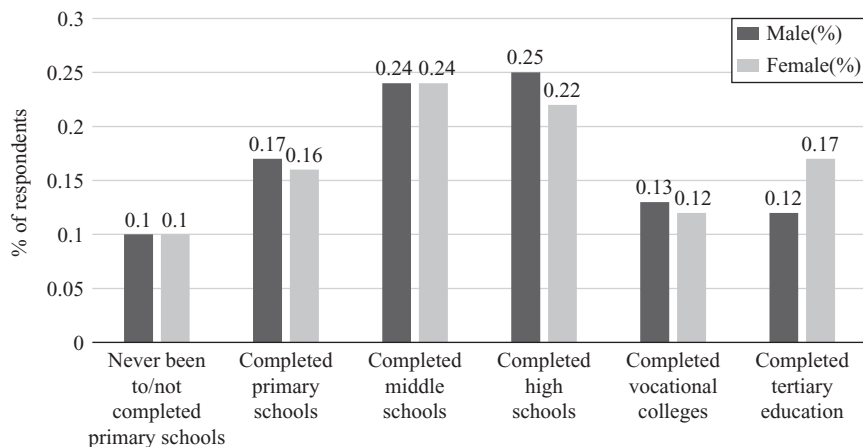


Chart 1.4 Level of education by gender (n = 224 males and 200 females). Data by the author.

Participants with disabilities related to self-care were included in the category of mobility disabilities because all participants who claimed to be with self-care disabilities also reported mobility disabilities, and nearly half of the participants with mobility disabilities reported that they could not take care of themselves and needed assistance.

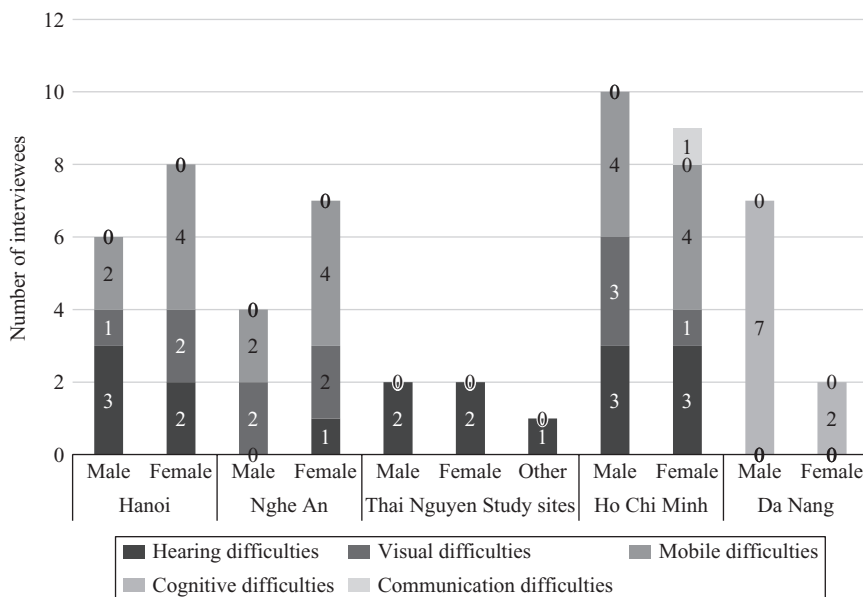
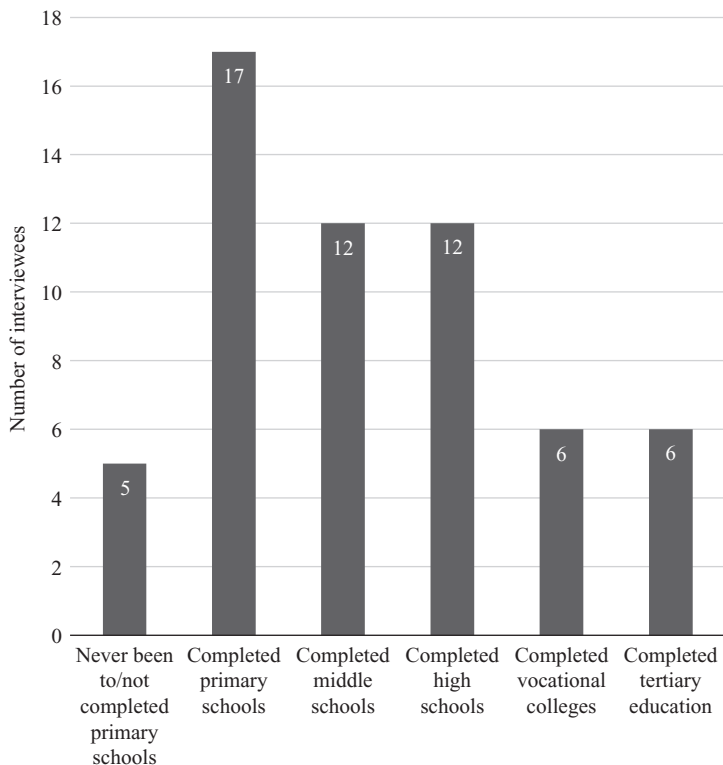


Chart 1.5 Number of participants by gender, region, and type of disability. Data by the author.

Participants with communicative disabilities were mostly people with hearing difficulties, who were thus listed under hearing disabilities. One person interviewed in Ho Chi Minh City via text message was put under the communication disabilities category because the person could hear and understand well but did not speak or speak very little (mostly yes/no).

Three of the participants with cognitive disabilities were aged 15. The qualitative research retained these participants in the sample since it was difficult to find people with cognitive disabilities to interview.

Most of the 58 interviewees had completed primary school (see Chart 1.6). However, only six had received university education (two women and four men), among whom some were with mobility disabilities, some with visual disabilities, and some with dwarfism. Five of the interviewees (two women and three men) had never been to school, among whom four were with visual disabilities and one with mobility disabilities.



*Chart 1.6* Number of participants by educational level (n = 58). Data by the author.

**1.5.2 Perceived stigma from the perspective of people with disabilities**

**1.5.2.1 Perceived stigma and influencing factors**

In Vietnam, a study was conducted by ISDS (2013) to measure stigma. The iSEE research learned from and, when possible, used the questions used by ISDS to identify stigma. The stigma measurement used by ISDS was intended for both people with and without disabilities (see ISDS 2013); the iSEE study selected the Perceived Stigma Scale (see Epping-Jordan and Ustun 2000), which solely focuses on disabled people.

The scale here consisted of two questions to measure the prevalence of perceived stigma among the research population. If respondents chose “a little” and more for both questions, they were considered to have experienced perceived stigma. The Perceived Stigma Scale was used in conjunction with the other three scales to assess the relations between perceived stigma, mental wellbeing and disabled people’s social participation (see Table 1.4).

The results from the analysis show that 43% of respondents (n = 481) experienced perceived stigma during the previous year. In general, gender, age, type of disability, and multiple disabilities status seemed to contribute to perceived stigma more than education level. However, this may have been different if the sample population was different. The results have shown that:

- Young people experienced perceived stigma more than older people (see Chart 1.7).
- Men experienced perceived stigma more than women (see Chart 1.8).
- People with visual disabilities experienced perceived stigma the most, followed by people with mobility disabilities. People with self-care difficulties experienced perceived stigma the least (see Chart 1.9).
- There did not seem to be a linear correlation between educational level and the perception of stigma. People who had completed primary school had the lowest response rate of stigma perception (at 36%), as did people who had completed undergraduate studies. People who finished vocational college had the highest rate of stigma perception at 62%, followed by those who had either never been to or not completed primary school (see Chart 1.10).

*Table 1.4* Scale of perceived stigma by people with disabilities

	<i>None</i>	<i>A little</i>	<i>Some</i>	<i>A lot</i>	<i>Extreme</i>
1. In the past 12 months, how much <i>embarrassment</i> did you experience because of your disability?					
2. In the past 12 months, how much <i>discrimination</i> or <i>unfair treatment</i> did you experience because of your disability?					

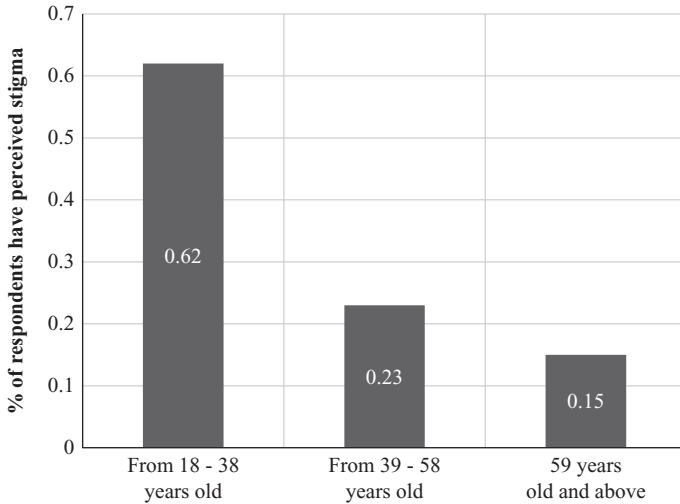


Chart 1.7 Perceived stigma by age group (n = 262). Data by the author.

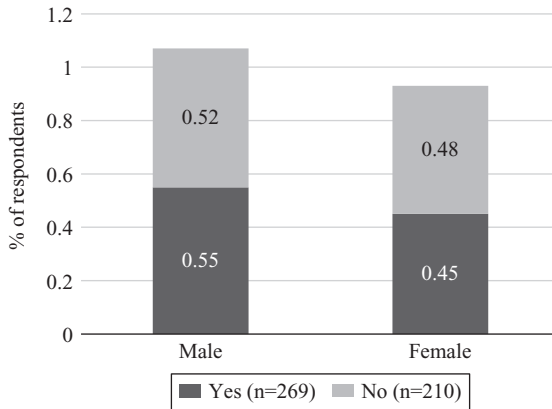


Chart 1.8 Perceived stigma by gender. Data by the author.

- Persons having more than one disability had a higher rate of a perceived stigma than those with one disability. A total of 68% of people with multiple disabilities (n = 222) reported having experienced perceived stigma, compared to 27% of those with one disability.

For interviewees in the qualitative research, slightly more than half (21 out of 40 people<sup>4</sup>) reported feeling embarrassed because of their disabilities: 13 men

<sup>4</sup> Out of a total of 58 interviewees, 18 were with cognitive disabilities and did not discuss disability-associated embarrassment. This was partly because some of them did not consider them-

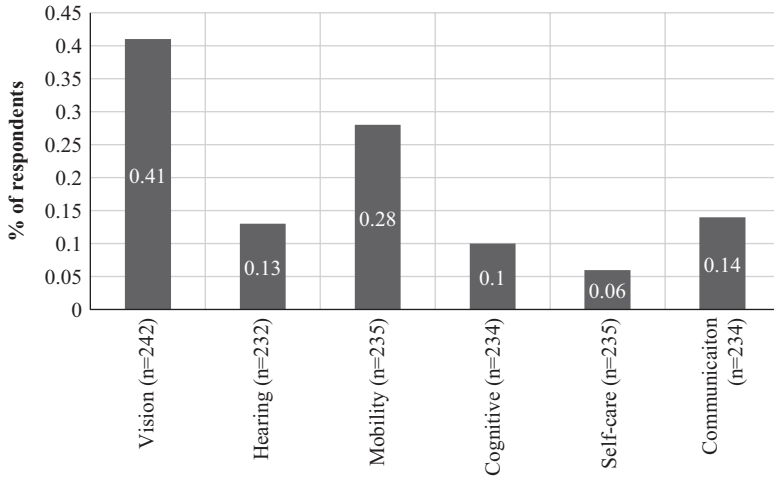


Chart 1.9 Perceived stigma by type of disability.<sup>a</sup> Data by the author. The numbers of respondents with different types of disabilities add up to 1412 because respondents with multiple disabilities were counted repeatedly. For each column, the % of its respondents showed the % of people with that particular type of disability who experienced perceived stigma. Consequently, the columns do not add up to 100%.

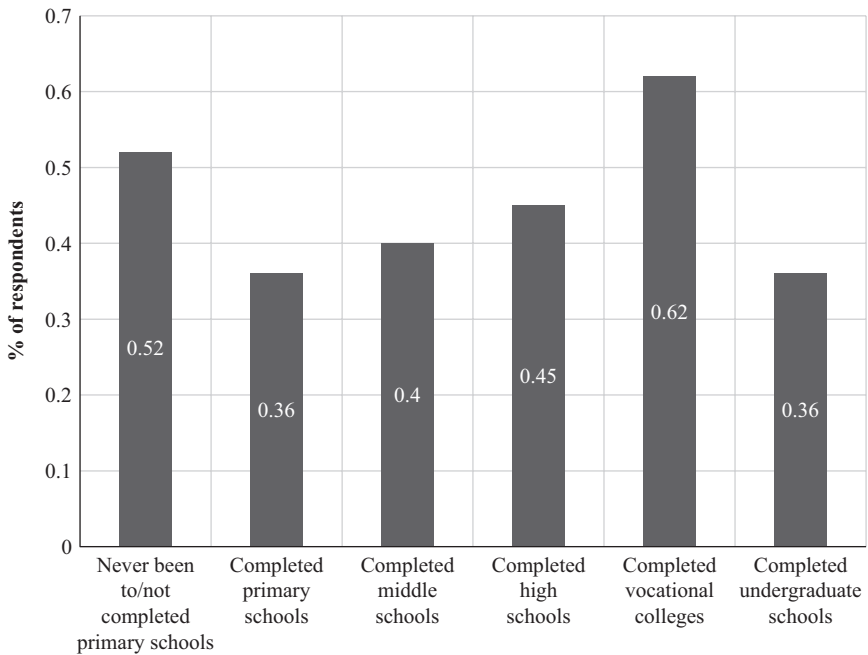


Chart 1.10 Perceived stigma by educational levels (n = 238). Data by the author.



and 8 women. The following quotes illustrated some situations that made the interviewees feel embarrassed. A deaf man living in Hanoi shared a story (through an interpreter) about his childhood experience:

When I was little, my mother was often insulted by our relatives because of having me and without a husband. And when I was found to be deaf, they cursed that my disability was caused by my mother's lack of maternal virtues and it was the fault of my mother that I was born with a disability like that.

Embarrassment was also experienced when the families hid their disabled members from surrounding people, as a woman with visual impairments from Hanoi shared:

People think that, when a child with disabilities is born, the whole extended family is not blessed. So, if a family has a person with disabilities, it is difficult for even his/her brothers in the family to get married. With my family, when there are no guests, I can play comfortably at home. But when there are guests, I must go inside a room to hide. That's why even our family's friends for decades still do not know that a member of my family is blind.

In general, interviewees shared that feelings of embarrassment lessened as they grew up. This explains why more young people reported perceived stigma. Many interviewees mentioned the lack of opportunities to share difficulties with others, especially peers in similar situations, or to discuss how to overcome them. They saw this as one main reason for their feelings of embarrassment. In addition, the absence of respect from people around was another reason for interviewees to feel that they were the targets of ridicule.

Among the adult interviewees, 37 people (out of 40 respondents) did not feel embarrassed because of their disabilities. Interviewees shared that, as they grew older, stigma and discrimination against them decreased because they had proven to people around them (usually neighbours) that they could live independently and work. Another reason for a lower level of perceived stigma was that the view of society towards disability and people with disabilities had also improved. Ideas like disability being caused by the family's misbehaviours had decreased thanks to awareness-raising programmes by the press and mass media. As described by a male interviewee with mobility disabilities in Nghe An:

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selves as people with disabilities and said they were just slower than others. Also, there were difficulties in communicating with this group about embarrassment. As a result, the total number of interviewees for discussion about "embarrassment" was 40.

In fact, in recent years, I can say that society has looked at people with disabilities with a more open-minded mindset. It's better. Because people with disabilities themselves have done things that ordinary people could not. In fact, I myself also have what I can assert myself with. They've looked at me differently. In the past, just for having poor eyesight or myopia, you could be teased ... Now, of course, when they see me like this, the look in their eyes may not have much goodwill but, in general, there are less discriminatory attitudes or behaviors. Now we have many associations for people with disabilities, but it was different in the past. Previously, as I walked out on the street and saw everyone, I felt very unconfident, felt that ... this world was so vast, and I was like a grain of sand in the desert, but now at least I have this group which makes it somehow a little better.

According to the definition of perceived stigma as stated above, feeling of embarrassment is only one manifestation of perceived stigma. Among the 37 interviewees who reported feeling no embarrassment, 18 (7 men and 11 women) reported that they learned to ignore or accept discriminatory behaviours as part of their lives being people with disabilities, or they would feel sad, angry, annoyed, or frustrated. These feelings and reactions are actually also considered as a perceived stigma.

When asked about discrimination, 45 (26 men and 19 women, including participants with cognitive disabilities) out of 49 respondents<sup>5</sup> reported having been discriminated against in the past. At the time of the interview, 34 (18 men and 16 women) respondents reported that they still felt discriminated against because of their disability. Discrimination was often related to employment, education, and travelling around (e.g., shopping, bus ride). The nine respondents who had cognitive disabilities (developmental delay, Down syndrome, mild psychiatric illness, and depression) reported frequent cases of ridicule at school before moving to a specialized school environment.

#### *1.5.2.2 Self-stigma*

One manifestation of perceived stigma by people with disabilities, as discussed before, is self-stigma. Self-stigma was not reported frequently among participants in the quantitative research. Manifestations of self-stigma were listed as options for questions related to access to education, health, social participation, and love life in the questionnaire. Percentages of respondents reporting self-stigma varied by issues. Regarding accessing health services, the percentage was relatively low (ranging from 2% to 3%). This rate increased slightly regarding education and social interactions but tended to

<sup>5</sup> Out of a total of 58 interviewees, nine reported not having experienced discrimination. As a result, the total number of interviewees for discussion about "discrimination" was 49.

Table 1.5 Self-stigma by issue

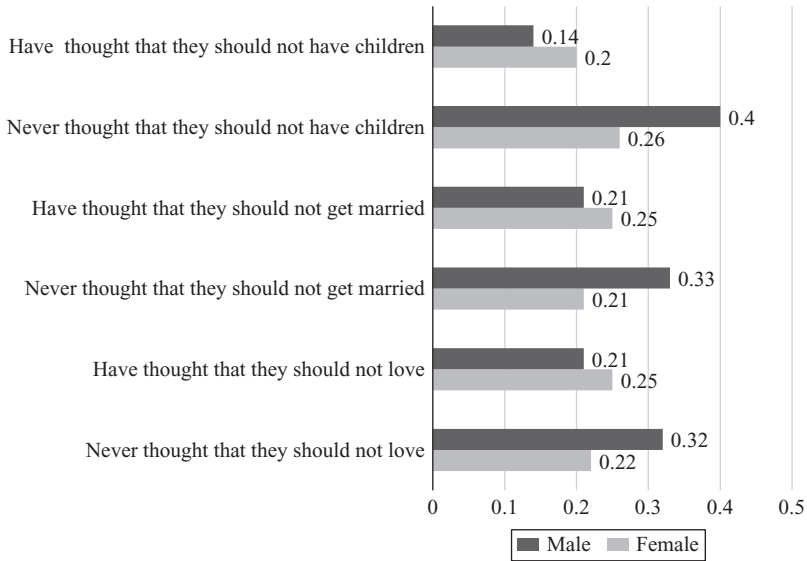
<i>Types of self-stigma</i>	<i>Areas</i>	<i>Response rate (%)</i>
Don't want to be identified as a person with disability so do not ...	use healthcare insurance	1.8 (n = 56)
Don't want to be identified as a person with disability so do not ...	go to sexual health check-up/counselling	1.9 (n = 316)
Don't want to be identified as a person with disability so do not ...	go to reproductive health check-up/counselling	2.6 (n = 11)
Don't want to be identified as a person with disability so do not ...	receive disability assessment	3 (n = 94)
Don't want to be identified as a person with disability so do not ...	want to engage in social activities	7.9 (n = 15)
Assume that a person with disability doesn't need to learn or learn much	Education	5 (n = 509)
Self-blame for their disabilities	Relationship with family	69 (n = 94)
Agree with the statement that people with disabilities are useless	Relationship with family	58 (n = 96)
People with disabilities should not love	Love	46 (n = 437)
People with disabilities should not get married	Marriage	46 (n = 421)
People with disabilities should not have children	Marriage	34 (n = 421)

increase rapidly when it came to family relationships. Concerning love life and marriage, the rate of people reporting self-stigma was high, too (see Table 1.5).

Gender differences existed when it came to love life and marriage. The percentage of male respondents who never thought that a person with disabilities should not love, marry, or have children was higher than female respondents, thus feeling less self-stigma (see Chart 1.11).

Self-stigma concerning love, marriage, and having children was discussed with interviewees at all research sites but discussion on this topic with interviewees with cognitive difficulties was not in-depth.<sup>6</sup> For all the other interviewees, marriage and family were important issues, particularly for participants with mobility and visual impairments. Interviewees did not think they should not love because of their disabilities. Instead, most of them considered whether to engage in a romantic relationship depending on whether they had a stable job

6 Lack of in-depth discussion on these topics with people with cognitive disabilities is due to several reasons. First, people with this type of disability were discouraged by families and schools to engage in romantic love relationships. Second, it was only possible to interview people with cognitive disabilities in school, where interviewees were 15 years old and had little life experience concerning romantic love, not to mention marriage. As a result, we only asked one question: "do you love or like anyone?"



*Chart 1.11* Self-stigma in love life and marriage by gender. Data by the author.

(in order to have stable incomes to cover the costs) and good health (to be able to have children and take care of them).

Regarding employment and health, gender differences in terms of self-stigma were clearly shown in interviews. For men, the concept of being the head of the family weighed on the minds of men with disabilities. This was a common manifestation of self-stigma in men with disabilities. In their mind, if they felt that they could not support their families, they would not move towards a romantic relationship or marriage. When opportunities for education, employment, or stable incomes were limited, many men chose not to have a love life. For women, if they felt that they could not do household chores such as cooking, cleaning, or caring for their husbands because of their disabilities, they would refrain from starting a loving relationship that may lead to marriage.

Interviewees with hearing disabilities reported not being embarrassed to express their love or their wishes to get married. This is often explained in that their lovers or spouses may also have hearing impairments so they would not feel inferior in any sense to each other. In addition, many said that when they could not speak or hear, they needed not to pay much attention to what the others said about them.

In group discussions, most participants shared that they did not feel stigmatized. This could be explained by the fact that the participants had social networks with people in similar situations, which was said to make them more confident. In the words of most interviewees: “I haven’t done anything wrong, so I do not need to be embarrassed.”

### 1.5.3 Education

In Vietnam, the ability of a child with disability to behave and learn will determine whether he or she can attend school (Nguyen and Mitchell 2014). This is contrary to the provisions of the Education Law, whereby every citizen has the right to education and the government should provide support so that all citizens, especially children with disabilities, are able to attend school. The right to education for people with disabilities in Vietnam is not universal but rather conditioned by their capacity. Moreover, although enabling all children with disabilities to receive inclusive education has been put into law since 2006 (see Ministry of Education 2006), the implementation is still limited. Teachers are not professionally trained in inclusive education. Schools lack specialized equipment and instructional materials, such as sign language or Braille materials, to meet the educational needs of students with hearing impairments, visual impairments, or autism (Lynch and Pham 2013). This leads to schools usually only admitting students with mild disabilities. In addition, although there are specialized educational centres for children with disabilities in big cities, in rural areas, this is not the case. Children with disabilities in rural areas, where their parents cannot afford to send them to cities, have to go to local schools that lack expertise and infrastructure to teach them. Under such circumstances, students with severe or specific types of disabilities, such as deaf or blind students, cannot follow the curriculum designed for children without disabilities, thus often dropping out of school (Le Xuan 2015). In terms of gender disparity, boys with disabilities are more often sent to schools, while girls with disabilities do not tend to receive the same treatment (Nguyen and Mitchell 2014).

#### 1.5.3.1 Formal education: reality and stigma

In quantitative research, 56% of respondents ( $n = 397$ ) had attended inclusive schools, 18% had attended specialized schools, and 14% had attended both specialized and inclusive schools. During their studies, 46% of respondents ( $n = 347$ ) did not think that teachers had tools (such as books and school supplies) or teaching methods appropriate to their disabilities, compared to 40% who thought the teachers did. A total of 45% of respondents ( $n = 345$ ) disagreed that the school had handled cases seriously in which children with disabilities had been teased, compared to 40% who agreed. However, the efforts of schools in helping students with disabilities to integrate into the learning environment were acknowledged: 57% of respondents ( $n = 345$ ) said that their schools had helped them integrate into the school environment.

Most interviewees with hearing impairments or who are deaf went to school late and faced difficulties in advancing from grade to grade. Most of them went to school around ten years old, with one attending first grade at 19. Some studied two years for each grade. In some cases, teachers did not teach in sign language, making it difficult for the interviewees to comprehend the words and concepts introduced by teachers. Even those who reached the

college level showed their unwillingness to write or speak because they often misspelled, and their vocabulary was not good. When reading books, newspapers, or online information about health issues, many people shared that they were unable to read or understand content with specialist vocabulary. This greatly affected their opportunity to study in inclusive classrooms for vocational training.

Interviewees pointed to four reasons for not being able to study at a higher level that they desired or not being able to go to school at all. First, poor financial conditions were a major factor causing many people to be unable to attend school. A man with dwarfism who moved to Ho Chi Minh City for more than ten years shared about his family's economic conditions and how it had influenced his education:

I stopped going to school long ago to work. Being poor, both sides of my parents had no land for them, so my parents worked as hired labourers to earn their living. The school was far away, I had to stop going because being born with a lack of growth hormone I have small legs that made it too challenging for me to trek the distance to the school. My father died early, so I worked since I was eight years old. I sold lottery tickets or did anything people asked me.

Facing financial difficulties, sending children with disabilities to school was not a high priority for parents. A woman with mobility disabilities in Nghe An said:

I never went to school because my parents were in great difficulty at the time. My brother worked away from home, my mother did not know how to ride a bicycle, my dad had a job, so no one took me to school. The school in the commune was only 1 to 2 kilometres away from our house, but no one could take and pick me up from school. I only crawled when I was little, I only started to learn to walk with crutches when I was more than 10 years old. I liked to go to school very much. I remember nagging my parents to let me go to school but they just kept silent without explaining.

Publicly funded educational programmes are in place in Vietnam. However, because children with disabilities usually go to school late, by the time they finish primary school they would be 15 or 16 years old and will then get some vocational training. A man with mobility impairments shared:

I started school when I was ten years old. It was a school for children with disabilities. I was a boarder student and did not have to pay anything. That school only taught up to fifth grade. When I finished fifth grade, the school let me live in a house with six people, it also granted us a piece of land for breeding, raising pigs and chickens and growing coffee

trees on our own. The coffee we cultivated was sold, we kept some the money as capital to reinvest and share the profit with others in the house, and the same went for chickens and pigs.

Second, schools without appropriate facilities to teach students with disabilities discouraged parents from enrolling their children in school. Visually impaired interviewees who had never attended school said that primary schools near their homes had been unable to teach them to read or write (because Braille materials were not available). Therefore, they had not been admitted to school, as shared by a blind man in Nghe An:

When I was little, my parents were so poor that I could not go to school. Mum and dad were always at work. There was no specialized school for the blind in the area. The inclusive school in the neighbourhood did not support Braille teaching, so they did not allow me to attend.

Even if admitted, children with disabilities usually received no support from school. Thus, they could not follow the curricula and had to drop out. Therefore, all deaf interviewees in Thai Nguyen only finished middle school and could not continue their studies. A blind man who was sent to Hanoi by his parents to attend schools when he was six years old shared:

I attended primary and middle school at Nguyen Dinh Chieu Blind School. I was sent to a normal high school under the inclusive program. However, there was no specialized syllabus. At that time, only maths and English books had Braille versions and for other subjects, such as literature, I had to record on audiotapes. In university, they did not have textbooks or reference materials printed in Braille. At that time, audio recordings were used. At exams, I would bring a typewriter and carbon paper with me to do the tests.

Third, specialized schools for children with disabilities were all concentrated in big cities. This meant that children in rural areas far from cities or lacking financial means were unable to attend school.

Fourth, attitudes of parents are a form of stigma itself, where they themselves think their children with disabilities are useless and dependent on the care of parents. Parents may think children with disabilities do not need to go to school because they did not have anything to do with the knowledge acquired there. A female interviewee shared about her family's responses to her achievements:

As I showed off a published article to my dad when I was still in a vocational school and said that I got paid, my dad replied, "you can write an article and they even published it?" ... He was very surprised. It was an assumption that I could not do anything.

A young man with hearing difficulties born and raised in Ho Chi Minh City shared (through a sign language interpreter) his dream of going to university and his parents' reaction:

My parents did not want me to go for higher education. If I wanted to continue my studies, I had to go to Dong Nai, which was so far that my parents did not want me to go and we also did not have enough money. Besides, my parents thought that grade 12 was enough for me.

A blind woman, born and raised in Ho Chi Minh City, shared in a group interview that her family had been through a lot of debates about whether she should continue to study after primary school:

It was in my family's mindset that they had to take care of me all my life, so they didn't know if it would make any difference if I attended school. Then they worried about me being bullied at school. So, when my mother got me into Nguyen Dinh Chieu School, my grandmother didn't agree, she was even angry at my mother, my uncles and aunts who helped me to enroll there.

#### *1.5.3.2 Vocational training: reality and stigma*

People with disabilities face many barriers in accessing vocational training and employment opportunities. Teachers in vocational training centres for people with disabilities have often not received professional training on how to teach people with disabilities and only attended short-term refresher courses. Therefore, their teaching skills are limited, so people with disabilities are not trained as well as expected. Employers are not enthusiastic about employing disabled people due to lack of confidence in their ability (such as worries about their ability to work on production lines) or resistance to change (see Lynch and Pham 2013; Nguyen and Mitchel 2014; Nhan Dan Online 2017). When employed, people with disabilities are exposed to a high level of stigma and discrimination in the workplace, such as often being paid lower wages than persons without disabilities doing the same job (ISDS 2013).

According to the quantitative study, 59% of the respondents ( $n = 463$ ) received vocational training. Occupations of respondents were not diverse, as listed in Table 1.6. Respondents are mostly trained in massage (this partly reflects the high number of respondents with visual impairments), computing, and handicrafts making. Although some other occupations such as drivers, musicians, waiters, and bartenders were also mentioned, they did not count more than twice each.

During interviews, it was shown that vocational training for people with disabilities was repetitious and conventional. Among the interviewees, 39 (out of 58) had received vocational training. Training for specific occupations was more likely to be provided for people with certain types of disabilities. For



*Table 1.6* Number of participants by occupation (n = 208)

<i>Occupation</i>	<i>Number of respondents</i>
Massage	92
Computing	54
Handicraft	29
Tailoring	11
Toothpick and broom making	12
Accounting	6
Beautician	4

example, young people with mobility impairment tend to take computer-related training, such as software design or image editing. Visually impaired people seem to have “default occupations,” which include massage, as well as making brooms and toothpicks. Deaf people are often trained as tailors or barbers.<sup>7</sup>

Vocational counselling for people with disabilities was almost unavailable. Stereotypes were imposed on persons with disabilities in terms of which occupations suit them better, and they were forced to attend training accordingly. Only four interviewees were given career counselling before choosing an occupation, and the counselling was given by family members, not by specialized counsellors at school. The rest of the respondents said they could not choose their career.

In many cases, the ability of people with disabilities to make their own career decisions was also hindered by stigmatizing attitudes of their family members and schools. In a group discussion, a woman with mobility impairment talked about how her father discouraged her from studying:

When I expressed my wish to go to a vocational training college, my father said, “my daughter, you can just stay at home under my care, why do you want to go out there when we can provide everything for you. Even after your training, who will employ you?” After my father passed away, I begged my mother and she finally let me go to a graphic design college.

A deaf man who was born and grew up in Thai Nguyen city also encountered objections from his parents, as translated by the interpreter:

When I said I wanted to study hotel management, my parents told me if I wanted to study that, I had to speak well. They also said that I was not capable of studying, so I should stop dreaming about that.

<sup>7</sup> This finding could differ if the sample population is bigger. The number of interviewees here is small.

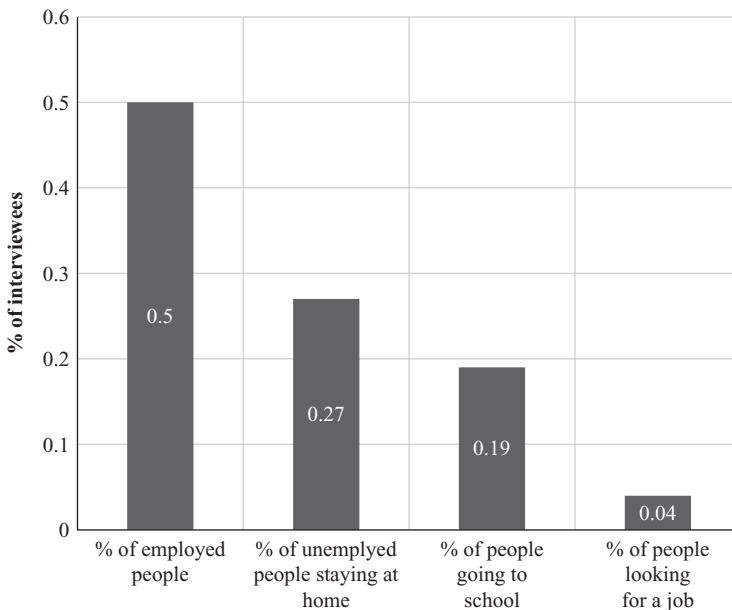
In addition, vocational schools usually focused on people without disabilities. People with disabilities were assumed to be incapable. As described by a deaf man from Ho Chi Minh City:

I wanted to study hotel management. When I enrolled in a school, the teacher rejected my application. She said that I would not be able to learn because I was deaf, it would be very hard, it would be impossible.

### 1.5.4 Employment

Half of the participants in the quantitative research were employed (including self-employed) and 27% of respondents answered they were not working. The number of people who were looking for a job or studying made up the remaining 23% (see Chart 1.12). Participants in the study did not tend to apply for recruitment tests; 66% of respondents ( $n = 389$ ) had never been to a job interview. Among those who went to job interviews, 53% reported having been denied jobs because of their disability.

A total of 80% of respondents reported receiving a state allowance. The median monthly income was very low. The average monthly income of Vietnamese people in the second quarter of 2017 was VND 5.4 million (MOLISA 2017b). Meanwhile, the highest median income among the disabled groups (the deaf/hearing-impaired group) was VND 3 million. Income disparity between high-income earners and low-income earners was very high



*Chart 1.12* Employment status of respondents ( $n = 495$ ). Data by the author.

*Table 1.7* Monthly income of respondents by type of disability

<i>Type of disability</i>	<i>N = 308</i>	<i>Median monthly income (VND)</i>
Deaf/hearing impaired	36	3,000,000
Blind/visually impaired	105	2,500,000
Communication impaired	39	2,000,000
Self-care disabled	25	1,700,000
Cognitively disabled	23	1,600,000
Mobility impaired	80	1,500,000

between the deaf/hearing-impaired group and the mobility impaired group (see Table 1.7).

According to the poor household standard in the period 2016 to 2020, people with household incomes below VND 1.3 million per month, and from VND 1.3 million to 1.9 million<sup>8</sup> are classified as near-poor and average, respectively, in urban areas (The Library of Law 2017). As most of the respondents lived in urban areas, according to the above income standard, respondents with mobility, cognitive, and self-care disabilities in the study were classified as average (see Table 1.7). As the difference between being near-poor and average is very close, and the respondents did not have secured jobs (to be discussed), the chance that they fall into poverty is high.

The qualitative research also showed that, in addition to restrictions on educational and vocational training opportunities, employment opportunities for people with disabilities were also very limited and characterized by low incomes and job insecurity. Out of 58 interviewees, 44 were employed; only 13 reported having sufficient earnings to cover their food and living expenses. Out of 44 employed interviewees, 31 reckoned that their incomes were not enough to cover their costs. Only 3 out of the 44 employed interviewees were completely independent of parental support or disability benefits and had money to travel, save, or pay for extra tuition for their children. A blind man working as a masseur and living in Ho Chi Minh City said that he was assigned only three customers each day and collected a total of VND 81,000 per day. Without tips, he would have had no money for other things like medicines. A married couple with dwarfism in Ho Chi Minh City shared their stories about employment, highlighting the uncertainty in the lives of people with disabilities as follows:

The two of us sell lottery tickets from 7 am to 1 pm, and then sell fish skewers from 2 pm to 11 pm. For example, on a typical day, both of us make VND 200,000. If we sell less, we won't have enough money to eat because that VND 200,000 has to cover the costs of gasoline, rent,

8 1 USD equals 22,710 VND.

electricity and water bills for both of us. Therefore, it is sad if on any day we only make VND 100,000. We are running a street vendor business, so it is very unsteady. Moving the stall around and not having a fixed place, it is easy to lose customers, and if customers come when the police chase us away, we cannot sell anything.

People with disabilities from other places coming to the cities to work have higher living expenses than native people, because they have to rent houses and pay for other related expenses. They often have to advance salaries. According to a man with visual impairments who worked as a masseur in Ho Chi Minh City and had a wife but no children:

My income is not really enough to live on. With this income, it's easy for those who don't have to pay house rent but hard for people who live in rented houses. In addition, because it's difficult for people with disabilities, in general, to travel around, especially the visually impaired who need to go by motorbike taxi or taxi, we have to budget additional funds for these expenses. Therefore, when we talk to each other, we all agree that we spend even more money than people without disabilities.

Nearly half (20 out of 44) of the employed interviewees reported having been discriminated against at work because of their disability. Discriminatory behaviours were often related to recruitment, wage, labour contracts, work hours, or training opportunities, as illustrated below.

Regarding recruitment, some interviewees said that they had been turned down for a job because of their appearance (they had dwarfism and/or mobility impairments). They met with such statements as, "What can you do with those legs of yours? Why do you keep applying for jobs when you cannot do anything?" They also reported being refused a chance for an interview because of concerns that they could not work because of their mobility impairments. In some cases, employers simply did not interview or receive applications from people with disabilities, even if recruiters had contacted interviewees before knowing they were disabled or even when the recruitment had been announced publicly. These cases were reported to be very common with open recruitment. Visually or hearing-impaired people often worked for enterprises employing people with disabilities, such as tailors or massage shops, so they experience discrimination not in the recruitment process but, instead, in terms of payments and working conditions.

In addition to low incomes, people with disabilities also had to deal with harassments and violence while working, as confided by a blind man who was a street vendor in Ho Chi Minh City:

Selling lottery tickets is generally sad but I still have to do it. For people with disabilities like me, if we don't sell tickets, there would be no money. I got swindled or got robbed of tickets many times. Currently, I

also owe a lottery agency quite a big sum of money. I still gradually pay back to them but don't know when it will come to an end. Many times, when I still haven't paid off old debt, I've incurred new one. Sometimes I got my tickets snatched out of my hands; sometimes someone would pretend to ask to look at the tickets then run away with them or replace them with expired ones. Blind people like me cannot avoid them all.

Sometimes, they did not get to sign an employment contract as another blind man in Hanoi who was a reporter said:

I worked there for eight years as a temporary worker without a long-term contract. I also thought many times about stopping working for them. They gave me a place to work, in short, it's kind of doing charity. At the time of dismissal, they only informed me two weeks in advance, without any compensation partly because they legally had no obligation to do so for temporary staff like me.

There were also cases of salary suppression, such as the experience of a deaf man in Hanoi who "makes a lot of products but gets low pay" or being forced to work overtime without getting paid for it, such as a deaf woman who was an embroidery worker at a factory in Hanoi, who shared that:

The boss often gives excuses to employees like he's in urgent need of products. When this happens, my one-and-a-half-hour lunch break is shortened. I have to go back to work without proper rest. Overtime is also not paid because my wage is calculated based on how many pieces I can make.

Some cases related to having to work long hours, as told by a woman with mobility impairments who worked as an online gamer in Nghe An:

Often, I have to work until 10 pm, then get up early the next morning at 6 am to start working again. There's no time for me to rest. I am not that physically strong to work with that intensity. It is difficult for a disabled person to find a good job, so many people like me just accept the type of job I am doing. Whatever employers ask, I still have to do it.

Discrimination is also related to not being given the same opportunities for on-job training as colleagues without disabilities, as in a case shared by a deaf teacher in Hanoi:

My fellow teachers who are not disabled say that they have coaching and training programs throughout a school year. However, I (and two other teachers with hearing difficulties) cannot enroll because

training providers don't have interpreters for deaf people, and vocabularies in textbooks are hard for us to understand. As a result, we often miss opportunities to improve knowledge and skills. In the long run, I just keep falling behind in terms of expertise compared to my colleagues. Being aware of this, I often feel inferior to my fellow teachers.

### **1.5.5 Mental wellbeing**

According to a report by USAID (Lynch and Pham 2013), although the right to health and rehabilitation services is included in the Law on Persons with Disabilities, the application in reality is still deficient. Many service providers whose mandates are to serve disabled patients are primarily focused on physical therapies for people with mobility impairments and occasionally provide patients with therapies to help them recover speech. However, poor infrastructure and limited professional training, especially at the commune level, have created a lack of trust among users. In addition, psychological counselling, which this study shows is greatly needed by disabled people (to be discussed next), is not available. The above-mentioned shortcomings have reduced the practicality of medical centres to provide necessary healthcare services to people with disabilities.

#### *1.5.5.1 Mental wellbeing*

Mental wellbeing was included in this research as it was recommended by research collaborators. According to the collaborators, although many people with disabilities have poor mental health, specialized medical services are inaccessible to them. To measure mental health, the research adopted the WHO Five Well-Being Index (1998).

A respondent's mental health status is calculated by adding up the scores for all five statements. The total raw score, ranging from 0 to 25, is multiplied by 4 to give the final score, with 0 representing the worst imaginable wellbeing and 100 representing the best imaginable mental wellbeing (see Table 1.8).

According to the questionnaire, 53% of respondents ( $n = 457$ ) had a low level of mental wellbeing, among which there were more men than women. Among those who experienced perceived stigma ( $n = 130$ ), 64% had mental wellbeing issues. Respondents with communication and self-care disabilities reported the lowest mental wellbeing level. Respondents with visual impairments reported the best mental wellbeing among the six groups (see Chart 1.13).

Among the interviewees, 31 (out of 49 who shared about their mental wellbeing situation) reported balanced and happy emotions in general. However, 42 believed that they were always concerned about job/income instability (to be discussed below), and this was the main reason which negatively affected their mood. Unstable jobs and insufficient incomes added to the weight of

Table 1.8 Mental health scale: Five Well-Being Index (in the past 12 months)

	<i>Always (5 points)</i>	<i>Most of the time (4 points)</i>	<i>More than half the time (3 points)</i>	<i>Less than half the time (2 points)</i>	<i>From time to time (1 point)</i>	<i>Never (0 point)</i>
1. I feel happy and excited						
2. I feel calm and comfortable						
3. I feel energetic and healthy						
4. When I wake up in the morning, I feel refreshed and relaxed						
5. My daily life is full of interesting things						

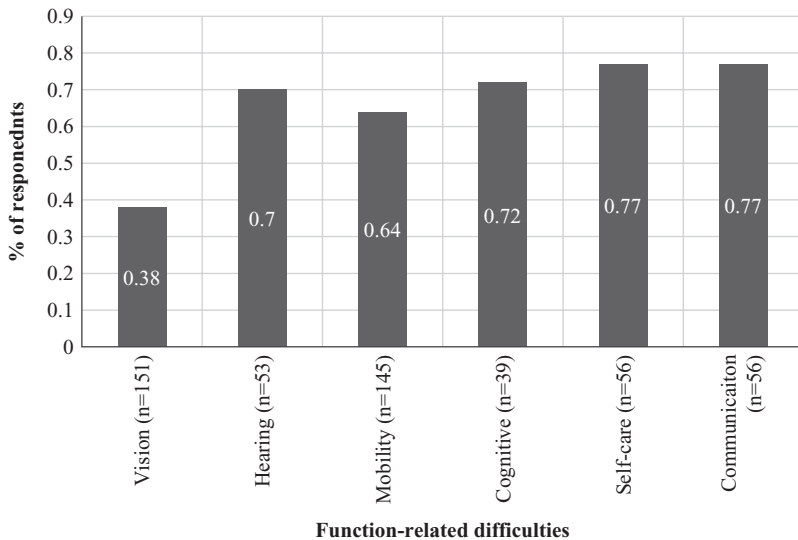


Chart 1.13 Percentage of low level of mental wellbeing among respondents by type of disability. Data by the author.

psychological pressure and led to a lot of worries, as shared by a man who was deaf, married with one child:

I am mostly sad than happy mainly due to work pressure and my salary is unable to afford expenses. My wife and I usually argue when any extra cost for my son occurs.

Health status is an important factor affecting the mental wellbeing of people with disabilities. This was discussed in a women-only group interview in Hanoi. A person with mobility impairments in the group stated the following, which was agreed by everyone in the group:

Now I think that we are not normal like you to have a husband and children who can take care of us if anything happens in the future. My parents are still healthy and can take care of me now. However, when my parents get older then pass away, I don't know where I will end up. Thinking about this makes me worried.

A participant with visual impairments in this group added, "such thoughts are always in my head." However, a man with mobility impairments living in Ho Chi Minh City who did not know how long he could live with his illness said that he always found motivations to overcome anxiety and sadness to find a job and work, to be able to contribute to a stable life for his mother and two brothers/sisters.

#### *1.5.5.2 Job satisfaction level*

The subject of employment is another field proposed by the research collaborators to explore the relationship between stigma and employment of persons with disabilities. In addition, improved understanding of job satisfaction can also shed light on the status of mental health (see Haile 2016), thus complementing research on the latter.

This study uses the WERS2011 (Workplace Employment Relations Study) scale to measure job satisfaction. A respondent's job satisfaction level is calculated by adding up the scores for all nine statements, ranging between 0 and 45. The higher the score, the more respondents are satisfied with their jobs. The threshold for considering that a respondent is satisfied with his/her job is 30 points (see Table 1.9).

As mentioned above, employment situation affects mental wellbeing. Therefore, this study investigated the level of job satisfaction of people with disabilities. Results from the questionnaire indicate that 62% of respondents ( $n = 246$ ) were satisfied with their jobs. Female respondents ( $n = 107$ ) had a higher job satisfaction rate than male respondents ( $n = 138$ ).

Deaf people had the highest percentage of job satisfaction (72%). People with communication impairments had the lowest job satisfaction rate (see Chart 1.14).

Some respondents were satisfied with their jobs because of adequate wages, management methods, and opportunities for on-job training, or because the nature of work suited their disabilities and health status.

Dissatisfaction was reported by most interviewees, but they often overlooked it because they considered that having a job was already lucky enough.



Table 1.9 Job satisfaction scale

	<i>Very satisfied</i> (5)	<i>Satisfied</i> (4)	<i>Neutral</i> (3)	<i>Unsatisfied</i> (2)	<i>Very unsatisfied</i> (1)
<i>Please indicate how satisfied you are with the following aspects of your job:</i>					
1. The sense of achievement you get from your work					
2. The scope for using your own initiative					
3. The amount of influence you have over your job					
4. The training you receive					
5. The opportunity to develop your skills					
6. The amount of pay you receive					
7. Your job security					
8. The work itself					
9. Your involvement in decision making					

It was common among interviewees to tolerate the dissatisfaction, due to lack of chances of changing jobs. The interviewees shared that they did not have many options due to limited training, health issues, and the stigma they face. Therefore, although they did not like their jobs and did not want to continue, many interviewees echoed the following sentiment:

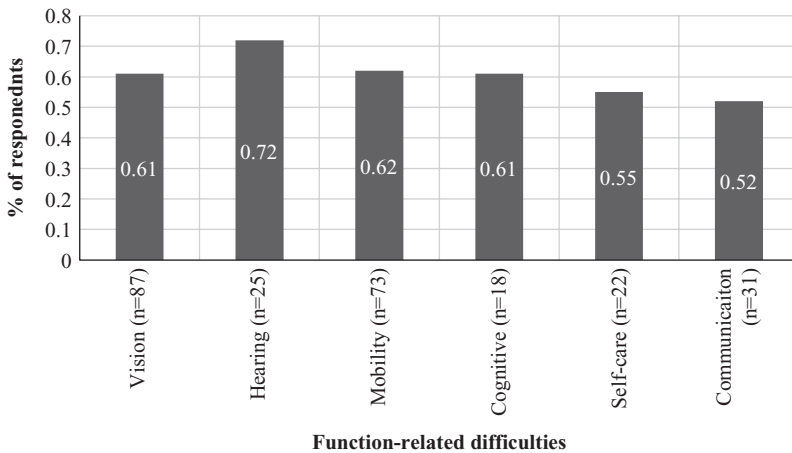


Chart 1.14 Job satisfaction by type of disability (n = 246). Data by the author.

I have to continue my job although I don't like it because this is a job to earn money. It's for my own life, so it can't be helped. There is no other way.

It is notable that this was said by a deaf man who was one of 3 out of the 58 respondents who said that they had enough confidence to provide for their families and for their children to go to school without support from the government or their extended families.

In interviews, there were also people who had been trained at vocational training colleges or universities and were doing things they loved and were passionate about, such as teaching and writing journals for the benefits of other people with disabilities. For these people, their dissatisfaction was often caused by discrimination at work. Inequality in working conditions, such as contracts, wages, on-job training opportunities, and feelings of isolation at the workplace due to the lack of welcome and appreciation from colleagues were the main reasons for the lower level of job satisfaction, although interviewees loved their jobs.

Being able to work with other people with disabilities was also reported to be an especially important factor for higher-level job satisfaction. Working with other people with disability was also said to motivate people because they could maintain or expand their social networks. This was shared by participants with all different types of disability. A visually impaired man from Vinh City who had a band of people with disabilities serving parties such as weddings and conferences shared that:

I like what I'm doing because I can meet others here and there. Incomes from playing music are low and can only cover travel expenses.

## **1.6 Research findings**

The study focused on analyzing stigma from the perspective of people with disabilities. The objective of this research was to strengthen the voices of people with disabilities to counter stigma against them in Vietnam. To do this, the study collected evidence of stigma which people with disabilities perceive and experience, and analyzed social settings where stigma was present, to identify causes of stigma and its impacts on the lives of people with disabilities. Interventions could, therefore, be identified and promoted through recommendations for policy advocacy to make policies more relevant to their lives.

Stigma against people with disabilities in this study appeared in several areas. In education, the fact that schools did not take seriously bullying of students with disabilities, and that teachers did not have appropriate teaching methods for students with disabilities have created barriers to education for people with disabilities. This indicates that students with disabilities cannot access and enjoy education in the same way or of the same quality as students without disabilities. In this respect, equal rights in education are not respected

for students with disabilities. As such, students with disabilities have been stigmatized and deprived of the opportunity to study to prepare for their future. This is also seen in other studies on education for students with disabilities in Vietnam (see Tran 2015).

The results also showed that discrimination in the education system was relatively systematic. It is reflected in the research that children with disabilities from poor families may never have gone to school or had to drop out of school; the compulsory education level is low because they were not taken to school or because there were no trained teachers or appropriate teaching aids. All these indicate systemic failures in ensuring the basic rights of people with disabilities. In addition to primary education, vocational training programmes were not adjusted to meet the learning demands of apprentices with disabilities. Vocational training programmes for people with disabilities focused on occupations that were commonly seen as suitable for people with disabilities (such as massage for blind people, tailoring for deaf people, computer graphics for people with mobility impairments). Those who wanted to pursue other occupations were denied access to courses at inclusive vocational schools for people without disabilities because these vocational schools did not have either accreditation or the necessary skills to teach people with disabilities. This has significantly reduced chances of choosing a profession freely according to the wishes of people with disabilities.

Findings from the research in the area of education call upon urgent actions to counter stigma against people with disabilities. Training in parenting skills for parents of children with disabilities will help them to become a primary source of encouragement to help their children access education. At the same time, the education system at all levels, including vocational training schools, must provide teachers with skills to teach and work with people with disabilities. Thus, people with disabilities will have greater opportunities to benefit from the educational achievements that Vietnam acquired after the *Doi Moi* (“renovation”) economic reforms. The above programmes must include options to learn in sign language for deaf people or people with hearing impairments.

Closely associated with the issue of education is employment. The findings from the research point out that discrimination in education has contributed to poor employment opportunities for people with disabilities. People with disabilities who participated in this research tended to have below average income and face insecurities in terms of employment. However, they rarely dared to change jobs because they believed that they had limited chances of finding better jobs. The quality of vocational guidance and training for young people with disabilities fail to prepare them effectively to enter the labour market. This did not help people with disabilities to fight against unfair working conditions, such as no signing of labour contracts, lower wages, and longer working hours.

The findings of the research show that perceived stigma is still rather common. The results also have revealed that perceived stigma is related to gender, age, type of disability, and the multiple disabilities status. However, perceived stigma did not tend to be linear correlated with the educational level of the research participants.

The findings of the research also show that participants often identified stigma and discrimination in their everyday social interactions, such as shopping and travelling around. When it comes to education and employment, people with disabilities seem to identify less disability-related stigma. While they would name the effects of stigma, such as feelings of sadness, anger, or embarrassment, they did not often link these feelings to stigma and discrimination against them in a workplace or at school. As many other studies have shown, recognizing the existence of stigma is the first step to eliminating stigma. Thus, improving the ability of people with disabilities to identify stigma should be a top priority. In the views of the research participants, raising awareness for children in school settings is seen as early intervention, so that, when growing up, they will not discriminate against people with disabilities.

To reduce perceived stigma, the study has revealed the necessity of enhancing the self-confidence of people with disabilities. The first step for people with disabilities to build up their self-confidence is to create venues for them to engage with people in similar situations, so that they can share and learn from each other on how to overcome barriers in life. Self-confidence is also created by having a job and a stable income. This means that vocational training and working skills should be promoted for people with disabilities. Training on working skills (including negotiation skills, interviewing skills, as well as basic information on labour rights and the right to equal treatment under the Law on Persons with Disabilities or in the spirit of CRPD) should be integrated into programmes of general and vocational education at specialized schools for persons with disabilities or in activities organized by associations, groups, and clubs of people with disabilities.

The findings from the research also have shown that research participants have a lower level of mental wellbeing. This can be attributed to concerns about job insecurity, low incomes, and job dissatisfaction. Improvement of the employment situation for persons with disabilities can both reduce stigma against them and improve their mental wellbeing. Respondents reporting a lower level of mental wellbeing tended to be those who reported perceived stigma and were males. This indicates that mental wellbeing programmes for people with disabilities should focus on these groups. Mental wellbeing programmes should incorporate activities that provide vocational training opportunities, or/and ensure equal working conditions, to create a higher level of job satisfaction.

## **1.7 Conclusion**

Some key recommendations for policy makers and practitioners are as follows.

- (1) Enhance research on perceived stigma.
  - This research indicates that, in Vietnam, there is still no consensus or equivalent local-language terms for different types of stigma. Terms

related to the concept of stigma, such as public stigma, are often mistaken with perceived stigma and self-stigma. Consequently, there is a need for a study to review and reach agreement on terminology for disability-related stigma. Consistency in terms and concepts in Vietnamese is necessary to avoid confusion in identifying beneficiaries of interventions addressing stigma.

- The purpose of this research was to collect evidence on stigma related to disability, the social contexts where stigma exists, and its impact on the lives of people with disabilities from their perspectives. The findings of the research reveal the need for: (i) further research and/or review at institutional and systematic levels, focusing on assessing current policies and programmes in Vietnam and their implications of stigma against persons with disabilities, paying attention to factors such as age, gender, type of disability, and one's multiple disabilities status; and (ii) simultaneous review of efforts at institutional and systematic levels to reduce stigma and/or discrimination, to find out which practices work. Based on the outcomes from (i) and (ii), measures can be mapped out to eliminate disability-related stigma at the institutional level.
- (2) Advocacy activities should focus on the right to equal and full participation in society for people with disabilities.

Policy advocacy should focus on the following areas to address the needs and demands of people with disabilities:

- Expansion (or inclusion) of sign language and Braille in inclusive schools and vocational schools and institutions providing public services for deaf/hearing-impaired and blind/visually impaired people, especially in remote areas. In the educational system, sign language and Braille should be introduced at the pre-school level.
- Increasing vocational/career guidance opportunities and diversity of vocational training for people with disabilities at both specialized and inclusive vocational training centres, by providing suitable teaching materials, methodologies, and languages for people with different types of disabilities.
- Enhancement and reinforcement of a disability-friendly environment at formal and vocational educational centres, for example, by increasing training opportunities for teachers, and building the capacity among teachers and school administrators to identify and handle stigma against persons with disabilities.
- Establishment of a mechanism to monitor the recruitment and employment of people with disabilities, ensuring implementation of relevant labour stipulations on working conditions. Following the CRPD, it is important to make it a legal obligation for companies to provide reasonable accommodations when recruiting and employing people with disabilities.
- Integration of mental wellbeing and awareness-raising programmes, such as counselling, into healthcare centres or facilities for people with

- disabilities or through their associations, clubs, and groups, with suitable communication channels and appropriate guidance materials for people with different types of disabilities.
- (3) The above intervention activities and policies should consider groups with a higher tendency to perceive stigmas, like men aged 18 to 38, people with multiple disabilities, and those with visual and mobility impairments.

With the above suggestions for interventions and policy advocacy for people with disabilities, this study seeks to help “people with disabilities change for society to change” (as a man with mobility impairment in Hanoi stated in an in-depth interview), “for the people with disabilities themselves to recognize stigma and discrimination in an attempt to eliminate the stigma and discrimination by themselves” (as a deaf woman living in Ho Chi Minh City said in an in-depth interview) by creating conditions for “people with disabilities to establish a position in society, such as having a job and asserting themselves through work and being able to earn a living themselves” (as said by a visually impaired man living in Hanoi). To bring about these changes, the research also hopes to help people with disabilities achieve their aspirations that “people with disabilities must be involved in the planning, development and implementation of programmes or policies related to their own life” (as said by a man with mobility impairment who was a Youth Union leader in Nghe An province) by sharing the results of the research mentioned above to people with disabilities, policymakers, and organizations working for the rights of people with disabilities.

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# 2 Understanding women with disabilities in China in the global context

*Luanjiao Hu*

## 2.1 Introduction

Globally, research has documented that women with disabilities (WwD) are doubly or triply disadvantaged compared with men with disabilities or people without disabilities due to their disability and gender status. This study examines women with disabilities in the global context and tries to understand women with disabilities in China within the global background. This study shows that though there has been an increasing amount of research on feminism and the situation of women in China overall, this body of research seldom takes women with disabilities in China into account. Women with disabilities in China face multiple disadvantages when it comes to autonomy, marriage, social support, and legal protection. Women with disabilities in China also encounter difficulties in accessing education and employment, and are more likely to experience violence compared to their peers without disabilities. This study calls for more research on women with disabilities in China.

## 2.2 Background information

### 2.2.1 Definition

A disabled person in China is defined as “one who suffers from abnormalities of loss of a certain organ or function, psychologically or physiologically, or in anatomical structure and has lost wholly or in part the ability to perform an activity in the way considered normal.” “The term disabled persons refer to those with visual, hearing, speech or physical disabilities, intellectual disabilities, psychiatric disabilities, multiple disabilities and/or other disabilities” (Law on the Protection of Disabled Persons 1990).

### 2.2.2 Data and statistics

According to the state report (2018) and the Second National Sampling Survey on people with disabilities (2006), China has about 85 million persons with disabilities, among which about 40.19 million are women or 48.45% of the disabled population.

### 2.2.3 *Legal framework*

Relevant laws and regulations in regard to disability include the Constitution, the Law on the Protection of Disabled Persons, the Regulation on the Prevention and Rehabilitation of Disability, the Regulation on Education of Disabled Persons, the Regulation on Employment of Disabled Persons, etc.

## 2.3 Objectives

There are only a few celebrities in China who are women with disabilities. Alternatively, there are not many female celebrities in China who openly identify themselves as persons with disabilities for fear of the stigmatization that may follow. Xiuhua Yu, a poet and writer, is one of the few female celebrities with disabilities in China; she is from a rural background and possesses extraordinary talents in writing. Yu has a visible disability – cerebral palsy – that affects her speech, mobility, and other physical characteristics. In 2016, a year after Yu rose to fame when her poems were discovered by a book editor, Yu publicly expressed her views on living with a disability in rural China in a TV programme hosted by Liaoning Province:

Disability does not only impact one's physical life but also the spirit. When I was a kid, my parents invited shaman doctors to see me. They said that I did bad things in my previous life, so I was punished in this life. I was despondent at that time. I asked myself, why not do something good in the previous life, why not be a good person? The idea was a heavy mental burden all through my childhood. Disability has huge impacts on a person. Sometimes it is devastating. My life is a life of struggle with my disabilities.

(Tencent 2016)

It is rare for a woman with a disability to publicly opine on disability and speak about her experience living with a disability in China. There has been long-established prejudice and strong stigma around disability in Chinese society, and people with disabilities are often “forced” to disappear from the public sphere due to both physical and social barriers which prevent their integration and participation in the community (Werner, Thuman, and Maxwell 1998). Discriminatory language is often found in people's daily conversations and/or written communications (Zhang and Gao 2016). In such an environment, the social space for people with disabilities, in general, is limited as attitudinal and institutional barriers exist to exclude and marginalize them (Li 2015).

This study examines WwD in the global context and tries to get an understanding of the current situation of WwD in China. It aims to answer questions such as: what is the existing research about the experiences of WwD globally, in both developed and developing countries? And what is the status quo for WwD in China? Guided by these questions, the study identifies challenges that

concern WwD in China and calls for more research on the topic. To do so, the paper first considers the situation of WwD identified in the existing literature in the global context. It then moves to the Chinese context and examines the situation of people with disabilities and specifically WwD. The final part of the paper concludes and suggests next steps.

## **2.4 Women with disabilities in the global context**

According to the World Report on Disability (2011), around 15% of the world's population are people with disabilities, and disability prevalence for men and women is respectively 12% and 19.2%. Others contend that perhaps as many as 20% of the women in the developing world have significant disabilities through at least some portion of their lives. Regardless of the percentage, one can come to a significant number of women worldwide that are living with certain disabling condition(s).

According to the US Current Population Survey (CPS), only 10% of all disabled adult women in the US are between 16 and 24 years old, yet more than 40% of WwD are between 55 and 64 years old (Bowe 1984; Nosek 2000). In other countries, we see a similar phenomenon: there are more females than males with disabilities who are 65 or older (e.g., the ratio between women with disabilities and men with disabilities is 10 to 7 in the Philippines). In China, from 1987 to 2006, the number of older people with disabilities over 59 has more than doubled, from 20.51 million to 44.16 million, among which more than half (52.7%) are WwD because of their longer life span (Shang, Fisher, and Guo 2014). Besides, studies show that women are more prone to prolonged debilitating illnesses, and consequently, they are more likely to acquire certain disabilities than men (Sengupta and Agree 2002; Macintyre et al. 1999; Merrill et al. 1997). Women worldwide are at an increased risk of becoming disabled throughout their life span, and they are at a higher risk of being sicker, more impoverished, and socially isolated than men with disabilities and non-disabled women (Groce 1997). Therefore, it is no surprise that there are significant differences in the prevalence of disability between men and women (12% vs. 19.2%; World Report on Disability 2011).

Globally, multiple research studies have documented that women with disabilities are doubly or triply disadvantaged compared with men with disabilities or people without disabilities due to their disability and gender status. They are the most marginalized of marginalized peoples (Clapton and Fitzgerald 1997). Their disadvantages manifest in different areas, including education, employment, intimate relationship, and so forth. WwD are more likely to live in poverty, have lower educational attainment, and are less likely to be employed than disabled men and people without disabilities (Guo, Xin, Zhao, and Hao 2013; Plummer and Findley 2012). Even when they are employed, they earn less compared to peers without disabilities and men with disabilities. WwD are more vulnerable to physical, emotional, and sexual abuses (Plummer and Findley 2012; Lin, Yen, Kuo, Wu, and Lin 2009; Nosek 2000; Nosek,

Howland, Rintala, Young, and Chanpong 2001). In addition, WwD are at high risk of being abused by caretakers, family members, friends, and others, due to a series of factors including strong stigmatization against WwD, WwD's reliance on their abuser, and difficulties in defending themselves or escaping from the perpetrator (Foster and Sandel 2010). Many issues WwD face in the global context are universal, as identified above. However, the complexity and severity of the issues that WwD face differ when taking into consideration poverty, class system, cultural value systems, resource bases, and other factors (Groce 1997). Therefore, there is a need to study WwD within developing countries such as China, where a significant number of WwD reside and live.

Despite the severe challenges facing women with disabilities globally, most of the existing scholarly and popular literature on disability does not specifically focus on WwD. Research and literature on WwD did not catch on until the last three decades or so. The majority of the research studies have concentrated on developed countries, yet the majority of WwD live in developing countries (Thomas and Thomas 2002). This body of literature includes writings from WwD scholars in the UK, the US, Canada (Matthews 1983), and Germany (Schrötle and Glammeier 2013). While research on WwD in developed countries is important, the living situation of WwD in the developing countries has been largely neglected and under-researched, where poverty exacerbates the disadvantaged status of WwD beyond that of their gender. The dearth of existing research on WwD in developing countries demonstrates to us the extent of marginalization and scant attention paid to this population.

Among existing research in the developing world, the studies focus more on medical or rehabilitation issues (Rui 2013; Groce 1990, 1997; United Nations 1986), reflecting the strong influence of the medical model of disability that sees disability as a problem requiring cure and treatment. Within feminist research, WwD, for the most part, are not included. Researchers worldwide have called for the inclusion of disabled women in the feminist agenda (Emmett and Alant 2006; Ghai 2002) rather than neglecting and excluding them. In terms of types of disability, the majority of the existing research focuses on women with physical disabilities rather than women with other types of disability, such as sensory disabilities, mental disabilities, etc. (Nosek, Howland, Rintala, Young, and Chanpong 2001; Nosek 2000; Deegan 1985).

## **2.5 Disability in China**

The word “invisibility” describes the life of people with disabilities in China (Werner, Thuman, and Maxwell 1998). Despite there being 85 million people with disabling conditions in China (1 in 16), the public seldom encounters people with disabilities in their daily lives, at school, at the workplace, in tourist sites, etc. (Hou 2015). In a way, people with disabilities are visible and invisible at the same time: visible in the sense that they are subjects of attention and discussion when spotted in “unexpected” public locations, and simultaneously, invisible in the sense that their need for social participation is generally

neglected by the public (Hu and Lin 2017; Barnes 2007; Tinklin, Riddell, and Wilson 2004).

The first Chinese national survey of people with disabilities took place in 1987, before the establishment of China's Disabled Persons' Federation (CDPF) in 1988. In the 1987 survey, disability prevalence was estimated to be between 1.4% and 13% based on different measurement methodologies. The process of quantification of disability was not entirely an objective one, but was instead subjected to the Chinese officials' will in shaping the country's image at the national and international arena (Kohrman 2003). Compared to the US, China presents a relatively lower percentage of people with disabilities. According to the newer National Sample Survey on People with Disabilities conducted in 2006, China has about 85 million people with disabilities, accounting for 6.34% of the total population. Despite the lower percentage, China still has the world's largest disabled population, and consequently, the largest WwD population.

Traditionally, people with disabilities/disabled people were referred to as "*canfei*," a derogatory term that translates into "disabled and useless." Today, the more commonly used Chinese characters for disability are "残疾" (*canji*). These two characters are hieroglyphics and reveal interesting etymological stories. For the first character "残" (*can*), the left part of the character means "death," while the right part of the character means "two spears." This reveals its original meaning, which depicts a picture of people fighting with weapons to kill each other. Today it usually means injured, incomplete, and evil in different phrases. The second character, "疾" (*ji*), originally depicts a picture of a person getting shot by an arrow, therefore becoming injured and falling ill. Today, "疾" (*ji*) usually means illnesses. As a result, the word describing people with disabilities/disabled people in Chinese is written as "残疾人" (*canji ren*), meaning injured, incomplete, and ill people.

In terms of disability categories, "*Canji Ren*" refers to those with visual, hearing, speech, or physical disabilities, intellectual disabilities, psychiatric disabilities, multiple disabilities, and/or other disabilities. The legal definition of "*Canji Ren*" spelled out in the Chinese Law on the Protection of Disabled Persons reflects the significant influence of the medical model of disability (Zhang 2006). The medical model of disability defines disability as a problem of the individual that is caused by a disease, an injury, or some other health condition and requires medical care in the form of treatment and rehabilitation (Mitra 2006). The medical model places the problem on the individual who has some unwanted health conditions and is considered "sick." Under the medical model, disability is seen as an individual problem that needs to be dealt with at the individual level. This is why disability is often narrowly viewed in China. Despite the ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2008, the Chinese government has yet to revise the legal definition of disability.

China has established a constitution-based legal system that protects the rights of persons with disabilities. According to the Constitution (Article 34 &

35, 1982) and the Law on the Protection of Persons with Disabilities (Article 3, 1990), people with disabilities in China enjoy the same rights as others, including the right to vote, right to stand for election, freedom of speech, etc. The Law on the Protection of Disabled Persons aims to facilitate equal opportunities and participation for people with disabilities in China, as well as to eliminate discrimination based on disability. Regulations on the Employment of Persons with Disabilities (2007) and Regulations on the Education of Persons with Disabilities (1994) further elaborate and supplement the provisions concerning employment and education for disabled people in China. With the influence of international advocacy and the trend in protecting people with disabilities globally, China became a signatory country of CRPD in 2007 and ratified the Convention in 2008.

However, there still exist other policies and regulations that explicitly or implicitly discriminate against people with disabilities. For example, the Advisory Guidelines for Physical Examination in Higher Education Student Admissions list various categories of disabilities that can serve as justifications for higher education institutions' decisions to deny a student's admission into certain programmes (Hu and Lin 2017). Also, according to local regulations implementing the One-Child Policy of 1979–2015, if the first child is severely mentally or physically disabled, the couple is allowed to have a second child (Tsui and Rich 2002; Hesketh, Lu, and Xing 2005). China has loosened its population policy since 2015 by allowing a couple to have two children, but it is still provided in most family planning regulations that a couple can have one more child if one or both of the born children have a diagnosed disabling condition (Regulation of Beijing Municipality on Population and Family Planning 2015).

In addition, there are gaps between legislation and actual implementation in practice. China failed to ensure the provision of reasonable accommodations such as a braille exam paper for students with visual impairments until 2014 (Li and Fu 2015), despite legal requirements (Article 54 LDPD). Additionally, although Regulations on the Construction of Barrier-Free Environments were passed and came into effect in 2012, the physical inaccessibility of public spaces remains a huge barrier for people with disabilities. A notable example would be Tsinghua University, one of the top higher education institutions in China. In the recent 3rd annual international conference on accessibility development hosted at Tsinghua University, the university was reported to have multiple accessibility issues (e.g., inaccessible entrance to the conference venue, inaccessible bathrooms) for wheelchair-user attendees (Mo 2018).

People with disabilities in China have a higher illiteracy rate and less access to education compared with those without disabilities. According to the 2006 National Sample Survey on People with Disabilities, the illiteracy rate for individuals with disabilities aged 15 or above is 43%, much higher than that of the total population in the same age group (less than 10%). People with disabilities also have lower educational attainment compared to those without disabilities, and they are greatly underrepresented in higher education (Li and Fu 2015; Hu and Lin 2017). Based on the 2006 Survey, 2,460,000 children

from age 6 to 14 had one or more disabilities in China. Of these children, 63% were formally enrolled in school settings that were either inclusive or restrictive. China has two parallel educational systems; one is the regular mainstream schools and the other is special education schools. The combination helps to provide increased access to students with disabilities. Yet the enrolment rate for children with disabilities was only around 60%, while over 99.5% of children without disabilities of school age are enrolled in schools (Li and Fu 2015; Hu and Lin 2017).

Socially and culturally, the perception of people with disabilities in China has remained quite stagnant over the years, despite some language changes around disability. In China, the image of a person with disabilities is often depicted in the media as pitiful, pathetic, dependent, childlike, and incapable; or inspiring when it comes to those who “have overcome or conquered” their disabilities (Zhang and Gao 2016; Li 2015). As mentioned above, disability is still primarily regarded as a medical condition and as an individual problem that requires treatment and a cure. Given these circumstances, people with disabilities can hardly find true acceptance for who they are, and rather, they are either regarded as pitiful beings or incomplete beings who are in need of treatment to be normal. Those who do not conform to the non-disabled “norm” are subject to stigmatization and rationalized to exclusion from social participation (Li 2015; Werner, Thuman, and Maxwell 1998; Clapton and Fitzgerald 1997). Immersed in such an inhospitable social environment, many people with disabilities have internalized such views and see their disabilities as the source of their exclusion and suffering. As shown above in the quote from the female poet Yu, disability affects her significantly in a negative way in her view. The concept of “disability pride” is rarely found in China.

## 2.6 Women with disabilities in China

What is the status of WwD in China? Among the 85 million people with disabilities in China, about 40.19 million or 48.45% are women (Second National Survey on PWD 2007). In general, WwD have benefitted less than both the non-disabled people and men with disabilities in terms of social and economic development. Additionally, rural women with disabilities fare worse in terms of education, employment, and access to healthcare services than urban women with disabilities. Unfortunately, they have received little academic attention.

Though there has been an increasing amount of research on feminism and the situation of women in China overall, this body of research seldom takes WwD into account. There is also little mention of WwD in the literature on women and poverty, even though global research has shown that the majority of people with disabilities suffer from poverty. Based on a real-name system survey conducted by the Chinese Disabled Persons’ Federation (CDPF) at the end of 2013, 12.3 million people with disabilities in rural China live under the poverty line, and 2.6 million urban-dwellers with disabilities live impoverished and difficult lives. Said differently, WwD are overlooked not



only in the general body of research but also in the area of gender or poverty studies. While searching for literature on WwD in China, I used the keywords “*Canji Nvxing*” and “*Canzhang Nvxing*” (both translated to “women with disabilities”) in a major research database in China (China Knowledge Resource Integrated Database [CNKI] – Academic Journals). With these keywords, I located 15 relevant studies, all conducted within the last two decades. For example, among the 15, there are quantitative studies using survey data collected from a northern Chinese province, Heilongjiang. The studies offer overviews of the status of WwD and focus on WwD’s social status, economic status, family life, health, and rehabilitation. There are also several qualitative studies: one on WwD’s perceptions of marriage and romantic relationships; one on marriage partner selection for rural WwD (Yang 2015); and one on the identity crisis of women entrepreneurs with disabilities. There is also research focusing on the legal protection of people with intellectual disabilities and their sexual rights – women with intellectual disabilities are often the subjects of study (Zhang 2018). Limited as the research is, the existing studies have pointed to a common theme: WwD face multiple disadvantages when it comes to autonomy, marriage, social support, and legal protection. WwD also encounter difficulties in accessing education and employment, and are more likely to experience violence compared to their peers without disabilities. In 2017, I had conversations with two disabled women during their participation in a leadership programme. Below are some quotes from our conversations at the time. These quotes, too, echoed the lack of research and opportunities for women with disabilities in China.

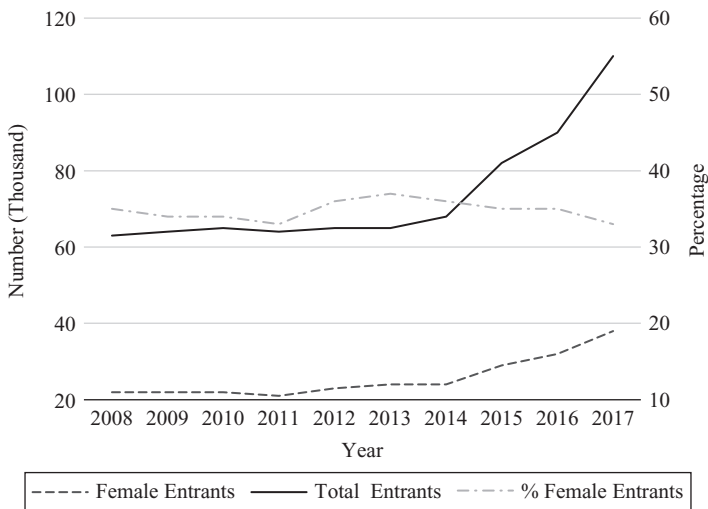
There is a lack of research on disability and gender in China. When we do projects on women and disability, I was often asked by people, do you have any research or data about women and disability in China? My reply was often – no, there isn’t much – with a weak smile. The disability awareness in the general public here is not just little; there is NONE  
(Michelle, Humanity & Inclusion, China  
Office, personal communication, September  
20, 2017).

The lives of girls and women with disabilities in China are not so well in my area. There’s a vicious cycle going on among them. With little education, little training opportunities, and little information, many of them are bounded at home and discouraged from going out to work. They are told that they are not capable of doing this or that. As a result, they do not have jobs or good jobs. No employment, no information, no further education, or training opportunities  
(Ying, Center of Self-Help Services for the Other  
Abilities, Chongqing, China, personal communication, September 22, 2017) (Figure 2.1).



### 2.6.1 Education

People with disabilities have lower educational attainment than those without disabilities (Li 2015; Second National Survey on PWD 2007). Indeed, the average number of years of education for people with disabilities is about 6.47 years, while the number is 8.46 years for those without disabilities. There is also a gender gap in educational attainment among people with disabilities. Despite the evidence of people with disabilities in China faring better than before in education access and attainment overall, girls and women with disabilities remain disadvantaged at different educational levels compared to both their male peers with disabilities and peers without disabilities. According to Basic Statistics in Special Education in the recent decade (Ministry of Education, see charts below), among all graduates with disabilities at the primary and secondary education levels, women with disabilities accounted for only 34% in 2017 (see Chart 2.2). The percentage of women with disabilities among entrants with disabilities at all primary and secondary education levels is at a similar rate of 33% to 37% (see Chart 2.1). They are enrolled at different educational levels at lower rates than their male peers with disabilities. Also, WwD are hugely underrepresented in Chinese higher education while the representation of their female peers without disabilities continues to increase since the late 1990s. By 2008, the percentage of enrolled women without disabilities in higher education came to be equal and then surpassed that of men (see Chart 2.3). On the contrary, the Ministry of Education does not have data on people with disabilities in higher education or on WwD. While the CDPF does have data on the number of admitted people with disabilities in higher education, it is not sex-disaggregated. However, one can predict from the data depicted in Chart 2.1



*Chart 2.1* Basic statistics of special education: number of female entrants in primary and secondary education level, 2008–2017. Data by the Ministry of Education, 2017.

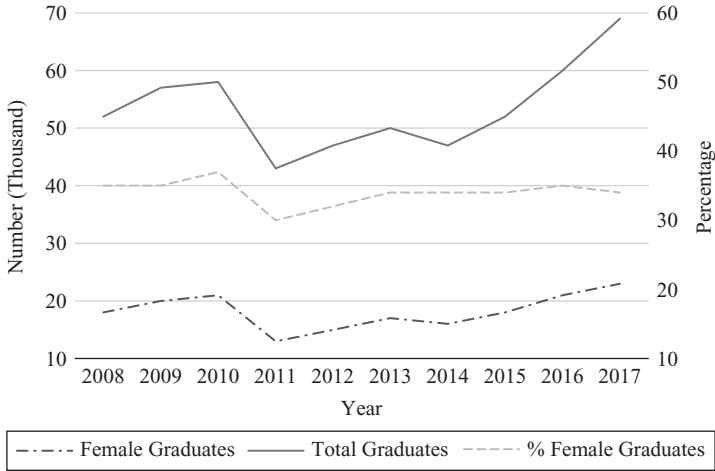


Chart 2.2 Basic statistics of special education: number of female graduates in primary and secondary education level, 2008–2017. Data by the Ministry of Education, 2017.

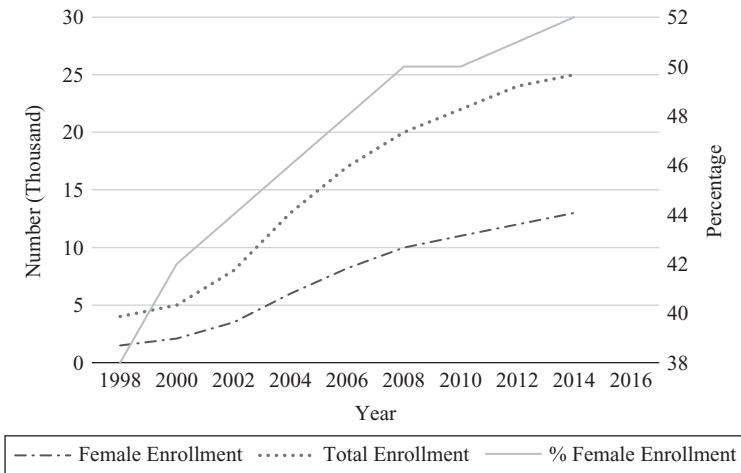


Chart 2.3 Enrolled female students without disabilities in higher education institutions. Data by the Ministry of Education, 2015.

below that WwD are less represented in higher education than their male peers with disabilities and their female peers without disabilities.

### 2.6.2 Employment

Studies show that WwD are more disadvantaged compared with their male counterparts with disabilities in seeking employment (Yang 2017). About 34.93 million or 42% of the people with disabilities are of working age in China (age 15 to

59) (CDPF). The labour force participation for women in China was about 72% in 1990 and decreased to 64% in 2014. However, the labour force participation for WwD in China is less than 20%, lower than the already low figure for all people with disabilities (26%), according to a survey conducted in Heilongjiang Province. Gender status significantly affects one's employment status in China: among people with disabilities of working age, 35.63% of WwD are employed while 64.37% of men with disabilities are employed. Even when employed, WwD earn less than men with disabilities. WwD's average yearly income in 2010 was about ¥3,503 (about \$507), which is about 85.9% of what men with disabilities earn and 28.5% of what women without disabilities earn in general. WwD in China are more likely to be subjects of employment discrimination compared with men with disabilities (Guo, Xin, Zhao, and Hao 2013). As the survey in Heilongjiang Province indicated, about 62.8% of WwD have experienced discrimination in job-seeking, more than that of men with disabilities.

### 2.6.3 *Violence against WwD*

Grassroot organizations that have conducted research and worked with WwD (e.g., Beijing Enable Sister Center, One Plus One Disability Group) often find that WwD are not only subjects of employment discrimination, but also sexual violence. During the #MeToo movement in China, WwD have also voiced and shared their stories of being survivors of sexual violence (Beijing Enable Sister Center 2018). For example, women with visual impairments (blind or low vision) who work in the massage industry have found themselves more vulnerable when it comes to sexual violence at the workplace. When sexual violence occurs, it is more difficult for women with visual impairments to protect themselves, as they may have difficulties identifying the perpetrator's appearance even when they report the case to the police. Or, when sexual assaults at the workplace happen, women with visual impairments are often not protected by their employers (for fear of offending the customers) but are asked to deal with the issue themselves. Women with visual impairments are sometimes forced to choose between withstanding sexual violence at work or quitting the massage industry altogether. Similar cases also happen among women with hearing impairments. The shaming and blaming of female victims also play a role in preventing them from reporting sexual violence. As a result, the stigma around both gender and disability put WwD at greater disadvantage when they encounter sexual violence. Here, gender and disability work together not just by adding disadvantage, but rather "multiplying" their disadvantages in workplaces.

The issue of WwD being subjects of sexual violence is prevalent in both urban and rural areas. Women and girls with intellectual and developmental disabilities are among the high-risk population for sexual violence, as shown in multiple news reports.<sup>1</sup> This is not a unique issue that is characteristic of

1 [http://www.legaldaily.com.cn/index/content/2014-03/05/content\\_5334701.htm?node=20908](http://www.legaldaily.com.cn/index/content/2014-03/05/content_5334701.htm?node=20908); <http://www.epochtimes.com/gb/18/5/21/n10414237.htm>; <https://www.the->

China: WwD in other contexts, both in developing and developed countries (e.g., US, Bangladesh, etc.) experience similar problems (Shapiro 2018; Hasan et al. 2014).

Besides sexual violence, WwD are also more vulnerable to emotional abuse and domestic violence (Zhang and Fang 2018; Nosek, Howland, Rintala, Young, and Chanpong 2001). The Heilongjiang survey (2011) indicated that about one-fifth of respondent WwD have experienced certain forms of domestic violence (e.g., verbal abuse, physical abuse, financial control, etc.). Compared with women without disabilities, WwD usually have fewer means to protect themselves from such abuse and violence (Guo, Xin, Zhao, and Hao 2013).

## 2.7 Conclusion

The lack of literature and research on WwD in developing countries (including China) indicates their invisible experiences and their powerlessness. Similar to many other parts of the world, people without disabilities have little knowledge or understanding of people with disabilities. When it comes to women and girls with disabilities, interest and understanding are even less. Among feminist studies, few talk about WwD. While disability scholars in some countries have demanded that feminist studies include WwD in their agenda, these appeals apply to China as well. There is a lack of research and attention being paid to WwD. As one disability advocate from China commented: “the situation (lack of research on WwD and people with disabilities in general) may change if there are more researchers with disabilities in China.”

Admittedly, the experiences of WwD in different countries differ based on their cultural contexts, religious beliefs, disability statuses, socio-economic statuses, educational attainments, geographic locations, etc. However, when one talks about how drastically culture and other factors differ from each other, there are commonalities about the situation of WwD shown in literature consistently across different countries and societies. Findings from this literature review show that most WwD are not full or equal participants in different societies and are excluded in systemic ways starting from the education and employment sectors. Even when they are employed, they are paid less and are more likely to experience discrimination due to disability and gender status. Besides, they are more vulnerable and likely to be subjects of violence (be it physical, emotional, or sexual).

As a country with a rapidly developing economy, China has a long way to go to fight against stigma surrounding disability and gender, without which WwD will continue to stagnate in the social development landscape compared

with other population groups. Currently, WwD not only are subjected to gender discrimination and inequality faced by women in general, but they are also susceptible to the oppression that people with disabilities encounter on a daily basis. They are multiply disadvantaged in accessing educational and employment opportunities while other social groups (i.e., men with disabilities, women without disabilities) are seeing signs of progress in both sectors. The lack of such opportunities has an impact on their access to healthcare and other services, and foreseeably, quality of life as equal participating members of our society.

Moving forward, the author hopes that more studies will be conducted on WwD in China. These studies are to serve multiple purposes: to establish the research foundation on WwD in China; to place WwD's lived realities and experiences under a scholarly framework and increase their visibility in academia; and to use research findings to better support disability advocates, policymakers, and other stakeholders on what women with disabilities genuinely need from our societies for them to be full and equal participants.

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# 3 Employment status of visually impaired women in Nepal

*Sarita Lamichhane*

## 3.1 Introduction

A survey was conducted to identify the real situation of visually impaired women in the sector of employment in Nepal. The survey helps to understand what sort of challenges the visually impaired women in Nepal have to face and to know their workplace environment, their skills, experiences, and their interest in working. Visually impaired women in Nepal are very capable and skilled in various sectors like music, teaching, and writing. Some visually impaired women are employed and they are supporting their family, and most of the employed visually impaired women are satisfied with their work and have good earning with good savings. The unemployed visually impaired people have many skills and qualifications; they should be given a chance to prove their capabilities and show what they can do. Support and empowerment should be given to the visually impaired women so those who are dependent on others can stand on their feet.

## 3.2 Background information

Nepali society still views disability as a penance for sins committed in previous births, that is to say, Nepali society believes that disability is a consequence of bad things one has done in a previous life. People with disabilities are treated as an object of pity in Nepal.

A visually impaired person's life is very difficult in Nepal, especially for women who have to cope with various physical, mental, social, and economic challenges. The visually impaired women are facing different types of problems in their daily life. They face violence in their homes, they face challenges while travelling, and they are considered a burden on their family. Many visually impaired women in Nepal suffer from depression as they feel very isolated.

The limited mobility of the visually impaired women excludes them from many opportunities when it comes to education and employment. The visually impaired women face challenges in the education sector as they are not provided with the required materials for them to study. There are very limited numbers of education facilities for them. Hence, not everyone has the opportunity to enroll in these special education facilities.

There are various agencies and organizations working in the visually impaired sector. They provide various training programmes for them which lead to empowerment and skill development. But the visually impaired are currently not able to utilize their skills effectively. Most of the visually impaired women did not get the chance to develop and enhance their career goals. As a consequence, many visually impaired women cannot contribute to the income of families, but depend entirely on support by family and community members. This has an impact on their self-confidence and they are perceived more like a burden than a full member of society with rights and responsibilities.

According to the census of 2011, 1.94% of the total population has disabilities. Among them, 18% of the population is visually impaired. According to Community Based Rehabilitation data of 2013, only 430 visually impaired people are working in Nepal. And most of them are involved in the teaching, reception work, and music field.

### **3.3 Objectives and methodology**

#### *3.3.1 Objectives*

This survey was conducted so that the status of the visually impaired women in Nepal could be known. This survey was to identify the real situation of visually impaired women in the sector of employment in Nepal, as well as to figure out the accessibility status in the employment sector.

This survey would help us understand what sort of challenges the visually impaired women face in their daily life. This survey would help us know how many visually impaired women are getting employment opportunities, and for those employed, to know their workplace environment, whether or not they are getting the facilities they need, and to know their skills, experiences, and interest in working. This survey would help us know how to utilize their skills properly. And this survey would also help us to find out the marital status of both the employed and unemployed participants.

#### *3.3.2 Methodology*

After finalizing the concept of the survey, firstly a predefined set of questions was made: one for employed visually impaired women and another for unemployed visually impaired women. Then these questions were discussed in meetings with different forums like the Nepal Association of the Blind (NAB), Lalitpur Association of the Blind (LAB), friends, and expert groups to collect feedback. After the discussions, meetings, and getting feedback from the network, the team prepared the draft of the survey questions.

To finalize the questions, the team met with Change Fusion Nepal and experts. After a discussion, the team prepared the final draft of the questions. In the final draft of the questionnaire, different fields regarding the women's type of disability, cause of disability, their challenges in the workplace, their interest area of work, their skills, their suggestions for the betterment in the future, how much they earn, and how much they save, were included.

After the final draft of the questions was prepared, different organizations, agencies, and hostels working in the visually impaired sector were contacted to meet the visually impaired women. The team went to different places like Kathmandu, Bhaktapur, and the Lalitpur Nepal Association of the Blind (NAB) for the collection of the required information. A specific number of people were listed and to be questioned to gather the required information regarding them. Focus group discussions and individual interviews were used.

Visually impaired people are the people who have low vision or no vision. There are many reasons why people become visually impaired. Some of the main reasons for the loss of vision are typhoid, eye infection, accidents, or impaired from birth. In this survey, all of the participants were visually impaired; some of them had low vision and some of the participants were completely blind.

### **3.4 Research results**

In the survey, a total of 83 persons participated. Out of the 83 participants, 50 visually impaired women were unemployed and the rest, 33 visually impaired women, were employed. After the collection of the data from the visually impaired women, data analysis was done. Data analysis was focused on visually impaired women's cause of disability, marital status, education, skill level, and training received. The objectives of the data collection and analysis were to find out the similarities and differences of the information. Data were divided into two different divisions, one for unemployed visually impaired women and another for employed visually impaired women.

#### *3.4.1 Age range*

Participants were mostly in the age range of 23–27 and only a few people were above 30 years old. Participants were from 27 different districts. They were mostly from Kathmandu valley and a small number of people were from places like Rautahat and Gulmi. The survey was conducted in Kathmandu valley. In the survey of the unemployed visually impaired women, it was found that there were a lot of people in the age range of 23–29 (see Tables 3.1 and 3.2).

#### *3.4.2 Type of vision*

There are two classifications of the visually impaired. The first one is blind and the second is low vision. Out of 50 unemployed participants of the survey, 18 had low vision, which is 36% of the total survey, and 32 were blind, which is 64% of the total survey (see Table 3.3).

In the survey of 33 employed visually impaired women, 26 were blind, which is 78.79% of the total survey and just 7 had low vision, which is 21.21% of the total survey (see Table 3.4).

*Table 3.1* Age division of unemployed women

<i>Age group</i>	<i>No. of people</i>
17	1
19	1
20	4
21	5
22	8
23	7
24	3
25	6
26	6
28	3
29	1
30	2
31	1
32	1
40	1
<b>Total</b>	<b>50</b>

*Table 3.2* Age division of employed women

<i>Age group</i>	<i>No. of people</i>
22	1
23	4
25	1
26	2
27	5
28	2
29	4
30	3
31	1
32	1
33	1
35	3
36	1
37	1
38	1
40	2
<b>Total</b>	<b>33</b>

### *3.4.3 Cause of disability*

Fifteen out of 50 unemployed women had lost their vision after birth. Eye infection and typhoid are the other major causes of losing their vision. A total of 70% of visually impaired women were impaired from birth, 12% from eye infection, 6% from typhoid, 2% had night blindness, 4% from

*Table 3.3* Type of vision for unemployed

<i>Type of vision</i>	<i>No. of people</i>	<i>%</i>
Low vision	18	36
Completely impaired	32	64
<b>Total</b>	<b>50</b>	<b>100</b>

*Table 3.4* Type of vision for employed

<i>Type of vision</i>	<i>No. of people</i>	<i>%</i>
Low vision	7	21.21
Completely impaired	26	78.79
<b>Total</b>	<b>33</b>	<b>100</b>

*Table 3.5* Cause of disability of the unemployed

<i>Cause of disability</i>	<i>No. of people</i>	<i>%</i>
Night blindness	1	2
Eye infection	6	12
Typhoid	3	6
Measles	2	4
Glaucoma	1	2
By birth	35	70
Not specified	2	4
<b>Total</b>	<b>50</b>	<b>100</b>

measles, 2% from glaucoma, and another 4% from other types of sickness (see Table 3.5).

For the cause of disability, there wasn't a very big difference between the employed and the unemployed. Among the 33 employed persons, 60.60% of people were impaired from birth, 15.15% from eye infection, 3.03% from retinal pigmentation, 9.09% from typhoid, 3.03% from measles, 3.03% from conjunctivitis, 3.03% by accident, and 3.03% from other sicknesses (see Table 3.6).

### *3.4.4 Education*

Nepal government provides free education for visually impaired people; it means they do not have to pay for their college tuition fee but it is not enough to get education. A visually impaired friendly environment, teaching materials in Braille, and other different facilities are also very important for them. Very few institutions are providing these facilities to visually impaired people.

Among the 50 unemployed participants, 35 visually impaired women were studying at bachelor's level, which is 70% of the participants, 5 of them were doing master's qualifications, and 6 were at the intermediate level. One of the

Table 3.6 Cause of disability of the employed

<i>Cause of disability</i>	<i>No. of people</i>	<i>%</i>
Retinal pigmentation	1	3.03
Eye infection	5	15.15
Typhoid	3	9.09
Measles	1	3.03
Conjunctivitis	1	3.03
Accident	1	3.03
By birth	20	60.60
Others	1	3.03
<b>Total</b>	<b>33</b>	<b>100</b>

participants had completed the School Leaving Certificate, two were literate, and only one person was found to be illiterate. At the intermediate level, five students out of six were studying Education, and only one person was studying Humanities. There was no student in the Commerce faculty. Of the 70% of participants studying at bachelor's level, 29 students out of 35 were studying Education, 5 students were studying Arts, and only 2 were in Commerce. Five participants were attending graduate school and four of them were studying Education. Only one was studying Arts.

Among the 33 employed participants, 15 participants had bachelor's qualifications (45.45%), nine had master's, six were at the intermediate level, two knew Braille, and one of the participants had finished the School Leaving Certificate. All employed participants had intermediate qualifications. All employed participants were studying in the Education faculty. Two of the participants had a Nepali major, and another four had Sociology, Population, Rural Development, and English majors. The ease of obtaining teaching and government jobs means students' attraction to the Education faculty is higher than others. At the bachelor's level, participants were similarly attracted to the Education faculty. Eleven participants had qualifications in Education, four of them studied Humanities, and no one studied Commerce or Science. In the Humanities faculty they have different choices: three of them studied Sociology and one had Music as a major. Very few of the participants had a master's qualification. A lack of an educational environment, time, and facilities are the main reasons for this. Nine people out of 33 had done their master's, five of them in the Education faculty and four of them in Arts.

### *3.4.5 Number of people with disabilities in the family*

In the 50 families of unemployed visually impaired women, 84 people were found with disabilities. It means the disability ratio is 1.6 per family. Six persons with disabilities were found in one family.

In the survey of the employed visually impaired participants, we found 66 people who were disabled in 33 families. It shows that the disability ratio is two per family.



#### *3.4.6 Marital status*

The marital status ratio of unemployed visually impaired women is 1:4. Ten women were married out of 50 participants. It means 20% of unemployed women were married and 80% were unmarried.

Among the employed visually impaired women, 15 women were married. It shows the marital ratio of the employed visually impaired women is higher than the unemployed visually impaired women. The marital ratio in the employed visually impaired women is 5:6 and the unemployed is 1:4. In the survey, out of 33 employed women, 15 were married (45.45%).

#### *3.4.7 Number of children*

Out of 10 married unemployed women, 5 had children. It shows that 50% of married visually impaired women have children and the other 50% have no children yet.

Among employed visually impaired women, out of 15 married, 7 women had children and 8 had no children. It shows that 46.67% visually impaired women have children. It also shows that the child ratio for employed and unemployed visually impaired women is almost the same.

#### *3.4.8 Training received*

In the survey, it was found that all participants had received training in at least one field. Different non-governmental organizations (NGOs) and governmental organizations are working in the field of empowerment of people with disabilities.

In the survey of the 50 unemployed participants, 36 participants were computer literate, but they are not using computers on a regular basis; 72% had received computer training. Similarly, 14 people received leadership training which means 28% of people had received leadership training. Visually impaired women received other types of training: knitting, candle making, chalk making, making plastic goods, handicraft making, making furniture, carpet making, soap making, etc. Some visually impaired women received journalism, advocacy, anchoring, radio jockey, music, and other skill-oriented training but they are not able to apply these skills on a daily basis (see Table 3.7).

#### *3.4.9 Work in areas of interest*

One of the main objectives of the study was to find out the area of interest for the work of participants and whether they are getting work in their interest area. Most of the visually impaired women were studying in the Education faculty and working in the teaching field. Most of them want to work as a teacher. Most of the visually impaired women are working in the primary level because all think that teaching is a secure job and they can get a pension after the job.

Table 3.7 Training received by the unemployed

<i>Type of training</i>	<i>No. of</i>	
	<i>people</i>	<i>%</i>
Knitting	9	18
Leadership	14	28
Candle making	5	10
Chalk making	5	10
Plastic goods making	2	4
Computer	36	72
Anchoring	6	12
Music	8	16
Handicraft	1	2
Cricket	3	6
Advocacy	5	10
Organization development	1	2
Journalism	1	2
Liquid soap making	2	4
Reception	3	6
Fight back	2	4
Report writing	2	4
RJ	4	8
Weaving	1	2
Furniture making	1	2
Office secretary	2	4
Mobility	1	2
On the job	1	2
Scented stick	1	2
Carpet making	1	2
Envelope making	1	2
Office management	2	4
CRPD	2	4
Not specified	1	2
<b>Total</b>		<b>100</b>

In the survey, it was found that they are interested in different fields. Teaching has the highest number because teaching is easy and comfortable for them. But they are interested in other areas as well. Among the unemployed, 20 of the participants were interested in teaching; it means 40% of all participants were interested in the teaching sector. Thirteen people were interested in reception work and other participants had different interests in work: NGOs, INGOs, music, radio jockey (RJ), video jockey (VJ), sports, etc. (see Table 3.8).

Some people work in one sector but their interest in work is different. The survey was also done to know whether the employed women are working in the area of interest. In the survey of the employed participants, the same result was found as for the unemployed visually impaired women. Most of the employed participants wanted to work in the teaching sector, around 30% preferred to work in teaching, and 15% wanted to work in the music sector.

*Table 3.8* Work in areas of interest of the unemployed

<i>Type of work</i>	<i>No. of people</i>
NGO	2
INGO	1
Reception	13
Teaching	20
Handicraft	2
Music	5
RJ	4
VJ	3
Cricket	1
Administration	1
Knitting	4
Anchoring	1
Public Service Commission	2
Caricature	1
Project work	1
Government office	1
Social work	1
Braille translator	1
Typing	1
Office secretary	1
Field mobilize	1
Field work	1
IT	1
Cooking	1
Organization officer	1

But the interesting thing is that they have multiple interests in the choice of work, like physiotherapy, reception work, government services, research, social work, trainer, and activist (see Table 3.9).

#### *3.4.10 Work experience*

Out of 50 participants of the survey, 36 visually impaired women did not have work experience, which is 72% of the total participants; 10% already have teaching experience and other people have experience in sports, instructing, Braille teaching, marketing, and knitting (see Table 3.10).

#### *3.4.11 Skills*

Visually impaired people have different skills. They are doing different types of work. They can do a lot of things and they have the capacity to do more. Although they have lost their vision, they are very capable and skilled in various sectors like music, teaching, writing, etc.

*Table 3.9* Work in areas of interest of the employed

<i>Type of work</i>	<i>No. of people</i>
Physiotherapy	1
Teaching	11
Music	5
Tourist guide	1
Reception	3
Section officer	2
Administration	2
Research	1
Social work	2
Literature	2
Permanent job	3
Trainer	2
Women activist	1
Reader	1
Others	1

*Table 3.10* Work experience

<i>Sector</i>	<i>No. of people</i>	<i>%</i>
Teaching	5	10
RJ	1	2
Cricket	1	2
Coordinator	1	2
Volunteer	1	2
Braille translator	1	2
Knitting	1	2
Marketing	1	2
Computer instructor	1	2
Braille teacher	1	2
No experience	36	72
<b>Total</b>	<b>50</b>	<b>100</b>

Among the 50 unemployed participants, 21 visually impaired women have teaching skills. Unemployed women have skills like knitting, music, cooking, computer work, RJ, VJ, and other skills (see Table 3.11).

The same things happen to the employed visually impaired women as well. Employed visually impaired women have multiple skills: 10 participants out of 33 employed participants have music skills and 11 have computer skills. They also have knitting, anchoring (hosting shows), different types of goods making, and other skills (see Table 3.12).

Table 3.11 Skills of the unemployed

<i>Skill</i>	<i>No. of people</i>
Knitting	6
Chalk making	3
Candle making	4
Teaching	21
Computer	12
Language	3
Plastic goods making	1
Cooking	1
Music	12
Cricket	4
Reception	2
Leading	3
RJ	2
Communication	2
Braille translator	1
Braille typing	1
Coordinating	1
Management	2
Braille writing	1
Literature	5
Anchoring	2
Office secretary	1
Carpet making	1
Envelope making	1

#### 4.12 Areas of work

Visually impaired women who are employed and are supporting their families are mostly satisfied with their work and have good earning with good savings. They have become the backbone of their family. They are working in different sectors: 13 people are working in the teaching sector, 7 are in reception work, and 4 are trainers in the music field (see Table 3.13).

### 1.5 Conclusion

Studies have shown that many visually impaired women in Nepal suffer from depression as they feel isolated. Their limited mobility excludes them from many opportunities especially when it comes to education and employment.

Through the survey, it was found that almost all the visually impaired women had received education. Some of them had completed the master's level and most of them had completed their bachelor's level education. Both the employed and the unemployed were almost equally literate. In the survey of both the employed and unemployed, it was found that most of the participants' expenses were college fees and study materials, rent, and food.

*Table 3.12 Skills of the employed*

<i>Skill</i>	<i>No. of people</i>
Computer	11
Teaching	3
Office management	1
Music	10
Knitting	4
Receptionist	1
RJ	2
Leadership	3
Office secretary	2
Mobility	1
Language	2
Chalk	4
Communication	1
Counselling	1
Handicraft	1
Sacramental works	1
Candle making	3
Scented stick	2
Facilitating	1
Proposal writing	1
Report writing	1
Cooking	2
Literature	1
Anchoring	1
Managing	1

The visually impaired women are not a burden, they can do what other people can do and might also do it better. The only thing is that visually impaired women are not getting enough opportunities to show their talents, skills, and knowledge in their related fields. Therefore, visually impaired women need to have opportunities to develop and enhance their career goals.

Many visually impaired women can contribute to their own income for families, instead of depending entirely on support from their family and community members. This will make a positive impact on their self-confidence and they can be recognized as an active member of society with contribution and responsibilities. And with the effective implementation of existing policy and laws for employment opportunities, the trust of employment providers towards the visually impaired women can be generated.

### **Acknowledgments**

First of all, I would like to thank all individuals who gave of their time for interviews and meetings, without which this report would never have taken its shape.

*Table 3.13* Areas of work of the employed

<i>Area of work</i>	<i>No. of people</i>
Teaching	13
Music	4
Reader	1
Massage	2
Reception	7
Trainer	4
Assistant	1
Government	1
<b>Total</b>	<b>33</b>

I would like to express my appreciation to Change Fusion Nepal “Youth Action Fund” for providing the opportunity to conduct the survey on “employment status of visually impaired women.”

Special thanks to Luna Shrestha Thakur and Ram Sapkota of Change Fusion for their continuous support, feedback, and suggestions during this review period.

I would like to thank Deepika Sharma and Anita Sigdel for their contribution during the design phase. I would also like to thank Sabita Lamichhane for editing all the information.

# 4 Survey report on discrimination on disabilities and SOGIE in Myanmar

*Wai Wai Aung*

## 4.1 Introduction

This survey report describes and reflects how persons with disabilities, LGBT (Lesbian, Gay, Bisexual, and Transgender) persons, and LGBT persons with disabilities are being discriminated against in sectors of education, employment, accessibility, and social inclusion in Myanmar. The survey was conducted in three regions (Yangon, Mandalay, and Magway) in Myanmar and was supported by 80 respondents. It can be seen from the survey that the LGBT persons with disabilities are being discriminated against more than persons with disabilities and LGBT persons. There are recommendations given by respondents of the survey with the aim of eliminating discrimination and promoting inclusion. There are rarely intersection activities and cooperation between the disabled persons' organizations and the LGBT organizations, therefore this study calls for more cooperation and mutual understanding between the disabled persons' organizations and the LGBT organizations. This study also suggests that Myanmar raise the awareness of the rights of the minorities and empower them in the society based on human rights.

## 4.2 Background information

The Republic of the Union of Myanmar is geographically situated in Southeast Asia and is bordered on the north and northeast by the People's Republic of China, on the east and southeast by the Lao People's Democratic Republic and the Kingdom of Thailand, on the south by the Andaman Sea and the Bay of Bengal, and on the west by the People's Republic of Bangladesh and the Republic of India. According to the 2014 Housing and Population Census in Myanmar, the total population is 51.4 million and there are 2.3 million persons with disabilities (PWDs) among them. In detail, there are 1,056,755 males and 1,254,495 females which comprises 54% of the total PWD population. However, data on population and the percentage of LGBT persons cannot be found. The disabled LGBTs are even more difficult to figure out in the data. Though both groups, persons with disabilities and LGBTs, are marginalized groups, the LGBT persons are more discriminated against in Myanmar



where some traditional norms and customs are unfamiliar with LGBTs. The Republic of the Union of Myanmar ratified the Convention on the Rights of the Persons with Disabilities (UNCRPD) on December 7, 2011. Thereafter, The Rights of the Persons with Disabilities Law of Myanmar was enacted on November 17, 2015. Furthermore, in the 2008 Constitution of Myanmar, Article 349 proclaims that every citizen shall enjoy the right of equality and the right of liberty. Yet, persons with disabilities and LGBT persons are still suffering from several types of discrimination.

There are many disabled persons' organizations and LGBT organizations working for marginalized groups such as PWDs, women, and children to ensure their rights, free them from any type of discrimination, and make them live independently in society. Though each group organizes activities eagerly around the country, collaborative activities of these vulnerable groups altogether are rarely seen.

### **4.3 Objectives and methodology**

#### *4.3.1 Objectives*

The objectives of this survey are:

- (1) To make assessments of discrimination against persons with disabilities and LGBT persons.
- (2) To develop and promote awareness, mutual understanding, and cooperative activities between persons with disabilities and LGBT persons.
- (3) To make up for the lack of surveys which reflect the views of LGBTs and LGBTs with disabilities.

#### *4.3.2 Methodology*

Through the networks of LGBTs and persons with disabilities from three regions in Myanmar, I tried hard to get the information of discrimination against persons with disability, LGBTs, and LGBTs with disabilities, even though such data resource is very rare in this country. For this reason, the survey was conducted on LGBTs and persons with disabilities who had different backgrounds. The assessment form was noticeably and mainly designed to cover the widely differing outlooks of discrimination in PWDs and LGBTs who are the minority and marginalized groups in Myanmar society. However, I had the wish to conduct such design in two ways – questionnaires and in-depth interviews. The survey data collection was conducted in three regions in Myanmar: Yangon, Mandalay, and Magway. The participants were recruited from snowball samplings. They were selected from networks of disabled persons' organizations and of LGBT activists that I had connected with when I worked in the Civil Authorize Negotiation Organization and Shwe Min Thar Foundation. The surveyor and focal persons from the network discussed and developed the survey questionnaires in order to get the exact and possible data

from the respondents. In total, the questionnaires contained 30 questions, and we sent the survey forms to all respondents by all possible and accessible means through Google form, Viber access, email, Facebook messenger, in person, and on the phone, for the purpose of reaching the grass-roots level. I assured respondents that all personal information collected in this survey is confidential and would not be disclosed in any way.

#### **4.4 Key sectors**

Four sectors were encased as the main conceptual driving elements in conducting the survey of discrimination against disabilities and SOGIE (sexual orientation, gender identity, and gender expression). The UN has also committed “No one left behind” and inclusion at the core of their 2030 Agenda for Sustainable Development Goals. The four sectors are as follows:

- (1) Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all.
- (2) Promote sustained, inclusive, and sustainable economic growth, full and productive employment, and decent work for all.
- (3) Reduce inequality within and among countries.
- (4) Make cities and human settlements inclusive, safe, resilient, and sustainable.

#### **4.5 Challenge**

I developed the assessment form and connected to the network of PWDs and LGBTs around the targeted areas. Herein, the targeted areas had to be chosen where persons with disabilities and LGBTs lived. I acknowledged it was difficult to get resources due to some social norms, customs, and religious views in society.

Other challenges were the limited time and financial and technical support because I had just a month to prepare and develop this survey when my former organization, CAN-Myanmar, had made a hand-over to conduct this survey to me through “Book Workshop on Disability, Sexuality, and Gender in Asia”.

#### **4.6 Research results**

##### *4.6.1 General information*

Statistics show that the largest percentage of respondents (33.8%) are between 26 and 30 in age, followed by 25% aged between 21 and 25. See Chart 4.1.

Statistics show that the respondents of male and female are of the same percentage (50%). Among them, 42.3% are the alliance of LGBTs and 15.4% are gays. Lesbians are 13.5%, followed by transgender persons, at 17.3%. Bisexual

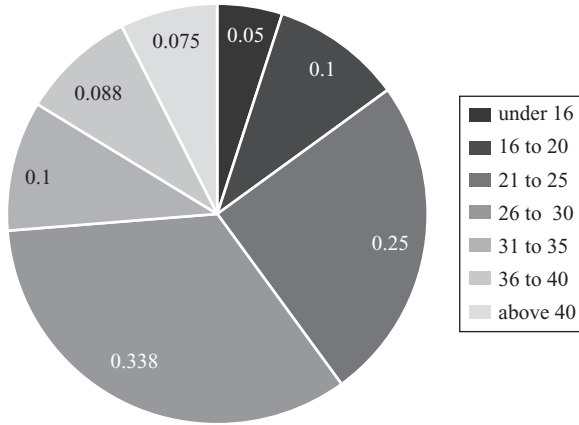


Chart 4.1 Age of the respondents. Data by the author.

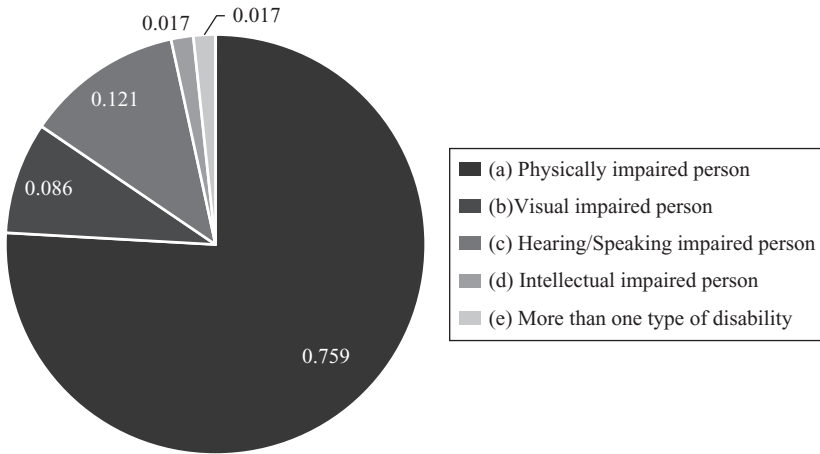


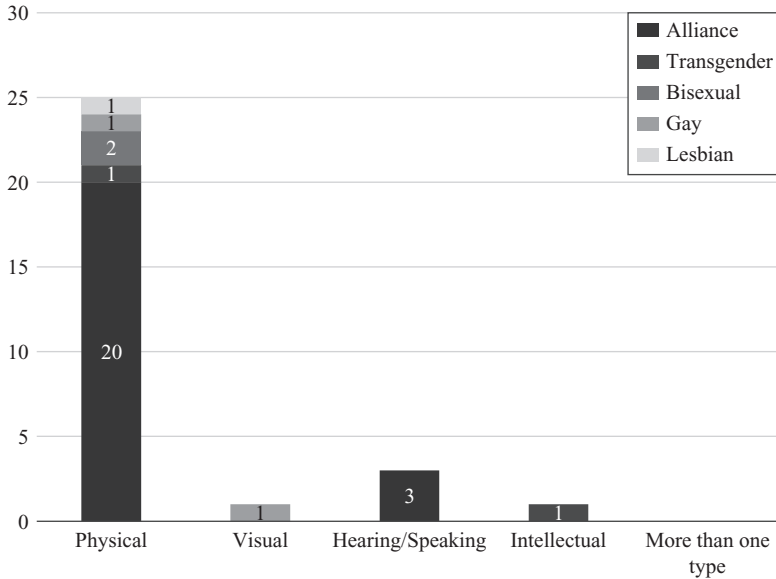
Chart 4.2 Disability of the respondents. Data by the author.

persons are 9.6% and Queer/Questioning is the smallest percentage, which is 1.9%.

According to Myanmar Persons with Disabilities Rights Law, there are four kinds of disabilities – physical, visual, hearing, and intellectual. Psycho-social disability is not included.

According to 4.2 Chart 4.2, out of 58 respondents of PWDs, most respondents are physically impaired persons (75.9%), followed by the hearing/speaking-impaired persons (12.1%). Visually impaired persons are at 8.6%, and those with intellectual impairment and with more than one type of disability are both at 1.7%.

Chart 4.3 show the intersection of disability and sexual orientation among the total 80 respondents. Among 23 alliances to LGBTs, 20 are physically



*Chart 4.3* Disability and sexual orientation of the respondents. Data by the author.

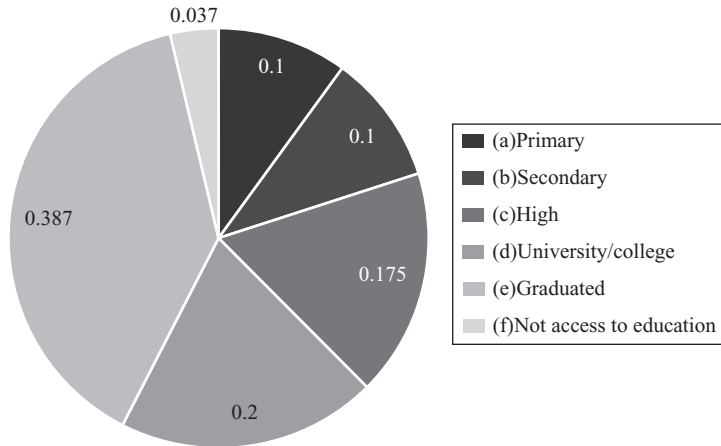
impaired persons and 3 are hearing/ speaking-impaired persons. There are two bisexual persons who are physically impaired. There is one transgender person with physical disability and one transgender person who is intellectually impaired. One gay person is with physical disability and another gay person is visually impaired.

#### **4.6.2 Education**

The statistics show that a large percentage of respondents in the target areas (38.7%) graduated with a degree, followed by 20% with a university/college education; the next highest education level is high school only (17.5%) and the lowest level, primary school only, is 10%. However, the percentage of those who have not accessed education is 3.7%. See Chart 4.4.

When asked “have you heard about or experienced any refusal directly or indirectly when you enrol in a school?,” 40% of the total respondents had heard about or experienced refusal directly or indirectly when enrolling in a school whereas 55% had not. However, 5% of the respondents gave the response of “don’t know” about that.

When asked “have you experienced any difficulty in enrolling in a school?” 28.7% of the respondents experienced difficulties in enrolling in schools whereas 66.3% of the respondents had no difficulty. Among 80 respondents, 45% of the PWDs had not experienced difficulty in enrolling and felt that it was up to the attitude and acceptance of the teachers. Only 36% of the



*Chart 4.4* Education of the respondents. Data by the author.

physical-impaired persons had not experienced barriers in attitude in enrolling. However, 1.2% gave no response to that question and 3.7% had no knowledge about that.

Some respondents had experiences when teachers held a negative attitude and imposed discriminator actions on PWDs and LGBTs to dress and behave according to their biological sex. Some PWDs were rejected for their disabilities. One reason for refusing to enrol crutch users was that it could be annoying to others if some classmates took and played with their crutches; another reason was because of the barriers and the inaccessible environment. Some respondents were told to enrol in training and special schools for PWDs.

When asked “have the teachers discriminated against you based on your disability or sexual orientation, gender identity and expression?,” 31.3% of the respondents experienced discrimination against their disability and sexual orientation whereas 62.5% had no experience of discrimination. However, 3.7% of the respondents “don’t know” about that and 2.5% gave no response.

For most of the LGBTs, teachers had a negative attitude and view about whatever they did. If they had a fight or quarrelled with other students, they were scolded and punished more than other students. The teachers even said rude words which included emotional and psychological violence and verbal abuse to them. Some LGBTs were scolded for their actions and behaviours which were against their biological sex.

For the PWDs, they were excluded from participating in physical exercise, collecting rubbish, and cleaning the campus because teachers thought of the PWDs as unable to do those activities due to their disabilities. Their abilities and skills were neglected and PWDs were also traditionally regarded with a negative attitude. Some teachers did not pay attention to or care about the PWDs as they had to pay more attention to other students.

When asked “do your friends treat you friendly without any discrimination?,” most of the respondents (81.3%) have been warmly treated and had a good relationship with their classmates. However, 12.5% had faced some types of discrimination, 3.7% gave no response, and 2.5% “don’t know” about that.

When asked “have you experienced any violence for your disability or sexual orientation and the ” 36.3% of the respondents had been bullied or abused for their disability and sexual orientation, but 57.5% said “No,” whereas 5% gave no response and 1.2% “don’t know about that.”

However, they could overcome these discriminations and barriers with the support of their family, classmates, teachers, and their eagerness to learn and to be educated. Some LGBTs made remarks that getting permission to dress according to their likes could lead to better performance in education.

When asked “are there any assistive devices for persons with disabilities in mainstreaming schools?,” most of the mainstreaming schools (76.3%) are not accessible for the PWDs and it is necessary to improve and develop more accessible designs and strategies for schools to be inclusive; 12.5% said there were assistive devices for persons with disabilities in mainstreaming schools, 1.2% gave no response, and 10% “don’t know about that.”

When asked “have you lost your chance of joining the school for your disability or sexual orientation?,” 33.8% of the total respondents had lost their chance of education because of their disability and sexual orientation. For PWDs, they could access primary education at their villages, but they could not continue their education as the surroundings of the school were not accessible and the location was too far from their home. Moreover, PWDs are not prioritized among their siblings; they are the last to make a choice because parents believe that they will not get any job even after graduation, so they put the hope on their abled children. At present, most of the PWDs are denied job opportunities for their physical impairment.

Some LGBT persons were looked down upon for their sexual orientation and gender expression. They were prohibited to dress as per their sex and thus one transgender man had to transfer from the university of engineering to another university. Actually, teachers should be the leaders of good ethics and mentors to eliminate discrimination and promote human rights. However, some cases happened because of the negative attitude of excluding the LGBTs.

When asked about their opinion upon special schools for PWDs, among the total respondents, 78.7% had a positive attitude towards special schools whereas 17.5% of the respondents did not like special schools, 2.5% had no knowledge on special education, and 1.2% gave no response for that question.

Education plays a vital role in the life of people. School is the essential and precious place where children were taught lectures and human rights. However, the PWDs lose their right to education for an inaccessible environment, the lack of adaptable and accessible devices, and a pedagogy for PWDs which indirectly pushes them away from schools and education. What’s more, teachers are the second mentor to keep in touch with them after parents. Thus, teachers should be skilful role models to provide good practices

and empower a good attitude of empathy and humanitarianism. Yet in reality, most of the disabled children are being discriminated against not only for the reason of over-protection but also for other people's negative attitudes to disability. Within the customs and religion in Myanmar, teachers usually hold a negative point of view on LGBTs' sexual orientation.

On application, a transgender man gained the marks necessary to attend the GTC university but he refused to join because the disciplinary department forced him to dress as his biological sex when he self-identified as a transgender man. He changed his choice of university to the ordinary major in which he could dress according to his likes. But he was not permitted to attend the convocation. So, he decided to get his graduation far away.

#### *4.6.3 Employment*

On employment, 78.7% of the respondents said that the LGBTs and PWDs did not have the same right to job opportunities and labour rights as other persons. Gender discrimination is still the major barrier to transgender men. Though they had the same ability as men, they got a lower salary rate than men. The PWDs were also more poorly paid than other persons.

When asked "have you experienced any discrimination for your disability and gender expression in your workplace?," 47.5% of the respondents had not experienced any discrimination whereas 35% of the respondents experienced discrimination in their workplace, 7.5% gave no response, and 10% of the respondents did not know about that.

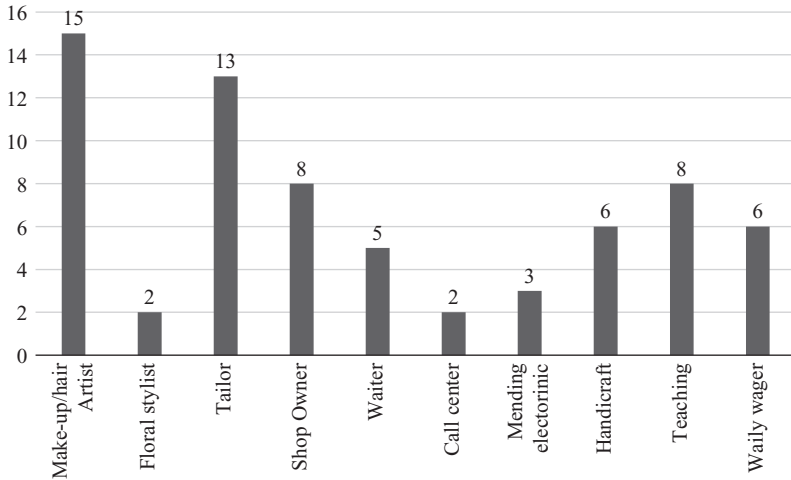
A transgender woman applied for a job and the HR manager told her that she would get this position if she could dress like a man. When she refused to dress like that, she failed to get the job.

Another LGBT person shared his experience of not being promoted and remaining in the same position for many years. Some colleagues in the workplace also held negative attitudes and were aggressive to the LGBTs.

A hearing-impaired person experienced mocking from her colleagues when she sometimes spoke out loud and they mimicked her sound just for fun. Some showed other discriminatory behaviour and mocked her activities.

Chart 4.5 shows that the respondents have the chance to get job opportunities such as vocational training in make-up, hair styling, and tailoring, provided by disabled persons' organizations. If not included in the above choices, PWDs have to run small businesses or work as vendors. The LGBT persons also could rarely escape from the custom of being hair and make-up stylists for persons with different types of sexual orientation. If they have the same ability and skill as other people, the job opportunities should come equally to them.

There was a physically impaired person with inborn weakness of her left hand who succeeded in getting a master's degree in English from a university. She tried for the position of college tutor and then passed the written test. During the interview, the teachers asked about her impairment and told her



*Chart 4.5* Job opportunities available to PWDs and LGBTs. Data by the author.

indirectly that she could not be a tutor for her weakness. Not surprisingly, she failed to be a tutor which was the goal of her life. However, she did not give up on her goal and tried for a second time. Again, she passed the written test with a top three score for the primary teacher. So, she requested an appointment with the deputy director of District (Education) and the representative of the township. The representative told the minister of the Division about the discrimination against her disability. In the end, she would not receive a fair decision for this case because policies had restrictions on teachers’ physical conditions.

#### *4.6.4 Family and social inclusion*

When asked “have you experienced any discrimination or violence from your family members?,” 26.5% of the total respondents had been discriminated against by their family members whereas 71.3% had not, 1.2% of the respondents gave no response, and 1.2% said that they did not know about that.

When asked “is there any refusing or negative attitude toward your request of joining a wedding or invitation or birthday ceremony with your family members?,” 22.5% of respondents experienced refusal to accompany their family members out to the ceremony. Some PWDs were discriminated against with verbal abuse and family members refused to accompany them to a wedding ceremony. Some PWDs would like to continue their education but their parents did not allow this, as their parents could not take them to the schools and give enough time to care for them. Some PWDs said that their siblings would not like to accompany them because they were shameful of having disabled siblings.



A transgender woman was not allowed to go out together with her partner and was suffering from physical and psychological abuses. Another transgender woman was often beaten and subjected to verbal and psychological abuses by her parents and sisters. They looked down on her sexual orientation and behaviour.

When asked “have your parents forced you to get married for your disability or sexual orientation?,” 6.3% of the total respondents were forced to get married for their sexual orientation and disability whereas 87.5% had the chance to manage their marriages as their wished, 3.7% of the respondents gave no response, and 2.5% “don’t know about that.”

When asked “is there any denial of your marriage for your disability or sexual orientation by your parents?,” 21.3 % of the total respondents were denied marriage for their sexual orientation and disability by their family, especially their parents, whereas 68.8% had the chance to manage their marriage as they wish. Around 10% of the respondents had no response for that.

There is a transgender woman who was once forced to join the army to become strong and behave like a man. Her parents believed that she would be manly and change her feminine behaviours. Then a marriage was arranged with a girl by her parents with the aim of leading a manly life.

Another transgender woman who was living with her partner was told by her family that her partner would get married to a woman and it would be a shame to live together with her partner. And she would not get true love from her partner and he was with her only for money.

Some PWDs shared their experience that their parents prohibited them from marriage as they thought that their PWDs son/daughter were not able to get married and have children of their own. Some parents thought that there would not be a happy and reasonable family in marriages between PWDs. Some worried that their disabled children would have troubles if they get married.

When asked “have you experienced any mocking of your disability or gender expression in your environment?,” 67.9% of the total respondents had suffered from verbal abuse for their disability and sexual orientation whereas 29.5% had not; 2.6% did not have the desire to answer that.

Most of the respondents suffered from verbal abuses for their disability and sexual orientation and some even experienced harassment and violence in the environment. A lesbian was told by her friend that she did not dare to share the room with her and sleep with her in the same bed. A disabled gay person and a transgender man said that they were discriminated against and experienced violence more than others.

Some LGBTs were greeted with shameful pronouns of their sexual orientation and disabilities. For example, a visually impaired person was abused by being called “the blind.”

When asked “have you experienced any exclusion in your social activities?,” 42.5% of the respondents were excluded in social activities whereas 51.2% could blend and cooperate with others in activities, 2.5% of respondents don’t know about that, and 3.7% gave no response.

There was a bisexual person who was always treated with contemptuous behaviour. A disabled gay man was verbally abused by comments like “oh, he is a blind and even a gay then,” or “such a bitch guy.”

#### **4.6.5 Accessibility**

Statistics show that just a small percentage of the total respondents (15%) had access to public places such as banks, hospitals, shopping centres, and toilets whereas most of the respondents (82.5%) were excluded from public places.

When asked “can you access Express Buses, trains and ships to travel?,” 36% of the respondents could access public transportation such as buses, express cars, trains, and ships whereas 58.7% could not, 1.2% gave no response, and 3.7% did not know about that.

When asked “can you access religious buildings including pagodas and monasteries?,” 42.5% can access religious buildings whereas 55% cannot, 1.2% gave no response, and a further 1.2% “don’t know about that.”

Statistics show that just a small percentage of the respondents (only 2.5%) think that they have access to human rights in general whereas 71.3% said they did not have access to human rights.

#### **4.7 Recommendations**

The “Survey Report on Discriminations on Disability and SOGIE” explored the discrimination experienced in different fields. There were recommendations given by respondents of PWDs and LGBT persons with the aim of eliminating discrimination and promoting inclusion.

In the education sector, most of respondents remarked that the attitude of accepting was essential for inclusion. Some mentioned that wheelchair accessibility, sign language interpreters, tactile paving, assistive devices, and the rising public awareness were crucial to eliminating discrimination. Some remarked that the teaching strategy, techniques, and teaching-aid materials should be considered to be accessible for all, teachers should be trained, and inclusive teaching strategies should be practised for different types of disabilities and the rights of the minority groups. In addressing the peer-to-peer discrimination, emotional and physical abuses, and harassment to PWDs and LGBT persons, the ethics of the teachers and knowledge of human rights, especially the awareness on disability and SOGIE among the teachers and the students, are needed.

On the discrimination in job opportunities and the workplace, it was found that the gender-based discrimination for LGBTs and lack of belief in the ability of PWDs influenced the workplace. Some transgender men’s recommendations are that they deserve to get the same salary rate as other men if they can perform their job as well.

In the social inclusion sector, there are two types of discrimination: one caused by family and one by society. The PWDs and LGBT persons are not allowed to make their own decisions in life. Most respondents recommend

that it is necessary to raise public awareness, including family members, and to make laws effective and promote the anti-discrimination law for LGBT persons.

In the sector of accessible infrastructure such as public transportation, some respondents recommend that the government and ministry of construction should regulate the universal design and building code. For gender and sexual orientation, public awareness should be raised and the attitude of society should be changed, and the society should view such orientation from the point of human rights instead of customs and norms.

Furthermore, it is necessary that there be more cooperative activities between PWDs and LGBTs and more survey data is needed to explore the discrimination against disabled LGBTs. We should make them come out in the society and try to protect their rights by enacting and implementing anti-discrimination law. LGBTs and disabled persons' organizations should collaborate together to combat these discriminations.

#### **4.8 Conclusion**

Myanmar has transformed gradually on the practice of democracy and federalism which values diversity in race, ethnicities, and religions since the 2010 General Election. Therefore, it is hoped that there will be a positive change to realize equal rights of the citizens, especially for the minorities including persons with disabilities or LGBT persons, regardless of sex, colour, and religion. The Union should raise the awareness of the rights of minorities and empower them in the society based on human rights, rather than from the perspectives of religion, traditions, and customs.

This survey report describes and reflects how the PWDs, LGBT persons, and LGBT persons with disabilities are being discriminated against in sectors of education, employment, accessibility, and social inclusion in Myanmar. The LGBT persons with disabilities are being discriminated against more than the PWDs and LGBTs. This survey is the very first one about the intersection of PWDs and LGBTs. We need more cooperation and mutual understanding between the disabled persons' organizations and LGBT organizations as there are rarely intersection activities and cooperation between them.

In conclusion, the Universal Declaration of Human Rights (10 December 1948), a global road map of freedom and equality, states that everyone deserves to be granted the essential basic rights: right to equality, right to education, right to work, right to social security, right to personal integrity, right to freedom of opinion and expression, freedom from discrimination, and right to participate in community.

Part II

# Intersectional identities



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# 5 Body image, gender, and disability in Chinese community services

*Yujiao Peng*

## 5.1 Introduction

This article mainly discusses gender, body image, and the disability philosophy that applies to Chinese community services. The perspective of culture ideology has a huge influence on self-awareness for persons with disabilities. The mainstream aesthetics is also one of the main factors affecting the evaluation of self-appearance for women and girls with disabilities. Most of them feel that their body betrays their soul. The consequence of the conflicts between their appearance and the mainstream aesthetic results in depression among disability communities. Every woman and girl with disabilities needs to be empowered. The first step is self-awareness and self-esteem. This article tries to explain how to change the negative self-identity of disabled women and girls to positive self-identity, through different forms of empowering activities. The research methods of this article include literature review and case interview.

## 5.2 Background information

The word “disability” is generally used as a term for a physical or mental condition that limits a person’s mobility, senses, or the ability to engage in certain activities. Though the term of “disability” also carries important legal implications, the focus of this discussion is more about culture ideology and mainstream aesthetic.

The Chinese government and civil society have both done a lot of work to ensure rights protection of those living with disabilities, such as the rights of equal access to health care, employment, housing, and education, but there remain challenges, particularly in the sense of stigma and the perceptions of disability.

The work of NGOs is important for rights advocacy and awareness raising for women with disabilities. Beijing Enable Sister Center is a Chinese DPO (disabled persons’ organization) based in Beijing and serves women with disabilities.

This article will first analyze how culture ideology and mainstream aesthetics view persons with disabilities. Then this article will talk about its consequent

negative effects, especially on women with disabilities. In the last part, this article will introduce different projects that Beijing Enable Sister Center has carried out to empower women with disabilities to increase their self-esteem.

### 5.3 Cultural perceptions and mainstream aesthetics

People live in a very visual society, surrounded by images that are considered as perfect. And generally, disability is not part of those images. Disability is defined as “different” or, at worst, “inferior.” People with disabilities are considered as imperfect. People with disabilities do not fit the perfect mode. In Asian culture, people with disabilities are often thought of as being sickly, feeble, and fragile with an unfunctional body. These negative perceptions and stigma invade almost every aspect of people’s cultural values, from the daily life they associate with, the performance of traditional masculinity and femininity, to beliefs about what is beautiful and what is strong (Taub et al. 2003).

In the mainstream aesthetics, men are expected to be muscular, strong, independent, athletic, and dominant. Women are expected to be thin, tall, traditionally attractive, sexy yet virginal, motherly yet youthfully attractive, feminine and submissive, decorative, and without opinions. People with disabilities may not be considered masculine or feminine enough. Disability often means that people are seen as nonsexual and always unattractive. This can free them from the pressure to achieve the perfect male or female body, or it can make this venture much more difficult.

Body is a very important part for most women. Asian women are required to be white and thinner. It’s a strong message that they internalize and repeat to themselves. When it comes to disability, people can be limited in terms of the disability types they have. Medication often leads to weight gain or loss, or skin problems. And the prevalent message they hear every day is that being disabled is their personal failing. They carry the burden of being disabled. And they are too far from being able to meet the beauty expectation (Nosek et al. 2003).

Women are often considered spoiled if they are beautiful and disabled: “Oh, she’s beautiful, it’s such a pity she’s in a wheelchair.” The narrative that those with disabilities should be asexual and shouldn’t be in romantic relationships can strip them of a sense of desirability. This is important because so often they are judged, or judge themselves, on who wants them (Turner 2001). Most women with disabilities find it easy to list negative physical aspects of their body.

Beibei, a wheelchair girl with a scoliosis, describes that her injury directly affects every aspect of her body image in our interview. “It directly affects every single inch of my perception of my body, how I think about it, how I act towards it, how I feel about it. It affects every inch of me.”

Beibei was once as pretty as a popular star. Since her injury, she has tried to save her appearance. Unfortunately, most aspects of her appearance changed for the worst, such as her back (due to rod placements eliminating her feminine

curvature), legs, buttocks, and skin (due to rashes and pressure sores). Her arms have become bulkier with muscle since the injury due to constant wheeling and transferring. Her frustration stems from not being in line with the thin ideal, as bulk is not found to be socially desirable in women.

However, most of the disabled men are satisfied with the size of their arms and shoulders because they are larger, which is consistent with the cultural male ideal. They also consider their wheelchair to be an important aspect of their appearance.

I've been feeling a lot better since I've got a different chair ... The chair you're in makes a huge difference on how you look at yourself. In my old chair, I used to be slouching. Now I look more upright and elegant and it makes such a difference.

Another wheelchair girl also mentions the importance of being in a manual wheelchair compared to an electric wheelchair. She says,

My therapist wants me to sit in a power chair and I tell my therapist "Well I don't really want to be in a power chair, I want to use a manual chair because it looks cool." Although manual chair looks cool and is easy to carry, some imported manual wheelchairs are still too expensive for me to buy.

Beibei says, as a woman with disability and sitting in the wheelchair, if she wants to live an easy and elegant life just like those without disability, she needs to try her best to make twice the salary of an ordinary girl, and she needs to buy a modified car and an imported electric wheelchair booster to achieve her elegance.

#### **5.4 Consequent negative effects**

These unique and almost invisible social challenges that people with disabilities face have a profoundly negative impact. Some consequent negative effects are as follows.

##### *5.4.1 Self-esteem impaired*

The factors that make up people's self-esteem are complex. But a common factor is their appearance, or how they feel about their appearance. Bodies may declare disabilities. Even "invisible" disability can damage their self-esteem.

##### *5.4.2 Sense of betrayal*

People can feel like their body is betraying them, and their body is the property of other people especially when other people wash it, dress it, undress it, and feed it. They might feel their privacy and physical space is regularly "invaded" by caregivers, doctors, physios, etc. All add to the feeling of loss of ownership of one's body. Increased need for assistance has been shown to



relate to negative feelings about the body dominance (Thomson 1997). Beibei says, “I used to get so angry at my body because I couldn’t do what I wanted because of my cerebral palsy. I felt like my body was failing me.”

#### *5.4.3 Body disconnection*

Their body can be the very part of a medical battle. It becomes a medical vessel, which contains possible pain, intrusive intervention, humiliation, and the ongoing, repetitive conversations about what’s wrong with the body rather than loving part of the body. Some women with disabilities say that they do not want to touch their lower body. They, emotionally and perceptually, describe their body as a machine. They feel desensitized to private aspects of their body, or they never want to see their lower body in a full-length mirror.

#### *5.4.4 Depression*

It is not unusual for a disabled person to experience depression or feelings of inadequacy as a result of their experience. Some suffer from those feelings all the time. Depression can affect sleep, diet, work, relationships, and overall health. It can impact the quality of one’s life. If people feel that they are spending too much time worrying about their body, it may be time to consider asking for help. Though issues like body image and psychological well-being are not generally a focus or priority in the health care system, they should be.

#### *5.4.5 Self-presentational concerns*

Some girls with disabilities have some sort of self-presentational concerns. Being perceived as “normal” or independent by others is important to them.

Some girls with disabilities are preoccupied with ways to enhance physical features to be perceived as more attractive by the opposite sex. Some methods used by these girls include being fashion conscious, wearing make-up and jewellery, and using clothing to hide or accentuate certain features. Some even get facial shaping surgery. They describe the surgery as a way to compensate for the physical disability. If they are not injured, they may not have considered seeking this type of surgery.

Beibei is always preoccupied with her physical attractiveness. She feels much less confident since her injury and becomes more self-conscious about how she appears to others. For example, Beibei said, “I am thinking ‘what man would ever want me? how am I going to get a boyfriend?’ I am all disfigured.”

Clothing is the main method described to enhance or conceal certain features, but some more dramatic methods like plastic surgery are also discussed by the interviewees. They have a strong motivation to be perceived as “normal” by others. Girls are very consciously aware of how their body appears to others and would engage in tactics to appear more “normal.” It seems that the cultural standard to look “normal” can be so powerful that some people

with physical disability may minimize association with other disabled persons because they fear that will threaten their desire to be perceived as “normal.”

## **5.5 Empowering projects**

People have the power to change their experience and make a difference. What Beijing Enable Sister Center does is to use some social work services to empower women with disabilities to improve their perception of body image, transform their internal oppression of physical stigma into the driving force for self-presentation, and let them become dignified people in a diverse society.

Beijing Enable Sister Center has conducted different empowering projects, such as the inclusive drama, portrait exhibition, and body defence activities.

### *5.5.1 Inclusive drama*

The inclusive drama is a good tool for people with physical or mental disabilities to recognize the identity of themselves, the external image, and the identity of the disability. A woman with physical disability in Guangzhou thinks that drama has helped her to regain her awareness of her own body. She gradually moves to the stage from a disabled person who was actively or passively hidden by society. The process of playing the role is also a process of being seen from the ground and being involved in social integration.

By stage drama performance, participants undergo mental changes which are subtle and positive, from self-doubt to self-acceptance, from self-acceptance to self-affirmation, and finally to the promotion of other disabled women to participate in the process of theatrical performance. The inclusive drama breaks stereotypes through the healthy and charming role of people who define the key perspective, adds the role of disability to the script, and incorporates the disability perspective into the mainstream life and mainstream script creation.

### *5.5.2 Portrait exhibition*

“Portrait exhibition of women with disabilities” is a project that emphasizes the physically impaired part of their body and their life stories through photo shooting and oral narration.

The method of photo shooting is to invite the photographer to focus on the physical challenges of women and girls with disabilities. Through photographs, the unconscious legs, the amputated part, the eyes, or other body parts that are not considered by mainstream society are redefining and treating themselves. Women with disabilities learn to accept their body as part of the fragile oneself. This is one of the important reasons to take pictures of their body and show their disabilities.

Oral narration is to let women with disabilities share their stories, such as being a scoliosis person, or being a wheelchair user. Different types of

disabilities may bring different experiences to these women in their daily lives. There are both good and bad experiences of their disabled bodies. Through oral narration, women with disabilities talk about the obstacles and the challenging parts of their bodies, about how they get along, and how they touch the hearts of people behind them.

For example, there is a girl who had 60% of her skin burned due to the fire. Her fingers were burned but her face was unhurt. She says,

People see the skin inside my clothes and my uninjured face and say that it's a pity that a perfect girl is ruined, they don't understand what I have suffered. I am still alive with a decent job and I work hard to make a living. People only sympathize with your misery. I can't show my injured hand inside my sleeve, but in portraits, I know I should show the whole me, including my uninjured face and my scarred body, as well as my experience and life stories. In today's world where everyone focuses on good looking and slim body, the presence of burned victims and other disabled people can be the rebellion against the mainstream aesthetic.

In the portrait exhibition of women with disabilities, the disabled women will not be objects to be gazed at, but active participants in the exhibition planning, and they actively present their imperfect bodies to the public. This is a challenge to the traditional stereotype of disabled women as fragile and incompetent, and also a challenge to the stereotype of weakness based on female identity and weakness based on disability identity at the same time. The women presented in the exhibition appear as proactive and powerful in the public vision, which also reflects on the advocacy of Article 6 of the Convention on the Rights of Persons with Disabilities because it is very important for women with disabilities to fight against discrimination.

Moreover, their life stories in this portrait exhibition not only bring healing to the individuals who are photographed, but also encourage the visitors to think deeper on personal identity and human nature.

### *5.5.3 Body defence activities*

In our workshop on leadership for women with disabilities, we also involve women's body defence activities. Most women with disabilities believe that they are vulnerable, easily bullied, not capable of resisting, and in need of protection. From a certain point of view, they are indeed in such situation. But strengthening this belief may bring more harm to these women because they will internalize the stereotypes and genuinely believe that they are weak and in need of protection, and thus they won't have any defences or awareness when they encounter potential harm.

Disabled women's self-defence techniques, such as the wheelchair Kungfu, or the deterrent training, fighting, and martial arts training,

confirm that disabled women can feel the strength of re-exercising their own body and build a sense of strength that their body can use. These techniques let them know from the consciousness of the body to inner empowerment and inner self-confidence. When their muscles become powerful, their confidence will spontaneously emit from their face. There is a saying that people are born by heart. In fact, a more powerful appearance will give people more confidence. In our leadership project, we also hope that these women can feel the power of their own hearts and their bodies, which will also help enhance their leadership ability.

However, it is also important that we should not strengthen another stereotype which only admires strength. There are disabled women who do not have any sense of strength in bed. Therefore, in the process of self-defence training, we will let participants know that they all have done their best. There is no unified standard of what is best. This is what we expect in the future to integrate into society.

## 5.6 Conclusion

More and more research has confirmed the unique challenges people with disabilities face with regard to self-esteem and body image. At the broadest level, studies have found that physical disability, in particular, has a negative influence on people's psychological experience, attitudes, and feelings about their own bodies. In the context of the modern body politic, the body is the container of one's spirit and will, which is also the political tool used by rights activists. But if people transform the negative perception of the disabled body to the positive one as a strong advocating weapon, it may break the stereotype of the fragile, unlucky body as well as gender issues (Gerber 2020).

People with disabilities deserve attention from mainstream society, no matter their images are strong or fragile, beautiful or bizarre, and no matter what kind of advocacy method is used to present their images. Beauty is never just a standard. The beauty of human beings is defined by human beings themselves. We need to keep challenging the traditional view of what is beautiful and what is strong.

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# 6 Difficulties disabled women in Japan face with regard to love, marriage, and reproduction<sup>1</sup>

*Naoko Kawaguchi*

## 6.1 Introduction<sup>1</sup>

The sex lives and sexualities of disabled women in Japan are hidden or invisible. This paper explores the difficulties faced by disabled women in Japan with regard to love, marriage, and reproduction. By interviewing disabled women, it is found that disabled women in Japan have difficulties in carrying out the dominant gender roles, finding love, and satisfying their sexual desires. Gender discrimination against disabled women in Japan is overlooked and not properly addressed. However, it is also found that disabled women in Japan are not merely subjects of discrimination; disabled women try to find ways to survive despite their discriminatory circumstances, such as meeting role models, uniting as residents, and having someone who understands and supports them.

## 6.2 Background information

### 6.2.1 *Concept of intersectionality*

This research utilizes the concept of intersectionality, which means to view the matter as an intersection of gender, “race,” and other (age, poverty, disability, etc.) types of discrimination simultaneously; that is, issues are not analyzed based only on one ground or separately.

“I began to use the term intersectionality to deal with the fact that many of our social justice problems, like racism and sexism, are often overlapping, creating multiple levels of social injustice” (Crenshaw and Dobson 2016). The concept was originated by Kimberle Crenshaw, an African American woman academic and lawyer in 1989 (Crenshaw 1989). Crenshaw tried to explain the case that a judge dismissed Emma DeGraffenreid’s lawsuit against an employer who was practising job discrimination against African American women. No African American women were hired but the court failed to see this double discrimination because African American men and white women were hired. Crenshaw argued, “that Black women can experience discrimination in ways

1 This article was originally published in *Ars Vivendi Journal*, no. 11 (March 2019: 48–60).

that are both similar to and different from those experienced by white women and Black men” (Crenshaw 1989, 149).

Disabled women may face discrimination differently from disabled men or non-disabled women.

### *6.2.2 Legal framework*

Currently, Japan lacks a comprehensive legal framework for addressing multiple/intersectional discriminations. It also lacks affirmative actions to avoid multiple/intersectional discriminations (Asakura 2016).

In 2013, an anti-discrimination act for people with disabilities was enacted in Japan; it was implemented in 2016, though it made no mention of the complexities/intersectionalities of discrimination.

For gender equality, there is an employment law that prohibits gender discrimination in the workplace; however, there is no comprehensive anti-discrimination act to deal with gender discrimination.

## **6.3 Objectives and methodology**

The interviews analyzed in this paper were conducted as part of the ongoing research by JSPS KAKENHI (Grants-in-Aid for Scientific Research) on the “Intersectional Approach for Structural Discrimination against Disabled Women” (<http://www.nabe-labo.jp/wwd/index.html>) from 2016 to 2019. A brief explanation of the research project “Intersectional Approach for Structural Discrimination against Disabled Women” is provided as follows.

### *6.3.1 Objectives*

The KAKENHI research project aims to identify discrimination against disabled women not only within the dimensions of “disability” and “gender” but also within the interlocking of other positionalities. At present, there is not enough data dealing with this issue collected in Japan. Thus, it is necessary to collect data related to disabled women’s narratives before identifying any intersectional discriminations.

### *6.3.2 Methodology*

The KAKENHI research project employed the “snowball” sampling method to gather the informants. The research members approached potential informants for the research through Disabled People’s Organizations, Service Users Groups, and various kinds of networks. Sometimes a woman who had been interviewed would kindly introduce the researchers to another disabled woman. The researchers tried to find informants across diverse impairments and age groups.

The interviews were conducted from December 2016 to March 2018, and as of March 2018, the research members have interviewed a total of 25 disabled women.

During the research, the following steps were taken. First, the researchers asked the interviewees to complete a profile sheet. For comparison reasons, some of the questions were taken from the official disability survey of the Japanese government (Government Official Disability Survey, available from [https://www.mhlw.go.jp/toukei/list/seikatsu\\_chousa\\_h28.html](https://www.mhlw.go.jp/toukei/list/seikatsu_chousa_h28.html)).

There were two to four researchers for each interviewee to conduct the semi-structured interview. Every interview lasted for about two to three hours.

The researchers did not define discrimination or oppression against disabled women in advance. The disabled woman being interviewed would decide what was hard or difficult in her life, what she considered as a disadvantage, the points at which she thought that things had become worse, and the experiences that she found painful. Researchers thus listened to the lived experiences from each disabled woman's perspective.

In KAKENHI Research, the interviews cover a wide range of topics related to disabled women's lives: life history, daily life, and social life (e.g. employment/social activities). The researchers asked the interviewees when and how they feel disadvantaged compared to disabled men and non-disabled women. And the research tried to grasp not only disabled women's personal perspectives but also the socio-economic situations they faced.

### *6.3.3 Privacy and consent*

Before the interviews, the researchers received written consent from the interviewees. The privacy of interviewees would be protected when researchers disseminated the results of the research. In addition, interviewees were free to quit the research at any time.

## **6.4 Research results**

The KAKENHI research project aims to investigate the overall picture of the difficulties disabled women face and the intersectionalities in their difficulties, while this paper focuses more on personal spheres such as sexualities and reproduction.

In this paper, I have extracted findings from the narratives of 12 disabled women whom I interviewed with regard to love, marriage, and reproduction.

The sex lives and sexualities of disabled women in Japan are hidden or invisible. In these interviews, I was barely able to hear the words "sex" and "sexualities" overtly. Disabled women I interviewed intended to talk about their difficulties, not limited to the subjects such as sex lives and sexualities. Hence I did not use the words "sex" and "sexualities" in the title of this paper, and this absence itself indicates the current situation of disabled women in Japan. Nevertheless, I was able to obtain some narratives involving subjects



such as “love, marriage, and reproduction.” These narratives can provide useful insights regarding the sex lives and sexualities of disabled women in Japan.

#### *6.4.1 General information*

##### (1) Impairment

Main impairment: physical 6; visual 2; mental health 4 (Notes: some of the women have multiple impairments. Besides the four women with mental health problems, four other women had experienced mental health problems at one time in their lives, though these conditions were not continuous.)

##### (2) Age

20s: 1; 30s: 2; 40s: 2; 50s: 4; 60s: 2; 70s: 1

##### (3) Onset of impairment

Childhood: 5; 10s: 2; 20s: 3; 30s: 1; 50s: 1

##### (4) Employment status

General employment (counted as a legal obligation of disabled people): 4;  
Sheltered employment type A (guaranteed above the minimum wage): 1;  
Sheltered employment type B (workshop; not guaranteed the minimum wage): 1;  
Teleworking: 2;  
Other: 4

#### *6.4.2 Love*

##### *6.4.2.1 Body norms: devaluation as a love interest*

Disabled women feel that they are devalued as love interests because their bodies are “deviant” compared to “normal” bodies.

##### (1) Appearance

Some women with physical disabilities find it difficult to maintain a positive self-image regarding their bodies. A woman with mental health issues felt stressed when she had to maintain a tidy appearance.

“I think my appearance is bad.” (Physical)

“I think I am ugly. My body did not develop properly as a woman’s body should.” (Physical)

“Women receive more criticism and feel damaged than men if they are not clean and decent. I can go out only when I am well-groomed. But it is so hard for me to do so. Men can go out more easily.” (Mental)

(2) Dressing up or being fashionable

Disabled women feel that they are regarded as asexual beings. Thus, their daily circumstances have created barriers to their enjoyment of fashion compared to non-disabled women.

A woman talked about her experience in an institution for the physically disabled.

“All the clothes were washed with a huge washing machine (like a concrete mixer), so it was impossible to wash beautiful clothes. I did not want to have my hair cut by the staff of the institution. I went to a good hairdresser when my parents came.” (Physical)

Another woman said that disabled women tend to give up on being fashionable, but she resisted that.

“People may feel pity for a woman in pyjamas at a restaurant. People may feel it is a breach of manners for a non-disabled woman to do so. I never want to be looked at with pity. I want to maintain the average level of fashion in my age group.” (Physical)

Another woman thought that people labelled her as disabled no matter what she wore.

“Does anything change if I dress up? I thought it was meaningless.” (Physical)

(3) Denial of femininity and sexual existence

“When human beings are divided into categories such as men and women, I do not feel I belong to either categories. From my perspective, human beings are categorised into men/women/disabled.” (Physical)

“I was never told ‘You are female. Be ladylike.’ Rather, wasn’t I recognized as a woman? I was not treated as a woman.” (Physical)

“My parents told me, ‘You shouldn’t expect love or marriage.’” (Physical)

Sometimes this denial of the femininity of disabled women intensified their desire for love or marriage, which is traditionally seen as the women’s *raison d’être*, much more so than the same desire of the non-disabled.

“I wanted to marry even if it could last for only three days.” (Physical)

6.4.2.2 *Affection, care support, and privacy*

Practical problems emerged when disabled women who needed care and support from personal assistants (PAs) thought of love.

When they establish intimate relationships with their partners, finding ways to get appropriate care support becomes a crucial matter. Disabled women do not want care support from their partners, but at the same time, they want to maintain their privacy. Disabled women find it difficult to satisfy both needs.

“I separated from my boyfriend when my disease worsened, and I started to ask for consistent care support. Our relationship changed, and it became unequal. I could not bear that. I didn’t want to be a burden to him.” (Physical)

She added that she would have married him if she had not suffered from her disease.

“I’m opposed to the connecting of affection with care support provision. If you regard care support as an expression of affection, you will be so exhausted when you quarrel with your boyfriend.” (Physical)

“I want to forget my impairment when I am in a romantic relationship. I dream about dating without having to consider the accessibility of trains or restrooms.” (Physical)

“I never want to be cared for by my boyfriend. I want to have my PAs carry out my care support. Then, how we (me, my boyfriend, and my PAs) will be able to stay together...I have no idea.” (Physical)

### 6.4.3 *Marriage*

#### (1) Marital status

Single (no experience of marriage): 6; married: 3; divorced: 3

#### (2) Children

Having children: 5 (divorced and raising the child by herself: 1; divorced and raising the child with an ex-partner: 2);

Having no children: 7

#### (3) Experience of marriage

(Before or after the onset of impairment/ where she met her partner)

Before the onset of impairment: 2;

After the onset of impairment/the university she graduated from: 1;

After the onset of impairment/social circle for people who have the same impairment: 1;

After the onset of impairment/matchmaking meeting for the general population: 1;

After the onset of impairment/matchmaking meeting for disabled people: 1

In the interviews, out of 12 women, five talked about their experiences in matchmaking meetings they had attended. Two women married through matchmaking meetings. “Matchmaking meetings for disabled people” are also held by some organizations; these are some of the main opportunities for disabled people to marry. Sometimes parents (mostly mothers) of the disabled people attend the matchmaking meetings.

However, rather than for disabled women, these meetings seem to be tailored towards the needs of disabled men (and their parents). For disabled women, this can lead to disempowering experiences.

Experience of matchmaking meetings 5;

Got married 2

- Attended matchmaking meeting for the general population

“A friend wanted to attend a matchmaking meeting with me. My husband and I became a couple thanks to a meeting. He wanted to marry, so we met at the right time.” (Mental)

Before she got married, she told her potential groom about her mental disease, but she did not tell his family. His family learned about her disease when her mental condition started deteriorating, and this angered his family.

- Attended matchmaking meetings for disabled people

Their parents also attended the matchmaking meeting.

“Compared to the other attendees, my impairment was mild, so many men approached me asking for dates. I chose the man my mother recommended.” (Physical)

There were some families looking for a bride for their disabled son in order to have a grandchild as a successor for the family.

Disappointed 3

Three women who attended matchmaking meetings for disabled people were left disappointed.

“I expected to meet someone nice. The man who asked me for a date was more severely impaired than I am. His mother (not he himself) said to me, ‘Please marry my son and take care of him.’ I drew back in surprise.” (Physical)

“I once attended such a meeting with my friend. I could hear the male attendees whispering that women should be good at housework and cooking. So, we realised that this meeting was not for us. There was no space for finding a life partner. It was so disappointing.” (Physical)

“When I attended the meeting, I found myself like a counsellor, and I listened to the worries of the male attendees. I want to meet a man who has no connection to the field of social care but who can look at me the way I am (not as a disabled person).” (Physical)

Disabled women are expected to carry out housework and perform care roles, even though they have disabilities. On the other hand, because of their disabilities, disabled men are not expected to carry out housework and perform care roles.

#### (4) Family members’ attitudes towards marriage

- Opposition

Some women experienced opposition from their partner’s family.

“His mother said that he might experience unnecessary hardships if he married a disabled woman like me.” (Physical)

“His family opposed our relationship when I told them that I could not have a child, even though he had the same impairment. He decided to break up.” (Mental)

- Promotion

Sometimes the families of disabled people can be the promoters of marriage. Some parents of disabled men look for brides of their sons in order to produce grandchildren as successors for the family and to honour their family names. Some parents of disabled women think that marriage can guarantee lifelong financial and social security for their daughters.

However, these marriages may reinforce gender roles, with women being expected to carry out the conventional gender role-related duties such as housework and care work for their husbands’ families after marriage.

“I wanted to give birth at my parents’ house (as same as non-disabled women), but I couldn’t. My mother in law did not allow me to do so.” (Physical)

A woman was expected to live with her husband’s parents, and not separately as a couple with her husband. Having disabilities was used for a reason to justify this decision. Her husband did not support her in housework or child-rearing not only because he had a disability but also because his mother allowed him to avoid fulfilling such roles. When she divorced him, she was unable to take her children with her.

#### 6.4.4 *Reproduction*

##### (1) Dealing with menstruation

Some women experienced hardships when they had to deal with menstruation.

“I began to experience the hardships of women soon after I got my first period. Some carers put a sanitary pad on me very carefully, but others put it on me roughly. When there was a leakage, the carers would put multiple layers of pads on me (instead of changing the pads more frequently). I felt uncomfortable, and it annoyed me very much.

Moreover, a nurse in the institution asked me, ‘How about getting a hysterectomy done to stop the menstruation?’” (Physical)

She did not accept the nurse’s recommendation, but there were some who followed the recommendation. (It should be noted that at least 25,000 people were forcibly or involuntarily sterilized under the former Eugenics Protection Act which existed from 1948 to 1996.)

“Nurses in the hospital didn’t care about how to deal with menstruation and continence care. No one taught me.” (Physical)

She could meet a woman with the same impairment to get information instead of the medical professionals in the hospital.

(2) Access to sex education

“In the institution, no one taught me about menstruation, so I was so surprised when I got my first period. Then, I learned about menstruation, but there was no education about sexual intercourse or the function of pregnancy.” (Physical)

“My mother taught me about menstruation. For me, it is not taboo, as I usually ask someone to help me deal with it. Regarding sexual intercourse and pregnancy, the special education high school provided this kind of education. I had to take this class alone from a male Physical Education teacher. He did nothing strange, and we just read the textbook, but I was so embarrassed.” (Physical)

(3) Denial of sexual desire

“I worry about my body in case I have sexual intercourse. But I cannot consult my doctor about such things.” (Physical)

“When the staff made rounds of the institutions, a girl with mild intellectual difficulties played with herself in bed. The next morning, it was known to everyone, and she was called amorous or nasty. Why didn’t the staff respect her privacy? I think that it was not right.” (Physical)

“I felt guilty about masturbating and worried that I was abnormal because of my strong sexual desire.” (Physical)

(4) Pregnancy

Disabled women talked about the barriers they faced when they tried to see gynaecologists and receive appropriate care.

“In addition to psychological barriers, there are physical barriers. We have to consider the accessibility of a lavatory, an inspection bench, and so on. We have to endure an unfamiliar person’s care. I don’t want to be touched by strangers.” (Physical)

“When I had a disease that affects the reproductive functions, I couldn’t receive appropriate care as a woman.” (Physical)

Losing reproductive functions was a big matter for the women, even though physical care, such as hormone therapy, and psychological care were not available.

(5) Medication and drugs

Some disabled women pointed out that the reduction or termination of medication during pregnancy could severely deteriorate one’s health condition. (Physical, Mental)

The risk could spread to their expected babies and, thus, not remain limited within their own bodies. The women themselves and their family members worried about teratogenicity.

#### (6) Parturition

Sometimes, it is difficult for disabled women to find hospitals where they can give birth.

“First, I thought about giving birth at a maternity clinic nearby, but the clinic asked me to go to the university hospital.”

“When I went to see a doctor about the pregnancy, the doctor didn’t say ‘Congratulations.’ Instead, the doctor recommended an amniotic examination, as I was at high risk of having a disabled baby. It was disgusting that the doctor described disabled babies in such a negative way.”

“When I went to the hospital to check whether I was pregnant, a doctor suggested that I should abort my baby because there was a possibility of my husband and I passing our impairments to the baby. I was so shocked, and I said that I would bring my baby into life at any risk.”

#### (7) Respect and recognition for women who are not expected to have children

“In fact, I physically cannot have babies. It is decided, and I have no choice.”  
(Physical)

“My health is my priority. I don’t want to sacrifice my health by giving birth.” (Mental)

Some of the disabled women felt that it would be difficult for them to give birth because of their body conditions.

However, they are not free to overtly express these words, for fear of being devalued as they are unable to perform traditional gender norms.

Once disabled women are recognized as not being able to give birth, they have no access to gynaecological care for issues such as sexual functioning and menopause.

Reproductive health rights should thus cover the lifelong health conditions of disabled women.

### 6.5 Research findings

The desire to have sex and to fall in love (experience relationships and intimacy) are inseparable; self-satisfaction is related to a partner’s satisfaction. These are the points to be considered when analyzing difficulties related to love, marriage, and reproduction.

The “arrows of consequences” are drawn as follows.

Difficulties in carrying out the dominant gender roles ⇒ Difficulties in finding love ⇒ Difficulties in satisfying one’s sexual desires (in the narrowest sense possible).

*6.5.1 Difficulties in developing gender identities and sexualities*

Disabled women find it difficult to establish gender identities because the disadvantages and difficulties of having disabilities are too heavy for them, and this affects their self-identity as disabled women.

How disabled women face difficulties:

Difficulties in carrying out dominant gender roles

+(Plus)

an environment where disabled women have to face the people who do not

accept their impairments and exclude alternative gender roles

= (Equals)

Instability of self-identity as a woman

Finding it hard to live

Disabled women have difficulties in establishing gender identities and sexualities. This does not mean that disabled women do not experience gender discrimination as I've described in this paper. On the contrary, gender discrimination against disabled women is overlooked and not properly addressed.

*6.5.2 Disabled women as subjects with rights who resist discrimination*

It should be noted that disabled women were not merely subjects of discrimination. They tried to find ways to survive despite their discriminatory circumstances.

(1) The existence of role models

"I've met disabled women who have the same impairment like me, who have created families and raised children." (Physical)

"I've met disabled women (disabled for congenital reasons or through accidents) who are cool, fashionably having manicured nails as well as accessories. I want to be like them." (Physical)

(2) United as residents

"I asked a friend who can walk to go to a washstand and wash my dress."

"When the institution tried to bring in male carers for assisting with the bathing, the female residents united to resist this move. We could stop that."

(3) Networking as mothers

"I could make myself understood to the other mothers and build social support networks. We share common ground as mothers."

"My children are a major source of my energy."



## (4) Existence of persons who understand and support them

“When the nurse suggested that I undergo a hysterectomy, I consulted a female staff member I could trust. She said that I shouldn’t do it, as I may meet someone in the future.”

“I met a PA who understood my sexual desire. I began to collect information and contact organizations.”

The survival strategies of disabled women and the identification of intersectional discriminations require further analysis.

## 6.6 Conclusion

This paper describes some of the difficulties disabled women face with regard to love, marriage, and reproduction.

Disabled women face difficulties differently from non-disabled women. Non-disabled women have been expected to follow traditional gender roles such as marriage, giving birth, and child-rearing, instead of pursuing self-realization. This is recognized as gender discrimination. On the contrary, disabled women have been excluded from such roles because of disability. For disabled women, performing such roles has positive meanings, getting out of disability discrimination. In turn, performing such roles could lead to gender discrimination.

Such difficulties are only experienced by disabled women. They would not have faced them if they were disabled men, or if they were non-disabled women. Disabled men and non-disabled women pass through and do not have to notice such difficulties. Moreover, disabled women have been denied their femininity and sexual existence so that they find it difficult for themselves to notice gender discrimination. For that reason, the difficulties of disabled women have not been fully recognized as discrimination on the grounds of both “disability” and “gender.”

The intersectional approach has made it possible to visualize the difficulties of disabled women that have been overlooked before.

In addition, the researchers have made contact with various kinds of disabled women’s networks. Without active cooperation of disabled women’s networks, the research could not have been carried out.

The perspectives of intersectionality emerged from black women’s activism in the United States. Likewise, the research gives the researchers the chance to recognize activism of disabled women in Japan.

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# 7 Construction of disability identity through social media among women with disabilities

*Yue Xu, Chengqing Shen, Jiani Guo, and Wei Tong*

## 7.1 Introduction

This paper presents an examination of the construction of disability identity among women with disabilities through social media within China. The first author started writing blog posts on disability studies' theories on a Chinese online knowledge-sharing platform called Zhihu (知乎 direct translation as "Do you know?") where she also disclosed her invisible disability. Readers were invited to join her disability activism by introducing concepts such as the social model of disability, crip time, and cyborg theory. A few readers with disabilities following her blog then developed an online group discussing issues surrounding disability and accessibility in China. This group has since been a vibrant online community for more than 500 youth and young adults with disabilities throughout China. Their blogs on disability identity and culture now have more than 12,000 subscribers. Through analyzing the process of identity development, this paper presents an effective approach to engage women with disabilities through social media and collective disability activism.

## 7.2 Literature review

### *7.2.1 Identity and disability identity development*

For individuals from marginalized groups, identity development is crucial as they navigate and negotiate with a normative world that punishes the existence of those who do not fit the normative subject (i.e., white able-bodied male). The literature on identity development largely comes from psychology and human development. The majority of the focus is on the individual and their nuclear family. Erick Erickson's eight stages of human development have been highly influential in the understanding of the psychosocial development of an individual. Erickson posits that in adolescence, a child's task becomes "identity vs. role confusion," i.e., developing a sense of self through their navigation of group membership, alienation, and autonomy (1968). Through a sense of belonging to certain groups or communities, and feeling of individual difference and un-subscription of group membership, adolescents develop both their individual and group identities.

Although Erickson's theory has shaped our understanding of the psychosocial development and identity development of adolescents, later criticisms have pointed out that the linear nature of human development in Erickson's framework does not allow for the fluidity of human development in complex and diverse social contexts. The focus of individual development also leads us away from a communal identity and the impact of society on an individual's identity development. Indeed, without looking at social factors such as how race, gender, and disability are viewed in society is problematic, especially when we are trying to understand a group of individuals locating in marginalized spaces due to their bodily differences.

Studies on racial identity may lend us some insights on how disability identity could impact an individual's physical and mental well-being. A recent systematic review on racial identity shows that racial and ethnic identity does have a modest relationship with the well-being of people of colour, especially for adolescents and young adults of colour (Smith and Silva 2011). Ethnic identity was also found to be more strongly related to positive well-being than to negative outcomes. Although the effects of disability identity and its impact on one's well-being are not documented, there is a reason to believe that this crucial intersectional identity could impact a person's well-being.

Disability identity, among the marginalized identities marked by physical and mental disability, has formed primarily in the United States during and after the Disability Rights Movement (DRM). Major legislation such as Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act marked the success of the DRM. As people with different kinds of disabilities and various needs came together to fight for a common cause, "disability" became a political identity. Gill's seminal work further decodes the types of disability identity (Gill 1997). Gill illustrated four different types of integration through her decades of clinical work with disabled people negating who they are and where they belong. The first type of integration depicts a disabled person's feeling of belonging to the society with the legal backing of equal opportunities and accessible environment. This feeling of belonging to the mainstream society does not form a disability identity until the individual integrates with the disability community (the second type of integration), and further reclaims one's disability experiences and rejects the mainstream society's values that deny differences (the third type of integration). The final stage of integration, which Gill named "coming out," marks the individual's proud identification of disabilities, hidden or visible, regardless of which communities they present themselves to (Gill 1997). These four types of integration illustrate elements of identity development that reinforce one another to form a positive and coherent disability identity. It also brings back the communal and collective elements essential to identity development. Similar to the four types of integration proposed by Gill, other researchers have also developed models of disability identity development. Affirmation and acceptance of disability is a recurring theme in the few proposed models on disability identity (Hahn and Belt 2004; Dunn and Burcaw 2013; Forber-Pratt and Zape 2017; Gibson 2006).

Other empirical studies on disability identity development have revealed a few important factors that are associated with the development of disability identity. Zhang and Haller collected survey data from 359 individuals with disabilities on their perception of media's representations of disability. Perceived positive images of characters with disabilities through media were found to be associated with an affirmation of disability identity. Even when the media representations were perceived as unrealistic, this positive affirmation effect still exists. However, negative media representations were linked with denial of disability identity (Zhang and Haller 2013). In another study with disabled activists, the issue of "cure" was explored in conjunction with disability identity. For activists with a stronger disability identity (affirmation of disability versus denial of disability), they were more likely to reject the idea of a "cure" for their disability (Hahn and Belt 2004). Hahn and Belt (2004) also pointed out that people with disabilities lack a sense of "generational continuity," which could allow them to pass on the information and cultural legacies from one generation of people with disabilities to the next.

### *7.2.2 Disability and intersectionality*

The disability identity, however, is often complicated when other identities come into play. Disability studies, along with the DRM, has long been criticized for its whiteness. Chris Bell's ground-breaking work on *White Disability Studies* (2006) pointed out the salient issue faced by disability studies as a field. Bell illustrated how disability studies scholars, or rather, "White Disability Studies" scholars' "unawareness" of their positioning on issues related to race and ethnicity in some way marginalize scholarly works on the intersection of race and disability:

If you enter a room that purports to gather together those interested and engaged in Disability Studies and see not a single person of color present, those people have been left behind or otherwise disinvited. Be still; speak not. Do not draw attention to their absence. Let them be remaindered out. They always have been, and besides, they have probably chosen not to enter the space. (Bell 2006, 279)

Indeed, the lack of disabled people of colour in both the history of DRM and the academic discussions of disability studies in some way forms a social space for these groups different from white Americans with disabilities. Though still in its early stages, research on intersectionality and disability has emerged in the past decade. Intersectionality is a concept first developed by Kimberle Crenshaw (1991) to capture the complex experiences of women of colour in the intersection of race and gender. Since then, it has been widely used as an analytical tool to critically study the intersectional positions of people with various layers of identity deemed disadvantaging. The racialization of disability has been well documented, both historically and in the current US special education system (Artiles 2013; Bolaki 2011). Other studies have documented increased levels of discrimination experienced by people

of colour with disabilities compared to people of colour without disabilities (Mereish 2012). In addition to the discussion on race and disability in the United States, some studies have also looked at how disability intersects with other identities in the developing world. For example, Nguyen and Mitchell analyzed how the intersection of gender and disability plays a role in the exclusion of girls with disabilities in Vietnam. In their analysis, they argue that for girls with disabilities in a patriarchal society like Vietnam, studying disability without gender means overlooking the significant disadvantages faced by girls with disabilities (Nguyen and Mitchell 2014). Much work is needed on the intersectionality of disability and gender around the world, especially for the developing countries of the global south.

### **7.3 Disability and gender in China**

Little is known about disability identity in China, especially regarding women with disabilities. According to the Conventions of Rights of Persons with Disabilities (CRPD) State Party report, China (mainland) defines disability as individuals with physical, mental, or cognitive disabilities, or chronic illness, whose impairment interacts with other environmental barriers that prevent one from equally and fully participating in social activities. There are approximately 85 million people with disabilities in China, with an estimated 40.19 million women with disabilities. Although China's fast economic development has advanced many people's quality of life, most people with disabilities still struggle with poverty. The majority of China's disabled population resides in under-developed rural areas where limited accessible infrastructure is available (Peng et al. 2010).

In 2015, a disabled female poet's verse "Crossing Half of China to Sleep with You" became viral on the internet. Yu Xiuhua, the author of the sensational poem, talks about her body and her experience of marrying a man that her family deemed fit to her, who was homeless. Growing up with cerebral palsy in rural China, Xiuhua never had the resources and support to pursue education. Her poetry stitched together bodily and mental pain, as well as sexual desire and salient emotions within the daily grind of rural life in China.

The reason we call Xiuhua Yu the first female disabled body in China is not because of her fame, nor because of the controversy caused by her poem openly expressing sexual desires in a still sexually conservative China. Her body, emotions, as well as her experiences of disability and urge for freedom, are present in her poetry, which separates Yu from other famous women with disabilities from China who often become inseparable from their inspirational objectification from the media. She resisted labels such as "female poet with cerebral palsy." She did not allow the objectification and the cliché making of "inspiration porn" by the media as her fame increased. She chose to divorce her husband by arranged marriage instead of following the cultural norm of a "good" woman, even when her terminally ill mother strongly opposed it. Though with her pain, emotions, and body "out of control," she constantly

attempts to gain control of her life. We are aware that many disabled Chinese women probably show similar tenacity in controlling their lives through both physical and cultural barriers. However, Yu was the first coming to fame without hiding her disability or letting it strictly become inspiration consumed by able-bodied audiences.

Issues faced by women with disabilities in rural China were captured in Yang's ground-breaking work "Disability Identity and Marriage in Rural China" (2018). Using grounded theory, Yang explored how disability intimately affects the life of a few women with various kinds of disabilities. Due to the heavy stigma placed on disability in a transparent village environment, disability becomes the primary identifier of women with disabilities and their families by other villagers. Their marriages often reflect the same pattern as Yu, where they or their families purposefully select someone much older, or men with criminal records, or men with disabilities. Selecting candidates with stigmatized identities serves as an equalizer so that women with disabilities and their maiden family could potentially avoid discrimination against them based on their disabilities. After teasing out how disability plays a role in their marriage, motherhood, and their relationships with their mothers-in-law, Yang concludes that situated in the rural village and the intricate familial web, marriage serves as a compensatory factor for these women's disability identity. Disability identity here is diminished or covered up as they become mothers, performing the roles of "good" daughters-in-law and caregivers. These women's experiences showcase the stigma attached to disability in rural China. Suppressing one's disability identity, however, is often not a choice but a necessity to survive poverty in a country without much of a social safety net. Many women with disabilities use marriage as a way to build partnerships with their spouses and their children in order to maintain financial stability.

#### **7.4 Disability identity development through social media**

Despite the hardship experienced by women with disabilities in rural China, much effort has been made to reach women with disabilities. One promising way of engagement is through the internet, where geographical barriers and cultural attitudes could be mediated. Disability online communities in China have been around for at least two decades. In 2005, Guo and colleagues (2005) examined internet use among people with disabilities in China. One of their key findings is that people with disabilities encounter fewer barriers socializing with others, and they are often assumed as able-bodied since they do not openly disclose their disability. The online disability community has since evolved. However, the group we are sharing about in this paper, we argue, is unique in its across-disability nationwide nature, and its focus on disability identity and knowledge sharing. It is also participatory where members of the online communities contribute to peer-support and identity development collectively.



In 2016, the first author, a PhD student in Disability Studies, wrote a knowledge translation blog post called “Basic Concepts of Disability Studies: Open Your Mind Please!” on a Chinese online knowledge-sharing platform called Zhihu (知乎 direct translation as “Do you know?”), a popular platform with 69 million users around the world. The platform selects well-written answers and posts them on their own online media news called Zhihu Daily. This post on disability studies was selected and published on Zhihu Daily and has since gained 10,000 views. A few Zhihu users with disabilities commented on that post and started an online group discussing disability-related issues in China. At the start, the group was full of discussions about what name we should choose and visions of disability in China as well as how to move forward. At the time, founding members internationally put the word “disability” out of consideration for the groups’ names. With a few rounds of discussion, the group decided to call itself “The Minority Pie” (少数派), and started a separate blog called Minority’s Voice (少数派说), which is operated entirely by members with disabilities in China.

The early days of the group witnessed lots of de-isolation and de-stigmatization. Group members shared stories of their experiences that are often ignored in their other social interactions. For example, members discussed how lack of inaccessible bathrooms led to wheelchair users having to “control their bladder” and plan out their day in intricate detail. Others talked about the challenges they faced going through a very ableist educational system. Through the process of de-isolation and de-stigmatization, group members collectively build a sense of disability pride. Although the numbers of disability activists continue to grow after China ratified the CRPD, such collective growth with a large number of people with disabilities online is pioneering. However, the process of forming a positive disability identity is not without challenges. The next section showcases how group members collectively resolve a challenge faced as they develop their disability identity.

#### *7.4.1 From fearing of rights and activism to action*

Though the themes of self-advocacy and peer-support ran from the onset of the group’s formation, members were wary of terms such as “activism” and “empowerment” due to the political atmosphere in China. One of the group’s members was among the activists pushing forward policy changes to enable disabled eligible candidates to become teachers without going through physical exams that often discriminate against disabled bodies. His disability identity and awareness were stronger compared to other members who had just begun to get exposed to topics on disability justice and disability rights. The topics this activist brought up made some members fearful of potential political prosecution. The activist was then removed from the online group. Later on, as the group recognized the importance of policy advocacy and the activist’s valuable work, they invited him back to the online group. This process of negation reflects group members’ collective process of identity recognition



and the building of solidarity among members of the online group. Afterward, the activist played a significant role in educating fellow group members on issues regarding disability policy advocacy and self-advocacy given his rich experiences.

Similarly, this process from what we call “fearing rights and activism” to “embracing rights and activism” is also reflected in China’s women’s rights movements. As Liu illustrated, the women’s rights movements initially marketed themselves carefully with 女性主义 “nv xing zhu yi” (directly translated as “women’s genderism”), which emphasized gender issues rather than “rights” due to the sensitivity of “rights” in post-cultural revolution China. As the movement saw the pressing needs to engage with “rights” and activism, more and more organizations started picking up the term 女权主义 “nv quan zhu yi” (directly translated as “women’s rights ism”) (Liu 2008).

#### *7.4.2 Representation of women with disabilities*

Although members of different gender identities share similar experiences due to their disability identity, women with disabilities often face unique challenges. Such challenges include the lack of confidence in relationships and bodily experiences that are unique to women. Many studies have documented the emergence of China’s women’s rights movement starting from organizing issues around gender to demanding equal rights. However, the literature on women’s rights in China often leaves disabled women out of the picture.

Among the leading members of Minority Voice, women with disabilities have been instrumental in writing and editing blog posts as well as coordinating in-person group gatherings. From 2016 to March 2019, female members of the group have published 84 blog posts. In that time frame out of the 62 offline gatherings nationwide, five of the gatherings were organized by male members of the group while the rest were all organized by female members from all around the country. These actions have led to a vibrant online community with more than 500 youth and young adults with disabilities throughout China. Their blogs on disability identity and culture now have more than 12,000 subscribers. In 2017, the group successfully pushed GaoDe, a Google Maps counterpart in China, to insert accessibility data for subway stations in Beijing. A few members attending college or about to start their college journey collectively wrote a letter to China’s Board of Education to advocate for accessible campuses. Such actions have been reported by mass media such as Phoenix TV, South China Morning Post, and Sixth Tone, to name but a few. Increased media representation of positive disability identity and image in China then leads to more members joining the ever-growing online community. In one blog, where members talked about disability identity, one young woman with a disability said,

I used to be afraid that others may see my body’s differences. I used to try very hard to hide myself as if I can hide disability along with my

body...after joining the group I no longer feel ashamed, and I see my potentials as others show how they live with their disability in a positive way.

Another young woman shared that she “used to feel inferior when dating others and always try to please others.” Joining the community helped her with balancing her self-image and knowing what are her strengths and weaknesses. Such reflections shed light on how collective disability-focused discussions, such as accessibility, crimp time, and the social model of disability, through social media and online peer-support groups can be an effective way of reaching women with disabilities. Positive disability identity is crucial for their social identity development.

Another unique element of this group is that it uses the minority perspective instead of an impairment-specific perspective. More and more impairment-specific peer-support groups have emerged in China, such as China Doll’s Center for Rare Disease. There is no doubt that impairment-specific groups can benefit members belonging to that specific impairment group. However, a disability-focused group stems from the social model of disability where bodily impairment is viewed as part of the individual’s lived experience in context with the social environment in which an individual lives. With such an emphasis on disability rather than impairment, the group welcomed members of diverse disabilities such as mental health conditions, rare diseases, physical disabilities, and developmental disabilities. In addition, the identity formed through a disability-focused group also links the individual with societal contexts, which leads to their recognition of the importance of self-advocacy and collective activism.

## **7.5 Conclusion**

The incubation and the growth of the group lend insight into how collective group identities initiate and develop. Founding members of the group collectively deconstructed their internalized stereotype of disability, fear of “rights,” and constructed a disability-pride identity. Among the founding members, a few women with disabilities actively share their stories covering topics ranging from relationships, intimacy, accessibility, to employment and education. The collective reflections of the founding members and other active members lead to the optimal result of greater public representation of disabled bodies in China’s social media.

By showcasing the founding members’ experiences in deconstructing disability stigma and constructing a disability culture, we invite scholars and disability activists to explore a participatory online community that focuses on disability-related advocacy and knowledge sharing. The online community allows for women with disabilities to develop a positive disability identity and to collectively construct a disability culture. Their experiences are valuable since it is not based on the western rights-based disability activism model.

Instead it provokes dismantling cultural taboos and increases collective pride throughout the community.

Future studies should further explore the process of disability identity development and what elements of such an online group provoked changes into identifying with a positive disability identity compared to other online disability communities. Additionally, it is worth noting how women with disabilities in this group play a much more significant role in terms of organizing and writing blog posts. Further discussions on how gender plays a role in the process of constructing a disability identity are needed.

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# 8 Working mothers' family-work conflict and care decisions in Chinese families of children with autism

*Xuehui Li, Shixin Huang, Luanjiao Hu,  
and Dong Dong*

## 8.1 Introduction

Research on the caring experience of families with disabled members not only focuses on individuals with a disability but also on the caregivers. In this study, the Chinese mothers of autistic children are placed at the centre. As the primary bearers of family care for special children, they have had a hard time finding a balance between work and family. In most cases, the diagnosis of an autistic child is a stressor for the family-work dynamic. These mothers face the dilemma of continuing to work or resigning to be at home. Based on 22-month participant observations at a special education centre located in Shanghai, in-depth interviews with eight mothers with autistic children, and textual analysis of parent auto/biographies, this study reveals that the mothers' decision of whether to resign is influenced by a variety of factors, ranging from economic burdens to individual fulfilment. The mothers who resign face greater parenting pressure and new adaptations; the mothers who continue to work develop coping strategies that include adjusting work objectives, reducing social interaction, and actively seeking assistance from the extended family. Finally, the family care model and gender division of labour, as well as improvements for social services are discussed.

## 8.2 Background information

Autism is a neurological and developmental disability that begins early in childhood and lasts throughout a person's life. Tao (1982) reported the first autism case, marking the start of autism research in China. According to the Second China National Sample Survey on Disability (2006), about 111,000 children have intellectual disabilities, accounting for 1.1% of children between ages 0 and 6 in China. Among these children with intellectual disabilities, about 41,000 them, or 36.9%, have autism. Another meta-analysis based on 18 research studies shows the prevalence of autism in mainland China is about 11.8 in 100,000 (Sun et al. 2013). If the 1% world prevalence rate for autism is applied in China, the number of Chinese with autism could reach over 10 million, among whom more than 2 million would be children between 0 and 14 years old.

Although a rights perspective of Disability Studies eschews a negative conception of the disability and caring experience, students of feminist disability studies have called for explorations of the mothering experiences under the oppressive mothering ideologies and disabling environments (Ryan and Runswick-Cole 2008). The diagnosis of autism among children causes an imbalance in the family system. Caring for children with autism creates a significant stress that affects the parents' mental health and quality of life in the processes of navigating disability stigma, discrimination, and insufficient support and resources (China Association of Persons with Psychiatric Disability and their Relatives 2014; Landsman 2005; Glass 2001; Lin 2015; Mandelco et al. 2003; Shakespeare 2013). Mothers play central roles in caring for children with disabilities. They are often the main caregivers of the families within the Chinese cultural context (Lin 2015). Along with providing care and support for the family, they are also more likely to leave jobs or lose working opportunities and face great pressure. Yet such type of work/family conflict faced by autism families has not been sufficiently studied.

Work/family conflict is a well-established research area, which can be divided mainly into two categories: (1) work-to-family conflict (WFC), or "work interference with family" (Weer and Greenhaus 2014b); and (2) family-to-work conflict (FWC), or "family interference with work" (Weer and Greenhaus 2014a). Existing research includes studies of the impact of WFC on one's life satisfaction and happiness (Kinnunen et al. 2004; Fellows 2016), and FWC's influence on one's work satisfaction (Bruck et al. 2002; Allen et al. 2000; Xu and Qi 2016). Many previous studies focus on the work/family interrelationship and their intense effects upon each other (Eby et al. 2005). More specifically, researchers are interested in the unbalanced work/family relationship experienced by various professionals (e.g., nurses, see Farhadi et al. 2013 or university researchers, Fox et al. 2011), special family settings (e.g., dual-earner couples with children, see Hammer et al. 1997, or comparing dual-income and single-parent households, see Duxbury et al. 1994), or people with a specific gender role (e.g., women, see Williams 2000), or people with intersectional social roles (e.g., Christian mothers in academia, see Oates et al. 2005). However, very little is known about how families of autism deal with work/family conflicts and challenges, especially in non-western social contexts, such as China.

Furthermore, a related but often neglected area is the care experience of Chinese families with children with autism (Lu et al. 2015). Previous studies find that, in China, it is primarily the women in the urban families who take care of the household chores (Third survey on Chinese women's social status 2011), and the main reason for Chinese women's unemployment is due to attending the care needs of a family member. Other studies reveal that compared with men, not only do Chinese women tend to invest more in the family, they also face greater pressure (Xu and Bao 2007; Third survey on Chinese women's social status 2011; Xu and Qi 2016). In 2013, the China Association of Persons with Psychiatric Disability and their Relatives surveyed the caring

needs required by individuals with autism in the family. It finds that, in China, mothers are the primary caregivers for children with autism (76.3%). In addition, 52.4% of families have one family member leaving a job to care for a child with special needs. Among these families, the majority of family members who leave jobs are mothers (90.2%) (CAPPDR 2014, 17–19).

Therefore, the work/family conflicts may have a more obvious and real impact on Chinese mothers of autistic children than their fathers. To add empirical insights into this small but important domain of research (Matthews et al. 2011), in this study, we investigate work/family conflict in families with autism in China, hoping to reveal how work-related characteristics and stressors interfere with their family life. Moreover, unlike many previous studies that only measure the “intention of quitting jobs,” we pay special attention to an extreme condition of the interference from work to family life, that is, the impact of familial incidences on one’s pause or withdrawal from employment.

The key concern of this research is to understand the mothering experiences of women with children with autism diagnosis, more specifically, whether these mothers continue to stay in their occupation/profession or choose to leave their jobs and care for the children with autism full-time at home. The reason why we focus on autism diagnosis as a critical familial incidence is that unlike other disability categories that are more visible and identifiable, autism’s assessment and diagnosis require a longer period for observation and final identification (Glass 2001; Lin 2015). Parents of autistic children also face more stress and higher aggravation if compared with parents of children affected by other developmental disabilities (Schieve et al. 2007). As a result, the diagnosis of children with autism could become a critical moment for one to study and examine family life and parents’ vocational development trajectory.

We ask: (1) For mothers of children with autism, what are the contributing factors in their decisions to leave or stay in their job? (2) How do the mothers make sense of such decisions? The data for this study come from multiple sources: (1) participant observations (conducted by the first author) at a special education centre located in Shanghai between October 2014 and July 2016; (2) in-depth interviews with eight mothers of children (aged between 6 and 12) with autism; and (3) autobiographies and biographies written by or on the parents of children with autism (Chen 2015; Lan, Guo, and Hu 2016). All the mothers being interviewed had full-time employment before their children’s autism diagnosis. Yet the interviewees’ decisions regarding their jobs and experiences of making decisions vary: three mothers left their jobs after their children’s diagnosis, one left their job at first and then rejoined the workforce, three mothers actually never left their jobs regardless of their children’s diagnosis, and one mother resigned and returned home but later found new interest in autism rehabilitation and became an “expert” in this area (see Table 8.1 for detailed information about the interviewees). This study aims to introduce a conceptual dimension of disability to existing literature on work/family conflict research. It also contributes to disability studies by

Table 8.1 Demographics and descriptions of the key interviewees

<i>Mother of autistic child</i>	<i>Age</i>	<i>City of residence</i>	<i>Education</i>	<i>Age/Gender of the autistic child</i>	<i>Work decision</i>	<i>(Former/Current) work nature</i>	<i>Monthly family income (USD)</i>	<i>Main income source</i>
1. Yuanyuan's mother	38	Shanghai	University (4-year programme)	8/Boy	Resign and return to family	Accountant for a private enterprise	>2,250	Husband
2. Hehe's mother	40	Beijing	University (4-year programme)	7/Boy	Resign and return to family	Staff in a company	≈1,500	Husband
3. Qiang's mother	33	Beijing	College (3-year programme)	5/Boy	Resign and return to family	NGO worker	≈900	Husband
4. Weiwei's mother	37	Shanghai	Postgraduate (Master)	9/Boy	Resign and return to family; then, back to work	Middle manager in a foreign company	≈4,500	Self
5. Tiantian's mother	35	Shanghai	Postgraduate (Master)	7/Boy	Work, never resign	Primary school teacher	≈1,500	Self & husband
6. Lelc's mother	32	Shanghai	University (4-year programme)	6/Boy	Work, never resign	Employee of a state-owned enterprise	>2,250	Self & husband
7. Linlin's mother	42	Shanghai	College (3-year programme)	12/Girl	Work, never resign	Staff in a company	≈2,100	Self & husband
8. Kaikai's mother	45	Shenzhen	University (4-year programme)	11/Boy	Resign and return home; then become an autism expert	Person in charge of an autism rehabilitation institution	≈1,050	Husband



providing empirical evidence on the coping process of families with autistic children and the impact of such coping processes on mothers within the specific social-economic contexts of China.

### **8.3 The onset of work-family conflict: how to take and how to cope with autism?**

#### *8.3.1 How to take autism diagnosis?*

Medical and psychological research has documented the effects of disabled children on the parents and the family. The impact includes not only the psychological and social pressure on parents brought by the children's disability, but also the investment and price of caring for the children (Shang 2013; Landsman 2005; Kearney and Griffin 2001; O'Connell et al. 2013). Compared to the care for children without disabilities, parents who care for disabled children experience greater stress (Ergün and Ertem 2012; Mandlco 2003). Mothers of children with mental disabilities face greater mental health issues of their own (Yang et al. 2007; CAPPDR 2014, 43). Even when dealing with the same stressful episode within the same family, fathers and mothers often play different roles and pay different prices. Statistics from different countries indicate that mothers of disabled children bear greater caretaking responsibilities and pay a greater price.

There are multiple ways a family could be affected by the diagnosis of a child with autism. The impact could be far-reaching for both family members and family relations. In terms of the pressure types, there could be role, mental, and economic pressures (Kearney and Griffin 2001; Ergün and Ertem 2012). The diagnosis of a child with autism often becomes the starting point for the parents to face all these pressures in the long run, forcing them to adjust or change their lifestyles.

Raising a child without a disability is almost every parent's wish. However, not all parents have that wish fulfilled. For the parents of children who are diagnosed with autism, the news can be shocking. Initial emotional responses of parents to the autism diagnosis include denial and shock (Chen 2015; Lan, Guo, and Hu 2016; Isenhour 2010). In one biography on autistic children's parents, a mother recalls:

Ever since Ming was diagnosed, my family and I have wished this were not true. We were planning to send Ming to kindergarten once he was three. We were planning to buy him nice schoolbags and stationeries. We imagined that he would grow up happily day by day, and we would send him to learn some skills based on his hobbies, for example, learn to draw or play a musical instrument. We imagined that he would excel in his school studies from primary school, to middle school, to high school, and eventually to a university. We were thinking that he would graduate from university and get a good job, have a stable income; he would marry a beautiful wife, and have a beautiful baby together.... But look at

the document of the diagnosis, and look at my “special” son, the reality is so cruel that it crushed all our dreams.

(Lan, Guo, and Hu 2016, 5)

While mothers of children with autism constantly refer to grief, tragedy, and even trauma in framing their first encounter with their children’s medical diagnosis, advocates of neurodiversity such as Jim Sinclair’s (1993) influential manifesto “Don’t Mourn for Us” pointed out that parental grief stems from a medical perception of disability and should be rejected. However, as argued by Ryan and Runswick-Cole (2008), mothers with disabled children also encounter disablements – discriminatory practices and attitudes their disabled children face. The lived experiences of mothering disabled children as well as the meanings underlying parental grief should therefore be examined.

The shock and undesirability towards disabled children that mothers experience, according to Disability Studies scholars, have been shaped by the negative cultural representations of disabilities. Disability representations in pregnancy and baby care manuals are either missing or portrayed as unlikely and undesirable (Gregory 1991); the cultural myths of good mother and perfect children (Thurer 1994) further shape the otherness of disability and disability family. In the Chinese context, mothers’ perceptions of an autistic child have also been intertwined with the Chinese ideas of filial family life, as depicted in the mother’s biography above. The coming of an autistic child not only means a medical diagnosis to the mother, but also the derailing of the dominant familial norms and values that regulate a mother’s role as caregiver and the children’s moral obligation to respect and serve their parents in adulthood (Liu 2008). The negative emotional and psychological stress of mothers in response to their children’s autism diagnosis should therefore be situated in both the lens of ableism and filial family values.

Parents are faced with role pressure as well. This pressure includes the effect a child with special needs has on the role of his/her parents, and the necessity for new information and knowledge on the part of the parents to care for that child. In China, it is not uncommon to hear people say that the disability is the result of a family member’s wrong-doing or someone has shown disrespect for the parents or deities in some understanding of disability (Lu and Inamori 1996, 367–372). The term, “Fridge Mother,” meaning that the cause of autism lies in the irresponsible mother, has been widespread in China via the mass media and popular readings written by early education experts. In reality, there is no lack of an accusation that a certain family member is responsible for causing autism in the child (Lan, Guo, and Hu 2016). Accusations such as these further increase the stress on the family member and exacerbate conflicts within a family, such as leading to a divorce.

In addition to the direct role pressure on the family, the children with autism also indirectly cause parents’ mental pressure. For example, Chan and his colleagues (2018) find that child autism symptomatology may be associated with parents’ mental health (such as depression and anxiety). As a result,

parents of children with autism have to readjust their social life. However, continuous rehabilitation services require significant financial means, which are beyond what many families can afford (CAPPDR 2014). In addition, caring for the child with special needs takes significant time away from the parents' leisure and study time. Therefore, a bigger challenge that the parents have to face after the diagnosis centres on coping with their children's disability.

### *8.3.2 How to cope with autism?*

Dealing with contradictory social norms regarding disability and familial life, as well as limited social support, parents of children with autism in China often find themselves trapped in considerable financial and psychological stress. In this context, parents have developed different coping strategies to negotiate and manage their daily lives as caregivers. This is especially true among families with double-earners. In China, the stress factors of work/family conflict include time investment, family incidence, family relations, and so forth (Gong and Zhang 2006). The balance between work and family is also affected by the national economic system and the social welfare system. The primacy of marketization in recent years' reform policies has increased the burden of work for families.

Under the current social welfare system in China, Chinese families with autistic children receive a fairly limited amount of public services and financial support. Children with disabilities in China rely mostly on family support and care. Families are responsible for the disabled children's medical, educational, and developmental needs (Shang 2013). This means that caring for children with special needs requires investment from more than one family member. Research shows that grandparents of children with autism are one important source of social support. The participation of grandparents eases the caring responsibilities of the parents and provides helpful experiences (D'Astous et al. 2013; Hillman 2007).

But the participation of grandparents in childcare is affected by many factors and causes new issues, such as the intensification of the father-son relationship between the father and the grandfather of the child with autism (Isenhour 2010). Additionally, the care for children with special needs requires knowledge and skills, which places more demands on the grandparents who are often less well educated. Meanwhile, some grandparents hold negative attitudes towards disability. They may have a hard time accepting their "imperfect" grandchildren. This can create additional barriers when it comes to family coping. For example, in one parent biography, "Mother of Pipi" describes such difficulties:

My mother-in-law never accepts our Pipi, she thinks he is a disgrace and embarrassment to her.... She nags continuously that her family has been all good. Now that I am married to the family, and give birth to such a child....

(Lan, Guo, and Hu 2016, 20)

As such, the grandparents of children with special needs are not necessarily a source of support, especially at the emotional or psychological level. Parents are still the primary caregivers. But how does the emergence of children with special needs impact the division of labour among the parents? Some research can provide a reference point. According to a survey with 509 parents of autistic children, about 46.2% of the parents are not currently employed, 93.3% of which are mothers. The top reason (accounts for 97.7%) for unemployment was to care for the family in a full-time manner. With respect to the specific cause of unemployment, the diagnosis of a child's autism is the key reason for one's resignation from the workplace (accounting for 65.8%). Second to the diagnosis is that one resigns from the job after getting married and giving birth to the child. This further proves that the birth of the child with special needs has a significant impact on the core family, especially the mother's readjustment in the socio-cultural contexts of China.

#### **8.4 Returning home: why did the mother resign and how did she fulfil the family role?**

##### *8.4.1 Why did the mother resign from her job?*

A family member's choice to leave a job and return home to care for children with special needs can be voluntary or forced. Some of them have to face up to the possible dismantling of their marriage or family and resigning from work becomes the only option (Lan, Guo, and Hu 2016). But some parents also suggest that returning home may not be the best choice and such a decision needs to be made with caution (Chen 2015).

For families with autistic children, some working mothers feel they have to resign and return home due to parenting pressure. But their final decision to leave their job may not be directly caused by the autism diagnosis, but rather by new issues and demands that follow the diagnosis, such as their children's behavioural problems, the demand for new knowledge about child-raising, social support from employers and educational systems, and so on. In addition, some Chinese families intended to have a second child after the first one was diagnosed with autism. The expanding number of children in the family is also part of the caring responsibility, and thus more pressure. All these factors contribute together to the working mother's decision on leaving her job. That is why not all interviewees of our study decide to return home instantly after their children's diagnosis. Rather, they wait and observe, depending on how well they cope with the situation. The decision process on dealing with work/family conflicts is therefore dynamic. One interviewee, Yuanyuan's mother, describes her experience as follows:

I left my job when my son was in third or fourth grade. I worked in the field of accounting. It was a relatively flexible job in terms of schedule. The boss of our company at the time knew the condition of my son. So

they allowed some flexibility in the schedule. But later my son's younger brother also started to attend school. At the time, the grandparents were helping at home and easing some of my burden. And I was able to continue to work and catch up with the workload. But now my in-laws return to their home and take care of their parents who are in their 90s. I have no choice. This is one of the issues. If I hire help at home, there might be issues with educating the kids. So I just left my job.

(Yuanyuan's mother)

For working mothers, leaving their job means revolving their life around the family needs and losing some opportunities for social life, which may increase their stress (Ergün and Ertem 2012; O'Connell et al. 2013; McCabe 2007). In one group counselling session, Yuanyuan's mother continuously voiced her dissatisfaction and reluctance about returning home:

This is more tiring than working. When I was working, Yuanyuan's grandparents not only took care of all the household chores but also offered guidance on the kids' homework. Now that the grandparents are not here, I have to do things all by myself. It is way more exhausting than working life. But we (the couple) do not have a choice. So we have to assign one to stay at home and take care (of family needs).

(Yuanyuan's mother)

It is evident that parents need time to adjust and adapt to every change in the family situation. For mothers who return home, they have to develop new skills in order to cope with their new roles as a full-time mother.

#### *8.4.2 How did the mothers fulfil the family role?*

Caring for the family full-time means that the mother is more involved in the autistic child's rehabilitative training and school education. It also means more opportunities to be in contact with families with similar situations. Based on the previously mentioned survey among 509 parents, 97.4% of the parents are members of online groups of parents of autistic children (QQ or WeChat, two mainstream mobile social network platforms in China), and 68.9% of the parents are members of parental support organizations (Li, unpublished). The parent-to-parent support enables the parents to inform and interact with others in similar situations, to learn new child-raising knowledge, and to share coping strategies (Isenhour 2010; McCabe 2007). With an increasing amount of interactions and learning, some parents become "expert" in coping with the behavioural issues of autistic children and their own psychological adjustment. In China, about a decade ago, parents of autistic children started to develop training and rehabilitation courses and institutions by themselves, due to the lack of professional support in this area. More recently, the parents have also expanded their service to nurseries and social work services.

Kaikai's mother, whose son was born in 2008 and diagnosed with autism at the age of three, opened a rehabilitation institution in Shenzhen in 2011, almost right after her son was diagnosed. As she told us, the main reason to do so was because there was no such institution nearby their home. She resigned from her job in an industrial corporation when Kaikai had exhibited lots of behavioural problems. When she found that the available rehabilitation services and training methods were not exactly what she needed, she started to learn all relevant knowledge and skills by herself. As she explained:

My son had been undergoing rehabilitation training for three months in an institution, and it took nearly three hours on the road every day. Later, we parents established an institution ourselves, and hired two special education teachers. To assist the teachers, I also began to learn a great amount of knowledge about rehabilitation, such as methods, applied behavior analysis, sensory training, social skills training, and so on. To be honest, learning these things is still difficult for me. But I have to keep learning just for the sake of my child. Now my child is in elementary school. He has encountered many problems and I have been accompanying him in class for more than a year. I now have to understand knowledge and policies related to social work and inclusive education. I also have to communicate with teachers well. I often share my experiences with other parents. I think what I have done is accepted and acknowledged by others.

(Kaikai's mother)

From the example above, it is clear that, for mothers who resign from their jobs, learning new knowledge and skills on helping with their children's rehabilitation is important for them during the process of adjusting and coping. On one hand, it creates a space for the new full-time mothers to keep socializing with others without being suddenly isolated from the world outside of their families. On the other hand, it recruits new members and generates new social resources for parental organizations and/or service-providing organizations. As a matter of fact, many returning-home mothers are becoming vocal and participating in policy advocacy activities more and more effectively.

However, the mothers' mastering of comprehensive rehabilitative training skills along with high involvement in the rehabilitative activities of the autistic children may lead to other implications. Not only does a mother's deep involvement reinforce the trend of having "an omnipotent mother and a hard-working father" in an autistic family, the impact of such a trend on its family structure and family beliefs may also be lingering (Isenhour 2010, 105–106). Some parents have come to the realization that becoming "experts" could lead to problems. For example, one parent from Hubei province reflected on the piece "Give Parents a Proper Role and Position" (CAPPDR 2014, 84–85). This parent's perspective is quite typical:

It is without doubt that parents have limited energy, ability, and time. A family with an autistic child not only faces double pressure from financial and mental aspects, but also has difficulties in keeping up the energy level. If we are asking the parents to be parents, and also to learn all the autism expertise knowledge; asking them to be a professional trainer in addition to be a parent, this is too hard. Parents of autistic children are human, not god! But professionals are different. Their main job is to provide services for people with autism. They could spend more time and energy on this field to do research, to think, to summarize, to discover, to improve. Because they are professional, so they can become experts.

....

Parents are just parents. Their main roles are to be fathers and mothers. Let your children feel safe and happy in your warm hugs. This is what we need to do!

## **8.5 Continue to work: why continue and how to keep a balance between family and work?**

### *8.5.1 Why did the mother continue to work?*

Not all mothers resign from their jobs. Autistic children require long-term rehabilitative training. The training is to improve their social adaptation skills. The cost of such training exceeds what many families can afford (CAPPDR 2014). According to the survey mentioned earlier, the average cost of rehabilitation for an autistic child is about RMB 4000 (around \$580) per month (Li, unpublished). This cost creates a major child-rearing burden for many parents. A mother leaving her job means a reduction in income, while the cost of rehabilitation increases the child-rearing pressure. As a result, many mothers choose continuing to work as a rational choice. As Tiantian's mother explained:

I once considered (quitting my job). But then I thought it is a bit troublesome to care for the child full-time too. On one hand, taking care of my child by the parent is the best, since we as parents are good with our child. However, for a family like ours, that will reduce our income significantly. We are a working-class family, one person leaving his/her job will reduce our family income quite much. In addition, the rehabilitative training in those training centers is still rather costly.

This case shows that the higher the cost of rehabilitation as a percentage of the family's income, the more sensitive the family will be to the issue of a mother leaving her job. However, having a job is not simply for economic reasons; it also allows important access to social interaction and participation in social life (Bruck, Allen, and Spector 2002; Kinnunen, Geurts, and Mauno 2004).



Parents of children with autism have to reduce their time and opportunities in their social life and individual development (CAPPDR 2014; Lu et al. 2015; Glass 2001), or they have to make changes to their jobs (Shang 2013, 170). This change in lifestyle further increases the parents' child-raising pressure and impacts negatively on their mental health (O'Connell et al. 2013). Therefore, for some mothers, the reasons to keep working are intrinsic, such as a way of providing mental support for themselves:

Honestly, my husband and I both have good jobs. Because we both work in central enterprises, we are both reluctant to leave our jobs.... We do our best to spend time with our child. But I think if I had to give up my job and career for my child, and my child is not going to recover even if I give up on myself (my job). Because Autism is different. If my sacrificing myself could contribute to him getting recovered, then I am willing to try. But if I sacrificed myself, and he is still not going to recover, then it is for the best if I grow together with him. Or I can provide him with better emotional and mental support or just do our best to keep him company. In a way, I think it is very important to keep our jobs at the moment. It is possible that we may complain to each other when we stay at home and there are issues at home. If he (the child) grows up and is still like this, then I think I will be feeling disappointed or....

(Lele's mother)

For some other mothers, continuing to work is a way to avoid tensions within the family, especially tensions between the couples. It is a forced choice because alternatives are scarce. Such is the case with Linlin's mother. Linlin's father has a hard time accepting that his child is autistic, and he invests little time in the child. Linlin's mother is the primary caregiver of the child, but she also has to work, even though at one point she had thought about leaving her job.

*Interviewer:* Have you thought about having one parent between you two (the couple) to take care of the child full-time?

*Linlin's mother:* I had thought of that. But I think, if taking care of the child means I do not work, it's better that I work. I think that if I work... things will be better. Because... I can say anything here, right? Because I do not have a good relationship with my husband, and also I am the primary caregiver of my child basically, I do not know how things will go if I do not work.

(Linlin's mother, the child is a 12-year-old girl)

Research shows that having a disabled child or the behavioural problems of the child do not directly create child-rearing pressures for the parents. Rather, the disabled child or his/her behavioural issues exert influence on the parents through creating tensions between the couple (Isenhour 2010). Previous



studies also find that parents of autistic children experience more tense and unsatisfactory marital relationships compared with the parents of children without disabilities. In other words, pressures are mediated by family structures and the couples' relationship. For families with disabled children, the pressures are not created by the children but by the fragility of family structure and marital relationship (Landsman 2005). Moreover, if the father's coping strategy does not work well, it will be difficult for him to support other family members, especially his spouse (Dardas and Ahmad 2015). In the case of Linlin's mother, Linlin's father's negative coping strategies exacerbate the situation of labour division and cooperation within the family, which in turn create more economic pressures on Linlin's mother. That is why she has to choose to continue to work.

### *8.5.2 How did working mothers keep a balance between family and work?*

For mothers who choose to continue to work, to strike a balance between work and family requires them to make adjustments to their work expectations and seeking support from their employers, so that they can gain more time to attend to family needs. This means that working mothers will have to forgo certain opportunities at work and reduce their social activities with coworkers. As Lele's mother describes:

So to speak, I need to make an adjustment at work. For example, my company is based in Beijing, there are some good opportunities for one to go to Beijing or somewhere else, or opportunities to promote you to a position where frequent traveling for business is required. I will give up opportunities such as these for the sake of my child because I need to attend to my family needs. I usually turn down opportunities to be a sales manager or some dinner or lunch networking gatherings, except for the really important networking opportunities. I don't go to the regular networking events. My child is the center of my world. But I also do not like to be pitied. Because to be in the society you need to have competence at work. Our company is not an organization aiming for public goods. Initially our leaders may think your situation is pitiable and deserves some special treatment because of this or that. But one has to contribute and exhibit competence in the long run, rather than get help from others. It's not good to ask for too much from the company...it is difficult to be honest. I've given up some professional development opportunities, some promotions. I just make sure that my job performance is stable. And based on the stable job status, I make sure that my child is the center of my world, and I have to give up on other things for myself.

(Lele's mother)

However, without reasonable accommodations from the employers, sacrificing opportunities in work will not guarantee that the mothers could keep their

jobs. For example, Lele's mother's company allowed her to make less business trips compared to colleagues in the same position and to leave the company earlier if there was no important work to complete. Also, the labour union of her company would issue her more employee benefits during public holidays. Only in such a way does it become possible to keep the balance between work and family.

Another important source for supporting working mothers is from the extended family. "Grand-parenting" is a common coping strategy adopted by many Chinese middle-class families when faced with parenting pressure. This is the case with families with autistic children. Grandparents will help parents care for the children, such as dropping them off at school and picking them up again. In this study, grandparents are involved to different extents in various matters, such as caring for children at home, school education, and rehabilitative training, etc. Take the case of Linlin's mother as an example, "during the day, his grandparents are in charge of sending and picking him up to and from school." Adjusting to the family coping process, some families have developed a relatively stable labour division model. For example:

My parents and my parents-in-law are all supportive in taking care of him during school. During the day while we are working, it's the grandparents who take care of the kid. At night, we will make sure to take turns and take care of the kid, no matter how busy we are. We usually turn down the networking activities beyond work hours. This means the weekend too, we will make sure we are there for the kid.

(Lele's mother)

In addition to such daily caring support, the grandparents also provide financial support to varying degrees. However, it is a dilemma for the parents of autistic children in terms of the "amount" of care that grandparents should shoulder. In some cases, offering help becomes a "burden" for the grandparents and thus throws a lot of pressure on them (Zhong and Guo 2017). When they cannot afford the burden or pressure, their withdrawal in the caring role would greatly affect the coping strategies that the families with autistic children have already become used to and force them to develop new coping strategies. In the case of Yuanyuan's mother, when the grandparents were no longer able to care for the child with special needs, Yuanyuan's mother had to resign from her job to return home and care for her two children.

Some autism families receive support from outside the family. But this support varies from individual to individual. Social service organizations in China can hardly meet all the needs of autistic children and their families (CAPPDR 2014). Additionally, there is a lack of specialized skills in caring for children with special needs among the existing home-care service providers. Sometimes domestic helpers, even with no special training, can become an alternative source of help. Although some mothers (such as Yuanyuan's mother) show concerns in hiring a helper, worrying that the

helper would not be able to care for the child wholeheartedly, Weiwei's mother considers herself to be lucky:

We have been having this Ah'Yi (literally aunty, meaning female domestic helper) since Weiwei was eight-month-old. So in a way this Ah'Yi is with him the whole time growing up. Ah'Yi learned how to get along with him from both me and the kindergarten teachers. So sometimes Weiwei interacts even better with her than with me.... I have been very grateful for this Ah'Yi.

(Weiwei's mother)

## 8.6 Discussions

This study discusses the diagnosis of autism in the child and its effect on the working mother's professional trajectory. The mothers adopt different family care models and develop diverse coping strategies when faced with a source of family stress. The influence of the autism diagnosis on the family member and family relations can be far-reaching. Parents have to adjust their lifestyle due to the dependence of children with special needs on family support and caring. Their lifestyle adjustment is reflected in the family labour division, cooperation, and individual decisions on whether to resign from their jobs or continue to work.

Leaving their jobs or not, working mothers' decisions are a product of the dynamic interaction among the child's disability, the family, and social systems. Specifically, individual factors such as how mothers see the importance of their jobs and mothers' understanding of the impact on their children's recovery should they resign from work are important considerations of working mothers. Moreover, support within the family, including the availability of extended-family support and the husband's willingness to share the caring responsibility, are important factors attributing to mothers' capacity to retain their careers. The involvement of the grandparents in caring for the child provides some support for the parents, whereas the support from the market seems unattainable. One also needs to consider that family members may not provide unconditional support, and sometimes, the unaccepting attitudes of family members could be a source of stress (Sharpley et al. 1997), as was the case with Linlin's mother. Last but not least, social systems in which families of autistic children are embedded also play a salient role. Mothers with employers who provide reasonable accommodations that allow flexibility in working arrangements, as well as those living in cities with more accessible social services are in a better position to stay in work.

Mothers are the primary caregivers for autistic children. Based on our observations of service providers supporting parents, mothers are also the main participants in the involvement of children's rehabilitative services. Admittedly, such services could improve the caring skill of the caregiver and reduce some of their stress. Yet, this may also create new stress and role expectations for

the mothers (Shen 2008, 3). Mothers who leave their jobs are more involved in the rehabilitation, education, and life process of their autistic children. Interdependent support among parents contributes to stress release and may give rise to a disability sub-culture (Ergün and Ertem 2012). These all indicate that parents with similar situations are engaged in new social circles due to their gatherings. They are learning from each other, and they are sharing information with each other based on their autistic children's rehabilitation and educational needs. The improvement of the mother's skills in caring for the child in turn creates more expectations for their motherly roles and further impacts the working mothers' work-life choices.

Mothers have to strike a new balance and psychological adaptation between the family and work no matter if one chooses to return home or continue to work. This study shows that adjusting the work objective is a common coping strategy. In addition, work also means a break from the family-caring responsibility to some extent. Other research conducted by the author further supports that the quality of life for working parents is higher than that of stay-at-home parents. This provides new evidence to understand the meaning of work and work adjustment for families with autistic children. Undoubtedly, working mothers' resigning from work contributes to the family-caring mode in which the "male takes care of the public sphere and female takes charge of the private sphere." Mothers attending to the family needs will continue to reinforce such a family-caring mode. Hence, social support services should focus on increasing the resilience of the family as a unit, rather than the resilience of one individual (especially mothers) (Shen 2008). Likewise, services provided to families with autistic children should also be geared towards parents rather than being limited to only the rehabilitation of the children. Social services are a major source of social support for families, and a major factor that affects mothers' decisions in regards to family and work. A lack of a family and gender lens in providing social services is bound to reinforce the existing family-caring mode and labour division. Some studies have connected the mother's role in caring for autistic children within the Chinese culture (Valle 2014; Lin 2015). Research also supports that mothers are the primary caregivers in Western countries, which propels us to reflect further on whether the Chinese families' labour division is driven by culture or by certain coping strategies.

Lastly, Chinese mothers' experiences are situated within the unique cultural values and social environments that shape the family system in China. The absence of adequate social support to children with autism and their caregivers has propelled the family system as a salient, if not sole, pillar in the provision of care for children with autism in China. As such, filial family values and practices play a significant role in shaping mothers' unique experiences in this study. The coming of a disabled child is seen as a disruption of the cultural ideals of filial families in China as impairments oftentimes undermine the child's ability to fulfil caregiving duties for parents in their old age (Wu 2020). This cultural assumption of disability thus influences how the autism diagnosis is perceived and negotiated within the Chinese filial family, as well as conditions the formation

of intergenerational solidarity and exchanges. As suggested by findings of this study, autism diagnosis is highly likely seen as a familial tragedy and stigma, posing psychological stress and grief not only to the nuclear family, but also the filial intergenerational families. Intergenerational solidarity and exchange, particularly grandparents' active involvement in childcare as a common practice in Chinese families (Chen et al 2011), might be disrupted and further impose strains on the mother to serve as the child's primary caregiver. Future care research and social service interventions should continue this line of enquiry to adopt a family-centred lens to unravel care experiences and support caregivers.

This study primarily explores the impact of the diagnosis of autism in a family on the working mothers' professional trajectory and their decisions, through the adoption of mothers' perspectives. It is equally important to consider the fathers' perspective (Landsman 2005). In addition, the impact of autism on a family is fluid. To some extent, the mothers' choices are only one of the many effects on the family and couple relations brought by the diagnosis of autism. In our future studies, we need to expand further from the perspective of the family support system to understand the families' coping strategies and their quality of life.

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## Part III

# Sexuality, body autonomy, and gender-based violence



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# 9 Sexual liberation of disabled people

## Voluntary sex services by Hand Angels

*Carmen Yau*

### 9.1 Introduction

Sexuality of disabled people has been a taboo topic in social work practice and society. The disability rights movement in the West has made a significant impact on ensuring the sexual rights of the disabled, which social work practice in the Chinese community can no longer neglect. Sex volunteers for the disabled provide an option for disabled people to exercise their sexual rights and promote better life-fulfilment as adults. This article reviews the narratives of service users and the sex volunteers in Taiwan in the hope of understanding the lived experiences, challenges, and impacts of sex volunteering for disabled people. Understanding the experiences of disabled people and sex volunteers provides insights and the ground to explore future social work practice.

### 9.3 Background information

Sexuality has become a buzzword in the disability rights movement and academia in the western world since the late 1980s. Sexual liberation implies autonomy that allows disabled people to make independent and informed decisions. This exercise of autonomy is the cornerstone of human rights (Appel 2010). Instead of studying the sexuality of disabled people only from a biomedical perspective, disability-sexuality research became more robust as the researchers deepened their understanding of sexual development, sexual lives, challenges, and barriers faced by disabled people as well as the concept of sexuality that recognizes flexibility and authenticity (Campbell 2017). The disability rights movement that emerged in the West did not only fight against sexual stigmatization against people with all forms of disabilities but also fought for sexual and body autonomy by advocating for sex assistance, sex accessibility, inclusive dating environments, as well as branding themselves as sexually advantaged (Campbell 2017).

Activists from the West and Japan legitimized commercial sex services as sexual liberation for disabled people when pushing for domestic policy reform. Kim (2010) criticized that these sex trades were merely a “release” of sexual desires of the disabled and reinforced the dominant culture of relegating disabled people out of the realm of sex. Such practice sees the sexuality of disabled people as “a problem” to be solved instead of acknowledging their sexual

agency and the subculture of the disability community; they over-simplified the sexual shaming and downplayed the oppression against disabled people manifested in government policies, cultural, environmental, and structural marginalizing practices (Kim 2010). Besides, such services reinforced heteronormative sexuality rather than valuing different sexual expressions and non-dominant sexual experiences of people with disabled bodies. These sex trades thus reinforced sexual stigmatization against disabled people instead of recognizing their sexuality in their own words and did not help with fighting against the de-sexualization and devaluing of their bodies. Also, these sex practices may not apply to the Chinese community due to the historical, cultural, and legislative contexts. Furthermore, these services failed to show how they could have positive impacts on recognizing the sexuality of individuals with disabilities as well as achieving social changes towards equality (Kim 2010).

The sexuality of disabled individuals is still a taboo among people with all forms of disabilities, their family members, helping professionals, and society in general (Shakespeare 2014). According to a systematic review of the sexual expression of disabled people, the lived experiences of sexuality of disabled people are under-researched. Besides, most of the existing studies focused on heterosexuality and were done in western communities (Campbell 2017). Research on disability and sexuality is traditionally dominated by the medical profession where sexuality of the disabled is pathologized and understood as displaced and “fetishized” (Campbell 2017). Based on this understanding of sexuality, disabled people are projected as having damaged and undesirable bodies. Besides, the hierarchy in the research process is clear, where medical professionals have full control of the research, and the lived experiences of disabled people are neglected. Disabled people often feel they are alienated “from the product of research, from the research process, from other research subjects, and from one’s self” (Morris 1992). Although more and more studies on disability are emerging to explore different dimensions of disability, researchers still prioritize issues concerning the public sphere such as employment and accessibility, rather than personal and intimate issues (Campbell 2017). Researchers have attributed such prioritization to the taboo around sex in the disability community and the feeling of embarrassment among researchers and helping professions in discussing such issues with disabled people. However, such neglect implies how sexuality is deeply embedded in the oppression as well as in our knowledge and support for disabled people (Campbell 2017).

From the perspective of social work, Kim (2010) described the de-sexualizing practices in institutional settings where sexual desires and behaviours of disabled people are disciplined. These institutions pre-emptively exclude all sorts of recognition of the gender identity and sexual agency of disabled people. This deliberated exclusion of sexual elements is taken as the most straightforward solution and was employed as a service protocol (Kim 2010). Also, sexuality is usually absent in the discussion in pursuance of equal rights for disabled people, which often included the right to education, right to health, and other civil rights. Sexuality is framed as a problem that requires interventions, and there is no room for disabled people

to make meaning of their own sexual experiences. Such discourse is also gendered in the sense that it does not only deny the sexual capacity and needs of men with disabilities but also portrays women with disabilities as vulnerable subjects prone to sexual exploitation (Kim 2010). De-sexualization thus poses significant barriers for disabled people to explore their sexuality and for their family members, helping professionals, and researchers to fully understand and respect their sexuality.

In the Taiwan community, the sexuality of disabled people came to public attention when Hand Angels, a non-governmental organization aiming to advocate for the sexual rights of disabled people, started to provide free voluntary sex services for disabled people regardless of their body conditions and sexual orientation. In Taiwan, sexual transaction is illegal except in “red-light districts.” As for Hand Angels, their volunteer service is legal as it does not involve any form of transaction. All volunteers and members of Hand Angels have clear guidelines to avoid any forms of transaction. Legal advice is pursued when necessary. Hand Angels often receive criticism for providing unethical service and is branded as a different form of prostitution from different disciplines like education, rehabilitation, and religion as well as the general public. Although voluntary sex services are not widely available and are socially controversial, Hand Angels constantly conducts projects and organizes events, such as sex-positive parties,<sup>1</sup> photo exhibitions, and workshops on gender identity and body positivity, to break the taboo around the sexuality of disabled people and assist them to explore their sexuality. However, the sexuality of disabled people, as well as the impact of voluntary sex services, has not been studied. For this reason, this article aims to review the experience of service users with disabilities and how their experience affects their sexuality.

### **9.3 Methodology**

To gain a better understanding of the lived experience of service users, the testimonies of service users have been selected. These testimonies are from service users to report and evaluate the whole process of service from 1) application process; 2) pre-interviews with disabled liaison volunteers; 3) preparation for service; 4) provision of service; 5) post-service reflections. No written guidelines or references are provided to service users on how to write a review. It is not compulsory for service users to review all five phases of service. Service users have full freedom to write as much as they wish on computers or via smartphones.

With service users’ consent, Hand Angels posted the original version of the testimonies on its website for public view. There were 23 posts written by disabled people up to November 2018. Of these, 22 posts were selected for analysis (there were 21 service users, and one wrote two posts as he received service twice, see Table 9.1). Only one out of 23 posts was excluded, as the narrator was declined service since he was aged 16.

1 Sex-positive parties refers to social events that reinforce positive attitude and expressions towards sex and body in diversity.

Table 9.1 Basic profile of service users

	<i>Name (pseudonym)</i>	<i>Type of Disability</i>	<i>Sex</i>	<i>Sexual Orientation</i>	<i>Post Date (yyyy-mm-dd)</i>
C1	Tea	Physically Disabled	Male	Heterosexual	2018-11-15
C2	Explorer	Visually Impaired	Male	Heterosexual	2018-08-10
C3	BlackJack	Visually Impaired	Male	Undisclosed	2018-03-21
C4	Blackie	Physically Disabled	Male	Homosexual	2018-02-06
C5	Hillbilly	Physically Disabled	Male	Heterosexual	2017-09-27
C6	Old K	Physically Disabled	Male	Heterosexual	2017-09-07
C7	SKY	Physically Disabled	Male	Heterosexual	2017-08-13
C8	Jieming	Visually Impaired	Male	Heterosexual	2017-06-21
C9	Xiǎo zhé	Physically and Mentally Disabled	Male	Heterosexual	2017-06-21
C10	Ahle	Physically Disabled	Male	Heterosexual	2017-04-06
C11	Beauty	Physically Disabled	Female	Heterosexual	2016-10-10
C12	Ahyong	Physically Disabled	Male	Heterosexual	2016-03-09
C13	Xiaoshuai	Physically Disabled	Male	Homosexual	2016-08-10
C14	Xiaogao	Physically Disabled	Male	Homosexual	2016-01-06
C15	Xiaolong	Physically Disabled	Male	Homosexual	2016-04-29
C16	Xiaotian	Physically Disabled	Male	Homosexual	2016-03-16
C17	Xianxian	Visually Impaired	Male	Heterosexual	2016-02-15
C18	Youth Bird	Physically Disabled	Male	Heterosexual	2015-07-21
C19	Little Prince	Physically Disabled	Male	Heterosexual	2015-02-21
C20	ND	Physically Disabled	Male	Homosexual	2014-11-04
C21	Steven	Physically Disabled	Male	Homosexual	2014-03-29
C22	Steven	Physically Disabled	Male	Homosexual	2014-03-29

As commonly used in qualitative studies and empirical research, this paper uses thematic content analysis, where themes emerge from the raw data other than being imposed by the researcher. Themes are developed based on tendencies, occurrences, as well as patterns that fit the aim of this study. Patterns that emerged from data can also be used to identify sub-themes in the coding process (Carey 2013).

The transcripts were analyzed and coded using thematic content analysis, as suggested by Saldaña (2016). In the first coding cycle, testimonies were broken down and separated into code segments. In this cycle, *vivo*, process and initial coding were conducted in the second coding cycle. The focus was to compare and re-organize the codes into categories as well as prioritize them so that axial coding and selective coding could be processed. For axial coding, the descriptive codes were clustered into groups of relevant categories. For selective coding, these categories were organized into common themes.

## 9.4 Results

As mentioned above, testimonies were analyzed according to the five phases of Hand Angels' service provision: 1) application process; 2) pre-interviews with disabled liaison volunteers; 3) preparation for service; 4) provision of service; 5) post-service reflections.

### 9.4.1 Phase 1 application

Most of the informants expressed their sexual desires and fantasies in this phase. The majority showed their lack of sexual experience in terms of sexual arousal and orgasm. Informants with muscular dystrophy, cerebral palsy, or other mobility challenges often reported painful body experiences such as during stretching exercises in physiotherapy or exhaustion and fatigue during masturbation or using sex toys. For an informant with spinal cord injury, body experience – particularly sexual experience – was a mystery to him:

I have spinal cord injury, and the lower part of my body is paralyzed. I don't have feelings about my sex organs, and I would not even have erections as normal people do... I feel very unfamiliar with my body, particularly when it comes to sex. I am not clear what I want to pursue sex.

— Little Prince, spinal cord injury

Service users usually started by explaining their motivations to apply for the service. Their obstacles in taking up gender roles, particularly in their adulthood, are closely connected to their perceptions of stigma and discourses in society. They perceived that society is only concerned about their welfare but neglects their basic needs of sexuality.



I am often warned that “since you can’t see, you must study hard. If you date a person and do not see a future, don’t be reckless because it is unethical to others.”

— Xianxian, visually impaired

They tended to have rigid gender stereotypes, primarily learned from parents and media that men should be heroic and women should be sexually appealing. However, they would describe themselves as incompetent or incomplete men/women due to their disabilities.

In my reckless teenage years, I aspired to become a heroic explorer. I dreamed of riding a tall, handsome steed to challenge the highest peak of the world. I would become a real man that makes other men feel ashamed and makes all women blush. However, I lost the light and became a man good for nothing and abandoned by dreams. I have no dignity nor freedom. No matter where I go, I need to beg for help... whenever I think about it, I always feel sad, and I just can’t be myself.

— Explorer, visually impaired

Both male and female service users expressed their guilt in having sexual desires and applying for the sex service. For physically disabled informants, some said they were treated with no respect for their privacy since they required intensive care from family members.

I did think of getting my personal space at home. Although my family provided me with a room, it is only a private room in the name. My family always interfere with my personal life in the name of caring. Even I am courageous enough to bring someone home, and I couldn’t lock my door. I don’t know how I could explain why I bring a man to my room. Moreover, I can’t tell my parents that I am gay. Facing these challenges, I don’t know what enjoyable sex is. The word “sex” to me is an unreachable luxury.

— ND, physically disabled

Many service users shared that they would watch muted pornography to keep it a secret from the family. Some informants expressed that they had a minimal opportunity to interact with others for courtship. They shared their experience in being rejected by ex-partners and sex workers. Also, due to lack of privacy, they often encountered numerous embarrassing scenarios, which made them anxious about sex.

There was an incident that occurred when I was young. My mother caught me masturbating in my room. Since then, I moved to the toilet (when I masturbated). However, maybe because I did not clean up properly after

masturbation, the toilet smelled strange, and my sister refused to use the toilet for a long time. Since then, I became extremely fearful of my sexuality. I dare not to have a positive attitude about sex. I even tried to suppress myself and not to let people know the other side of me.

— Jieming, visually impaired

Although informants were aware that their curiosity and desires for sex were forbidden, they considered that media coverage of Hand Angels indicated a change in social culture in recognizing their sexual needs. This cultural change was evident as some informants pointed out they were introduced to Hand Angels by their significant others, signifying a more accepting attitude towards the sexual needs of disabled people. This change has motivated informants to explore opportunities to approach Hand Angels. Some of them shared their concerns before submitting the application, for example, to be exposed to their family members. However, there were cases in which family members and friends showed acceptance and acknowledged informants' needs, giving informants the courage and approval to proceed with their applications. An informant shared his experience in seeking consent from his sister:

How am I going to tell my sister? If I say it directly, I will definitely be scolded furiously. I typed a long text and was struggling with whether I should send her the message for days. I worried that she would see me being abnormal or watching too much pornography, so I decided to cautiously check her views by asking, "did you watch the news about Hand Angels?" She said, "so you want to try?" After I sent her the long message, she replied, "it's normal, I don't see you as a pervert. It is your instinct given by nature." At last, I was relieved as she promised to keep it confidential about my application.

— Youth Bird, physically disabled

#### *9.4.2 Phase 2 pre-interview*

In this phase, disabled volunteers serve as mentors to prepare service users before receiving the service. Volunteers and service users are free to exchange their experiences, share their desires and fantasies, as well as discuss their difficulties and concerns. Informants agreed that talking with disabled volunteers was empowering. Constant communication with disabled volunteers over months not only helped informants understand the purpose and procedure of sex services but also helped them develop an in-depth self-reflection of their attitudes towards sex as well as establish realistic expectations of sexual relationships.

Over a few months of constant telephone conversations with volunteers from Hand Angels, they gained a better understanding of how my body works. We also had a lot of in-depth discussions on sex and my attitude towards sex, which is taboo in our daily life. After several telephone

conversations, we came up with a date to meet up for service. Before we met, I was nervous. However, thanks to the conversations we had for months, I was not afraid.

— Little Prince, spinal cord injury

In this phase, disabled volunteers serve as mentors to assist service users in exploring their sexual fantasies and interests. They also provide alternatives and solutions for service users to tackle their challenges, such as moving to the bed, dressing, and other preparation.

As usual, I arrived at the hotel earlier than our appointment. When I saw the volunteer team, I was so nervous. There were about six to seven volunteers to transfer me to the bed. The liaison volunteer came to my bed for a briefing and interview. They helped me take off my pants and closed the door. I was alone waiting for my sex volunteer.

— Old K, physical disabled

#### *9.4.3 Phase 3 preparation for service*

Informants received practical assistance from liaisons and supporting volunteers on the day of the sex services. Service users with mobility challenges shared their experience of being moved to the bed and getting undressed with the help of volunteers. Since some service users depended on caregivers to prepare them to leave home, some asked for escort services from home to hotel or other practical assistance to tackle their challenges:

Who knows why my domestic helper insisted and refused to put on my shoes for me that morning while I was going out. I was so excited for the day, but all hopes were dashed to pieces. How come something like this would happen? After telling Steven (a disabled volunteer), he helped me turn the tables. Then a group of us marched to the train station from my home.

— Hillbilly, physically disabled

Informants expressed how volunteers prepared a relaxing service environment by providing aroma oil, clean towels, playing their favourite songs and pornographies. Some of them had difficulties in purchasing sex toys, outfits, or other items for sex, and their volunteers assisted them to buy. Also, some of them required specific assistance in the preparation process:

I headed to Room 520 in a hotel. While two female volunteers assisted me in the shower, I asked one of them, “can you touch my vagina? I want to feel where it is.” She put her index finger into my vagina for about one centimetre deep; I felt the finger was huge. It was uncomfortable and

painful, but I didn't tell her as I just wanted to make sure I know where my vagina was. After the shower, the volunteers helped me to put on sexy lingerie, which was my first time, and it was purchased by the volunteers. It was a red thong and a bra with stripes. It was kimono-styled with colorful flowers on it that looked jubilant.

— Beauty, physically disabled

After laying service users in bed, liaison volunteers usually had a final “chat” with the service users to make sure they were ready. Such discussion helped service users lower their anxiety and feel more assured and prepared before the sex volunteers entered.

#### *9.4.4 Phase 4 provision of service*

##### *9.4.4.1 Equal relationship and interaction with sex volunteers*

Sexual interactions involved in the service included undressing, cleaning up, caressing, massaging, hugging, kissing, handjobs, or oral sex. Not all service users had the same standard sequence of sexual interactions as they would communicate with sex volunteers and follow their paces. They felt the relationship was open and safe. They emphasized a sense of equal relationship by expressing how they sought consent from each other as well as providing options to negotiate.

It was my first time having a sex volunteer for sexual liberation. I used the communication board to communicate with the beautiful volunteer. She encouraged me to speak slowly, and she would understand. I asked if I could touch her breasts. She said, yes! “But you need to tell jokes or tell me your stories.” So, I immediately agreed and started talking about my stories in the twenty years of my life.

— Sky, physically disabled

##### *9.4.4.2 Feeling accepted by sex volunteers*

Service users expressed the importance of small talk at the beginning of the service. One important thing is that service users felt they were accepted despite their disfigured bodies and disabilities.

The sex volunteer first sat in front of me. We started to chat to get to know each other. Actually, it was extremely awkward for two strangers to do a handjob in 90 minutes. So, we kept chatting and talking for one hour until I dared to face my “little le” (i.e. his penis). Finally, I decided to take my penis out. It was the first time to experience sex in the last two years.

– Ahle, physically disabled

*9.4.4.3 Positive sex experience*

Service users reported that they had a positive experience in sex by interacting with sex volunteers. A majority of service users stated it was their first experience, while some found it different compared to their previous experience. They described that the experience was beautiful and therapeutic.

When she wanted to help me masturbate, I stopped her and asked if we could slow down. This is because of my previous experience that a lady left immediately after helping me masturbate. I was scared, and the shadow remained. She asked me not to be afraid and promised me that she would be here with me for one and a half hour.

— Xiaolong, physically disabled

You gave me a new experience and a new definition of sexuality. Yes, sex is unbelievably good and beautiful... it was you who swallow up all my deep-hidden unhappiness, loneliness and sadness. You did not only satisfy my physical needs; you also emptied all the sadness in my heart.

— ND, physically disabled

Intimate interactions did not only satisfy their sexual needs, but it was a spiritual journey of self-exploration and acceptance.

Today, I felt I had both spiritual growth and physical satisfaction.

— Ahle, physically disabled

I, physically and mentally challenged, had a girl willing to lean on my shoulder. She was a sweet and kind girl. Her every movement on me baptized my soul.

— Xiaozhe, physically disabled

Despite the physical comfort, the emotional warmth nearly made me cry. The needs lying deep in my heart were being accounted for and respected. We were not doing a sex service; it was life counselling.

— Xianxian, visually impaired

*9.4.5 Phase 5 post-service reflections*

*9.4.5.1 A belated coming-of-age ceremony*

Although all service users are adults and some are middle-aged, they claimed that such experience was a “real” ritual of entering adulthood. From their point of view, such experience was a symbol of adulthood which they should have had much earlier. Some named such experiences as an essential milestone of life while some regretted such late accomplishment.

I shouted with joy, “Dad, Mom, I made it! (In Taiwanese Hokkien)”  
— Explorer, visually impaired

I didn’t even know where the vagina was. I touched a naked man and a penis for the first time. I made an application to fulfil my sexual dream. I was angry with myself. Why was I obsessively yearning with fantasies until I reached 45 years old to get them realized? Compared to ordinary women, I was late for 25 years. Why? I was speechless.  
— Beauty, physically disabled

#### *9.4.5.2 Recognition of self*

Most service users expressed how they were sexually oppressed during the communication stage with liaison volunteers, but their belief and acceptance about their sexual desires became more assertive after such sex experience. Instead of feeling guilty and shameful, they felt no shame in pursuing pleasant experiences to continue living positively.

So... I have entirely wallowed in the sex that I have never experienced all my life. The experience was incredible and beautiful. I wonder if that was the kind of caress most people have enjoyed. Such thought triggered a sense of sadness in my heart. Why have I never had such an experience for the past two decades? When most people regard sex as a basic matter like eating and drinking, I could only suppress my impulses and desires in the dark corner? It’s so unfair. Why is a disabled person like me not allowed to enjoy sex? We are disabled and humans too. We are not gods. I have dreams, emotions and desires too.  
— ND, physically disabled

I want to say that the sexuality of people with physical disabilities is being neglected. It doesn’t mean that those who are severely disabled do not need sex. To me, sex is a way to relax, and we should feel ashamed. I think adequate use of sex can help us relieve pressure and make us shine in daily life.  
— Blackie, physically disabled

#### *9.4.5.3 Making changes in life*

The majority of service users shared their changes in attitude on sexuality, particularly those who saw their sexual orientation as a taboo in the past. With their experience in sex, they were eager to share and encourage their disabled peers to step up and strive for their own happiness.

I took a break for a couple of days and collected my thoughts after the experience. I did not have much expectation on love, but suddenly I

anticipate – I wish, one day, I can speak aloud that I like boys and will find someone that I will declare my love to out loud. Hand in hand, we will spend every day together, may it be days with hardship, joy or sorrow. Even if I cannot find him, I will not be afraid as I still have Hand Angels. I will make good use of my two left chances for the service and use it in the moment of solitude when comfort is most needed.

— ND, physically disabled

Apart from education and vocational training for people with visual impairments like us, we need genuine experience in intimate relationships. This time, I learned that true sex requires mutual respect and interaction. I was freed from the shackles. In the future, I will be more honest about my needs. I have a better understanding of women's bodies. I will stop thinking of breaking laws to explore sex.

— Xianxian, visually impaired

Individuals with physical disabilities also desire sex. However, in such a conservative society, the sexuality of disabled people like us are deprived. It doesn't mean we did not want it. We need resources for sex services and hope this service would be recognized, supported and accepted. We all have positive mindsets. We don't have to be ashamed of sex. A bad attitude is as pathetic as no empathy.

— Steven, physically disabled

## 9.5 Discussion and reflections on social work practice in the future

### 9.5.1 *Needs assessment: reconstructing the sexual identity of disabled people*

Based on the result of the analysis, disabled people tend to hide their sexuality to avoid demonstrating socially undesirable behaviours. However, they are clear about their suppressed needs.

Goffman describes social life as a theatre with front and back stages where one transits between stages, putting on and off different characters and symbols (Jacobsen and Kristiansen 2015). On the front stage, people play the role of social actors and make adjustments in their performances according to the social norms and interactions with other actors in a drama. These everyday-life actors, including themselves and their significant others, reciprocally create impressions of each other and construct a sketch of self from others' attitudes and interactions, according to the "looking-glass self" theory (Jacobsen and Kristiansen 2015). People understand their own identity by mirroring how they perceive their significant others see them. We use particular frames and symbols to present ourselves, interact with others, and make meanings of our experience and the world. For example, disabled people have specific frames,

verbal and non-verbal symbols to interact with their caregivers and others. These frames and symbols are composed of their specific use of words, behaviours, and the way they present their disabilities in front of the “audience.”

On the other hand, caregivers and other people attempt to create an image of the disabled by reading and interpreting this information, and thus constructing a “sketch” identity of the disabled based on their impression. However, the interaction between the “actor” and the “audience” does not stop here. Disabled people will take this “sketch identity” into account and adjust their frames and symbols in their next “performance.” And the interactions go on.

Referring to the experience of disabled people, they play their social roles – such as sick people who need care at home, students with special needs, and trainees at vocational centres and workplaces – according to their interactions with significant others and social norms. In their perceived reality, they acknowledge that their family members, caregivers, and the society view their sexuality as taboo. They have learned that their social roles are limited to “children” at home, students in schools, and users of services provided by non-governmental organizations. Any sexual expressions or symbols would be judged and “punished” by their significant others. They assume that others would interpret their sexual desires as “perversions.” Disabled people imagine others seeing and judging them, and in response to the perceived judgement, they feel stripped of the freedom to express their sexuality freely. However, media coverage of Hand Angels is an important indicator signalling the attitude of the “audience.” As they consider that society is more open to their sexuality, they would explore opportunities to negotiate for a new role on the front stage.

Backstage, the self can withdraw from social roles and interactions so that the person has space to plan, rehearse, and evaluate for the next play. The self can take time to reflect and manage the impression it wishes to project before the audience in the hope of achieving individual or social goals (Nunkoosing and Haydon-Laurelut 2012). We constantly interact with reality in the hope of interpreting and (re)defining it (Jackson and Hogg 2010).

For disabled people, they are aware that they are chained in the rigid social scripts at the front stage. Backstage, they have space to explore opportunities to express themselves differently in the next play. For this reason, applying to Hand Angels is an initiative to seek a chance to start a new drama/story in their life. The whole process of sex service has provided opportunities for them to plan with their disabled peers and interact with sex volunteers as a rehearsal for future plays as well as an evaluation of the new play. Based on what they gain from sex service, they formulate a new identity as a social actor which they can play with their significant others in the future.

### *9.5.2 Theoretical model: understanding relational approach instead of the social model*

Under the social model, the sexuality of disabled people is understood as being oppressed by the social system and norms. Due to the lack of accessibility to



social spaces for adults, disabled people do not have many opportunities to date or interact with others for courtship.

Although sex is to some extent a taboo in Asian communities, sexuality is the core of self-acceptance as well as acceptance by others as a mature and independent individual in the community. While the majority of people have legitimate and natural urges to pursue a mature identity to be a sexual partner or spouse, disabled people have been excluded not because they are asexual or sexually passive, but because they are not being encouraged, as the sexuality of disabled people is socially constructed as threats and risks. In terms of awareness, unlike most non-disabled peers who have better access to media, fashion, and social events from schools and communities, disabled people mostly adopt their parents' attitudes to build their value system and identity. As a result, they are often disqualified from taking "conventional adult roles" (Addlakha 2007).

Vaidya (2015) points out that disability is often viewed negatively as karma or punishment on their parents and family members in some cultures and historical contexts. The stigma has led to a sense of inferiority and low self-esteem, which is internalized by disabled people, particularly by women with disabilities. Women with disabilities are viewed as biologically defective and inadequate caregivers of their offspring as they would probably be in need of care themselves. They are regarded as incapable mothers and undesirable sexual partners, and this attitude has led to the denial of consensual sexual relationships and equal responsibilities for child-raising for them (Vaidya 2015). As a result, they are often controlled to avoid risks of them being sexually active.

Shakespeare (2014) suggests a holistic, relational approach to understanding disability as an interaction between individuals and the structural dimensions instead of only focusing on the impact of social disadvantages. In the individual aspect, the nature and severity of one's disabilities and impairments are crucial to their experience and attitudes. Their attitudes towards their disabilities serve as a lens to interpret their growth and lived experiences. Their personalities and abilities are essential factors as well as their values and beliefs in formulating how they perceive things and act in daily life. Based on the testimonies from Hand Angels' service users, the nature and severity of their disabilities is one factor affecting their understanding and exploration of sexuality. For example, muscular dystrophy and other physical disabilities pose barriers to mobility and challenges in performing self-pleasuring activities, which has impeded their exploration of sexuality. Spinal cord injuries affect the sensation of the lower part of one's body, which consequently affects them when exercising their bodily autonomy, exploring sexuality, and pursuing an intimate relationship – a crucial component of constituting oneself, which goes beyond merely sensory pleasures. Unacceptance of their disabilities will lead to a sense of failure and defeating one's self-identity. Some disabled people consider themselves shy, pessimistic, and passive and this has a close relation to their experience as they grow up. They would place family harmony and the

good of others before the realization of their sexual needs. They consider it unethical to pursue their interests without seeking consent from their families. To accommodate expectations from family and friends, disabled people deliberately adjust their “frames” and present themselves as introverts.

The structural dimension analyzes the interactions at the societal level. It should be noted that the analysis should not be confined to social attitudes towards disability in general. Indeed, equal attention, if not more, should be paid to whether the social environment enables or disables disabled people, and how those basic settings are made possible. In this research, informants recalled how society perceived them and their bodies as abnormal, useless, and pitiful. Socio-economic situations and government policies are crucial to the welfare and quality of life for disabled people. The informants acknowledged how society became more inclusive so that they had better opportunities for education and employment. However, they also pointed out a missing gap to realize their autonomy and independence as an adult. The emergence of Hand Angels is to fill this gap. Its media coverage has been influencing the dominant culture and discourse on the sexuality of the disabled. As the informants described, they think that society has become more open to recognizing their sexual needs.

To sum up, disabled people tend to be sexually conservative about their own sexual identities and do not have many options for their sexual expression that are accepted by society.

### *9.5.3 Future social work practice: advocating for intimate citizenship*

Plummer (1995) suggests “intimate citizenship” as an extension of the existing realms of citizenship, different from the concept of sexual citizenship for sexual minorities. Sexual citizenship concerns equal rights for people of sexual minorities such as equal rights for same-sex couples, as well as equal rights in health and medical services (Richardson 2002). Intimate citizenship concerns the right to organize one’s personal life. Intimate citizenship entails, for example, the right to pleasure, sexual autonomy, reproductive rights, as well as freedom of sexual expression.

Shakespeare, Gillespie-Sells, and Davies (1996) take the definition of sexuality further and suggest that sexuality is more than sex and intimate relationship with others, it is the sketch of how they see and present themselves for recognition and acceptance from others. For disabled people, they are being isolated at home due to inaccessible physical environments, being marginalized due to poverty and limited opportunities to develop, being excluded from friendship and intimate relationships due to social stigma. Disabled people are also social animals like non-disabled individuals and should be recognized and accepted by others. Liddiard (2017) suggests three ways to gain intimate citizenship for disabled people.

First, disabled people should be able to take control of their bodies, emotions, and relationships with others. For example, they should have the

freedom to express their desires and have enough support to execute their wishes.

Second, they should gain access to information resources as well as access to social spaces for adults. Besides enhancing the accessibility of information and physical spaces, disabled people should be empowered to feel free to access and collect sex-related information, for instance, pornography. Kim (2010) suggests assistance for disabled people in accessing sexual experiences such as escorting them to sex-related venues (e.g., hotels, sex toy shops), assisting them in purchasing sex toys and other items. Should their assistants not see sex assistance as a violation of their ethics, they could assist masturbation and other sexual activities (Kim 2010).

Third, people should have the freedom to make decisions about their gender identities, sexual experience, and erotic exploration. They should not feel ashamed about their choices regarding their sexual orientation and preferences. They should have equal rights to explore sexuality as others in society.

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# 10 The situation in sexual reproductive health rights of women with disabilities in Nepal

*Rama Dhakal*

## 10.1 Introduction

Sexual and reproductive health problems affect the lives of women with disabilities in Nepal. Women with disabilities find it hard to assert their sexual and reproductive health and rights. Disability rights groups across Nepal submitted a report to the Committee on the Rights of Persons with Disabilities and suggested specific recommendations on how the State of Nepal can guarantee the rights of women with disabilities in the country. Recommendations include ensuring effective implementation of the laws related to sexual violence and sexual harassment in Nepal, developing and implementing a comprehensive strategy to eliminate harmful practices and stereotypes that discriminate against women with disabilities, ensuring government institutions and offices include information and services that are accessible, ensuring proper training to actors in the justice system, ensuring the collection and publication of reliable data on violence against women with disabilities and so on.

## 10.2 Background information

Nepal is a small, landlocked, and mountainous country located between India and China. With a population of 26.4 million spread over 147,181 square kilometres, it is one of the most impoverished developing countries within South Asia (CBS 2011). Nepal is divided into three primary regions: the Terai, Hill, and Mountain areas, which constitute approximately 50.27%, 43%, and 6.73% of the total population, respectively. These regions are further divided into seven provinces and 75 districts for planning and administrative purposes. Individual village development committees (VDCs) comprise one political unit, and there are approximately 3157 VDCs in total with one metropolitan, twelve sub-metropolitan, and 217 municipality cities. Nepal is an agrarian-based economy with more than 86% of its population residing within rural areas and only about 14% living in the city. With great diversity in culture, social structures, linguistics, and religion, Nepal is one of the most unique countries in the world (CBS 2011).

According to the census of 2011, people with disabilities (PWD) make up 1.94% (513,321) of the population, out of which 45% (233,235) are females.

The constitution of Nepal upholds every citizen's right to equality and protects them from any discrimination in the application of general laws and otherwise, based on gender and/or disability. Despite a constitutional framework, women with disabilities (WWDs) face intersectional forms of discrimination: as women, as persons with disabilities, and through other social dimensions such as caste, class, and access to education and health care. In terms of health, accessibility, education, economy, and employment opportunities, people with disabilities are treated as second-class citizens. Moreover, a large number of people with disabilities have still not got any treatment, which could be due to a lack of knowledge and awareness that impairment can be treated. It could also be because the family does not have the resources or because health facilities do not function properly, and the staff does not know about disability. Women with disabilities have been facing double discrimination, first as a disabled person and second as a woman (Panthi 2011).

Sexual and Reproductive Health and Rights (SRHR) incorporates the rights of all people, regardless of age, gender, and other characteristics, to make choices regarding their sexuality and reproduction, provided that their rights do not infringe on the rights of others. Thus, it promotes reproductive decision-making, freedom from forced abortion, access to information and appropriate reproductive education, freedom from harmful traditional practices and gender-based violence, and freedom to express one's sexuality.

Sexual and reproductive health problems continue to affect the lives of women in Nepal. In the age group 15–19, 29% of girls who are already in marriage lack access to critical information on SRHR and related services. A total of 87% of women in Nepal would either like to delay the birth of their next child or want no additional children. Unmet need for family planning for girls in the age group 15–19 is 42%, and for the 20–24 age group it is 37%. A quarter of all women of reproductive age in Nepal experience unplanned pregnancies; 47% of girls who first had sex before the age of 15 were forced against their will. Only 29% of women have ever heard of emergency contraception and only 0.1% have used it. Among girls in the age group 15–19, 17% have already had a birth or are pregnant with their first child. Although the maternal mortality ratio (MMR) in Nepal decreased between 1996 and 2006, from 539 to 281 deaths per 100,000 births, it is still very high. Unplanned pregnancies expose women to the risk of unsafe abortion. Unsafe abortion is the cause of up to 20–27% of maternal deaths in hospitals, which is significantly higher than the global average of 13% despite the legalization of abortion in 2002. Sexual and reproductive health should incorporate the idea that sexuality must be critically analyzed with and within the discourse of power, which controls an individual's sexuality. This will help us to understand sexuality by moving beyond the issues of reproduction, health, and violence to incorporate its other dimensions (SRHR 2013).

Societal attitudes may influence the sexual self-image of women who have grown up with disabilities. Becoming disabled may alter a woman's self-image, and fears of losing independence and of being viewed as "sick" can erode sexual confidence (Basson 1998). Sexual abuse and sexual harassment are

more commonly experienced by women with disabilities than by able-bodied women and can be particularly devastating in view of the already vulnerable self-esteem of women with disabilities. Recognition of a woman's sexuality, provision of information to enable her to express that sexuality safely, and accurate assessment and management of any sexual concerns are integral components of care and fall within the province of the "generalist" (Basson 1998).

According to the Sexual Reproductive and Health Right Act 9, 2075 B.S, family planning, sexual health, safe motherhood, safe pregnancy, safe abortion, emergency delivery, newborn care, and reproductive health morbidity should focus on adolescent girls and women with disabilities. According to this Act, no one should be discriminated against regarding their origin, religion, race, caste, sex, gender identity, community, occupation, business, health condition, disability, marital status, pregnancy, ideological faith, any disease or bacterial infection, status of risk or injury, reproductive health (morbidity) condition, personal relationships and family planning, or sexual health.

The report was submitted by 13 disability rights groups across Nepal with the goals of providing the Convention on the Rights of Persons with Disabilities (CRPD) Committee with substantive elements for consideration about the status of the implementation of the Convention in Nepal and for suggesting specific recommendations on how the State of Nepal can guarantee the rights of women with disabilities in the country. The focus of this report is on the sexual and reproductive health and rights of women with disabilities. In addition, language on sexual and reproductive health and rights is not available in sign language. For those with visual impairment, it is further challenging to get knowledge on sexual and reproductive health and rights because of the lack of materials and methodology in an accessible format (SRHR 2013).

### **10.3 Women with disability and sexuality**

Women with disabilities have been facing double discrimination first as a disabled person and second as a woman. Disability has an impact on a woman's sexual identity and confidence, her sexual desire and function, and her ability to find a partner. A disabled woman remains a sexual person with the potential to have sexual experiences and to build relationships that include sexual aspects with their associated sense of bonding, commitment, and fulfilment – but she will need help (Basson 1998).

According to the World Health Organization (WHO), sexuality is a central aspect of being human throughout life and it encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles, and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious, and spiritual factors (WHO 2006).



### 10.3.1 *Sexual rights*

All people have the right to sexual wellbeing, but more often than not, people with disabilities are regarded not only as non-sexual but also often not even as people.

According to the WHO, sexual rights include the right of all persons, free of coercion, discrimination, and violence, to:

- The highest attainable standard of sexual health, including access to sexual and reproductive health care services;
- Seek, receive, and impart information related to sexuality;
- Sexuality education;
- Respect for bodily integrity;
- Choose their partner;
- Decide to be sexually active or not;
- Consensual sexual relations;
- Consensual marriage;
- Decide whether or not, and when, to have children; and
- Pursue a satisfying, safe, and pleasurable sexual life.

The responsible exercise of human rights requires that all persons respect the rights of others (WHO 2006).

Myths about sexuality and disability still prevail. Many myths about women with disabilities include that they are asexual and only independently functioning women can handle sexual relationships. Women with disabilities who are single are considered celibate and incapable of being mothers. They are viewed as incapable of reproduction or too weak to carry a pregnancy. Also, they are viewed as being unattractive or unfit for marriages or being sexual partners (Basson 1998).

### 10.3.2 *Some SRHR problems in Nepal*

Sexuality is a taboo in Nepal, which leads to reluctance to discuss and address sexual health issues. Poverty and food insecurity limit women to assert their SRHR and force them into practices that violate their right of bodily integrity. People are stigmatized if they do not conform to socially accepted norms of behaviour, such as adolescents having sex before marriage and people with different sexuality. Most women are economically dependent on men and have limited power to claim their SRHR. Due to unequal power relations based on gender, women are often unable to refuse sex or negotiate safe sex or access health services. Violence against women leads to violation of SRHR. This is the situation for able-bodied women and we can assume the situation for women with disabilities in sexual and reproductive health. Some traditional practices and beliefs also affect sexual health and access to services (SRHR 2013). For intellectually disabled girls, some parents would use contraceptives without



the consent of their daughter. There is no information on the use of contraceptives for women with disabilities. Women with disabilities are asexual.

#### **10.4 A report submitted to UNCRPD, 2018**

As we know that women with disabilities are not getting any health services, ten organizations representing different disability groups came together and decided to write the supplementary report on Sexual and Reproductive Health and Rights of women with disabilities. After identifying the issues, disability-specific focus group discussions (FGDs) were conducted. There were nine focus discussions from different categories of disability in Nepal and from different districts.

During the FGDs with women with disabilities, they spoke of their experience of sexual harassment when seeking help in lifting or carrying them. In such situations, they cannot voice the violation because of the vulnerable situation they are in during that time. Schools and institutions are not safe for girls with disabilities, either. There are incidents of sexual harassment and violence happening inside schools and institutions, often perpetrated by the staff at these places. There are some case stories shared by the group. In one of the FGDs, a young blind woman shared a story about a close friend of hers. She said:

There were two girls in school, and as they had to come to school from very far, they usually did not attend the morning assembly and just sit in the back of the classroom. Every day a person would come from behind and touch their breasts and run away. After they filed a complaint, it was found that the gardener of the school was doing so.

Though parents and teachers of girls with autism, intellectual disability, and Down syndrome find that providing the girls with knowledge on sexual and reproductive health and rights is extremely important, they do not have enough materials and tools to address these issues. In fact, parents themselves are unaware of sexual and reproductive health and rights concerns of their daughters, especially when it comes to managing their menstruation. Girls with disabilities still miss out on school during menstruation, mostly because of the lack of support in schools. Women with severe physical disabilities think it is a burden to have menstruation every month because they need someone else to take care of them. Also, women with disabilities are not given prior information on sterilization and contraceptives.

A young woman with a disability from Hetauda said she thought, “husband and wife reproduce children by sleeping next to each other, (my) parents never informed (us) about it. However, even the teachers are timid and unwilling to share about sex.” Schools, as well as parents and caretakers of adolescent girls, are still hesitant towards providing sex education.

In a case from Kathmandu, a 25-year-old woman with a hearing impairment fell in love with a man and got married. They had a boy from her first

pregnancy. Two years later, she became pregnant again. However, she and her husband were not financially ready for another child, and she sought safe abortion service. When she went to the hospital and explained to the medical professionals in sign language that she wanted to have an abortion, they did not understand her and repeatedly said the baby was healthy and fine. In this way, she was not able to get safe abortion service and had to keep the pregnancy. The case shows the lack of sign language and information, education, and communication materials regarding sexual and reproductive health.

During an FGD in Kathmandu, a woman with a physical disability said, “a doctor had told me not to have any other children after I had given birth to my son. She told me I would suffer a lot if I had any more children.” This was the doctor’s personal judgement that she would not be able to take care of more than one child because of her disability, instead of medical necessity. Health professionals still perceive women with disabilities as incapable of taking responsibility for their children (NAPD-Nepal 2018).

### **10.5 Suggested recommendations for UNCRPD**

Ensure effective implementation of the laws related to sexual violence and sexual harassment including the Constitution of Nepal, the Civil Code (Muluki Ain) 2017, Domestic Violence Crime and Punishment Act 2009, and Domestic Violence (Offence and Punishment) Rules 2010 in a manner that adequately accounts for the violence faced by girls and women with disabilities.

Develop and implement a comprehensive strategy to eliminate harmful practices and stereotypes that discriminate against women with disabilities, including through increased awareness-raising campaigns for police, lawyers, judges, and community and religious leaders in rural and urban areas by effectively prosecuting and adequately punishing perpetrators.

Ensure government institutions and offices including police stations and courts include information and services that are accessible (and in easy-to-read version) including provisions in sign language, Braille, with visual support, captions, and tactile signing.

Ensure proper training to actors in the justice system including magistrates, prosecutors, police, and health service providers on understanding the rights including the types of disabilities and needs of different groups and laws that protect women and girls with disabilities.

Ensure that the right to exercise full informed consent to any family planning intervention for women and girls with disabilities as guaranteed by The National Family Planning Costed Implementation Plan (2015–2020) is not violated.

Ensure the collection and publication of reliable data on violence against women with disabilities as well as information about investigation and redress.

Provide safe and accessible reproductive health services for women with disability (safe abortion, maternal health services, pre-natal care, emergency

obstetric care, safe delivery and post-natal care, skilled birth attendants, maternity leave, etc.).

Ensure inclusion of sign language and in easy-to-read version as a national language in addition to Braille.

Provide girls and women with disabilities with the age-appropriate information and awareness on contraceptives, safe abortion, puberty, menstruation and menstrual hygiene, pregnancy including nutritional plan, and childbirth and breastfeeding using different and multiple channels of communication in an accessible way in both urban and rural settings.

Provide comprehensive sexuality education for girls and women with disability in school and out-of-school through the accessible curriculum and conduct training for teachers and community leaders to impart the curriculum.

Ensure implementation of the Nepal National Adolescent Health and Development Strategy 2000.

Release disaggregated data on the basis of age, gender, and disability to provide timely sexual and reproductive health and rights information to the girls and women along with the specific information and education in relation to their disability type.

Ensure proper implementation of existing policies, laws, and verdicts related to sexual and reproductive health and rights.

Ensure physically accessible healthcare services such as low beds, labour bed, information desk, softer mattress, clean and hygienic environment, toilet, signage, audio support, and visual support in all government and private centres and hospitals.

Ensure the presence of sign language interpreters at all health centres who have undergone gender sensitization training and are aware of issues for women and girls with disabilities.

Provide budgetary allocation for information on reproductive health care and services including family planning in a language that is accessible to women with disabilities, which includes: provision of sign language interpreter or easy-to-read version, visual support, tactile signing, personal attendant, and disability-friendly ICT materials.

Provide women with disabilities with free access to or discounts for commodities and services including menstrual products, adult diapers, contraceptives, and Clean Intermittent Catheterization (CIC).

Take concrete steps to train health care workers on issues concerning women and girls with disabilities and provide services that are based on the constitutional right to dignity and that respect the autonomy of persons with disabilities (NAPD-Nepal 2018).

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# 11 Gender-based violence against women with disabilities

## Prevalence and experience<sup>1</sup>

*Carmen Yau*

### 11.1 Introduction<sup>1</sup>

This study aims to investigate the prevalence and experiences of gender-based violence against women with disabilities in Chinese communities. A mixed-method study is applied by conducting a questionnaire survey with 80 women with disabilities to draw an overview of prevalence and nature of violence, survivors' coping strategies, and challenges in seeking help, as well as three in-depth interviews to outline the experience of partner violence against disabled women. According to the results of the survey, 30% of the respondents reported having experienced domestic violence, 34% have experienced sexual harassment, and four respondents indicated that they experienced sexual violence. A total of 66% of the respondents who experienced domestic violence reported that they did not seek help and 85% of the respondents who experienced sexual harassment did not seek help. For those who experienced sexual violence, none of them sought help. Findings from interviews echo the results from the questionnaire survey. Interviewees further shared their experience in terminating partner violence. Recommendations for policymakers and service providers are provided.

### 11.2 Background information

According to research and studies on gender-based violence against people with disabilities over the years, women with disabilities face a higher prevalence of domestic and interpersonal violence (Hughes et al. 2012; Krnjacki et al. 2016; Ruiz-Pérez et al. 2018). The World Health Organization (2017) defines violence against women as “any act of gender-based violence that results in, or is likely to result in, physical, sexual, or mental harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life.” Interpersonal violence,

1 A portion of this article was presented at the Conference on Disability and Gender Equality in October 2017 (Seoul, Korea) and the Conference on Disability, SOGIE and Equality in Asia in August 2018 (Kyoto, Japan).

as a broad definition of violence against women with disabilities, implies all sorts of violence in the various relationship with family members, spouse, or even paid caregivers. However, this study mainly focuses on violence conducted by family members and intimate partners. The term “domestic violence” implies violence with family members. As for intimate partner violence, it means any acts by an intimate partner which cause harm physically, sexually, and psychologically (World Health Organization 2017).

In terms of partner violence, women with disabilities tend to experience more extended periods of abuse in various forms perpetrated by their spouses and live-in partners (Hasan et al. 2014; Ruiz-Pérez et al. 2018). Compared to women without disabilities, women with disabilities may experience hostile comments and humiliating behaviours targeting their disabilities, denial, or excessive use of medical devices/exercises or forced sexual activities in exchange for help (Nosek et al. 2001).

While caregiving stress is a significant factor contributing to high risk of partner violence against women with disabilities (Salwen et al. 2016), other contributing factors include low level of education, poverty and unemployment (Krnjacki et al. 2016), unmet needs of partners (e.g., needs for intimacy and sex), and dissatisfactory relationship (e.g., constant argument and conflicts) (Copel 2006; Salwen et al. 2016). Since women with disabilities depend on caregivers for daily living activities, they feel reluctant to escape and tend to stay in the abusive relationship (Nosek et al. 2001; Young et al. 1997). Disabled survivors suffer both physical consequences (such as bruising, unwanted pregnancy) and psychological consequences (such as depression, post-traumatic stress symptoms, and suicidal thoughts, etc.) which may, in turn, lead to challenges in school performance, social life, and daily activities (Bonomi et al. 2018).

Such an abusive relationship not only has impacts on their physical and psychological wellbeing but also influences their self-identity. Ogińska-Bulik (2016) points out that these traumatic experiences would twist the way they interpret the traumatic events and distort their beliefs and their relationship with others. Kearney (2001) describes the “shrinking of self” of battered women with disabilities in the sense that they tend to ignore the patterns of abuse and the escalated risks in the hope to maintain their intimate relationship and families to fulfil the role as “normal” women who fit social and cultural expectations.

Violence against women without disabilities is well documented in qualitative research, but the complicated situation and experience of intimate partner violence against women with disabilities are still under-researched, in particular, the relationship between disability and violence (Copel 2006; Krnjacki et al. 2016). Hegarty et al. (2013) raised the necessity of understanding the special needs of women with disabilities who experience violence since it determines what support from mainstream helping professionals is adequate. Research has indicated that Asian women are more vulnerable to physical and sexual violence (McFarlane et al. 2001). Nevertheless, domestic violence and its potential consequences in Chinese contexts require further research.

This article is based on a mixed-method study on gender-based violence against women with disabilities in Chinese communities. An online survey was first conducted to outline the prevalence and nature of violence, survivors' coping strategies, and challenges in seeking help. Biographical narrative enquiries were followed to explore how women with disabilities face and cope with intimate partner violence.

### **11.3 Methodology**

The study adopts an explanatory sequential mixed-method design suggested by Creswell (2014) in the hope of combining quantitative and qualitative approaches to gain comprehensive understanding of gender-based violence against women with disabilities. The quantitative survey aims to provide an overview of the landscape of gender-based violence against women with disabilities, while the in-depth interviews aim to provide detailed portraits of their lived experiences in different phases of violence. The preliminary quantitative survey provides information to formulate interview questions as well as assists in the selection of suitable participants for the qualitative study.

For the initial quantitative survey, 80 Chinese women with disabilities were recruited, and informed consent acquired, to complete a set of online questionnaires via social media platforms and the website of the Association of Women with Disabilities Hong Kong (AWDHK) during summer and autumn in 2018. The ethical approval of the study was obtained by the AWDHK. Such an online survey method has been commonly applied in social science research and intervention (Chan and Holosko 2016; Chan 2018). The questionnaire was developed based on a survey conducted by the Hong Kong Women's Coalition on Equal Opportunities in 2013 (HKWCEO 2013). The survey focuses on the disability-related and socio-demographic characteristics of women with disabilities, the nature and experience of violence, as well as their coping strategies. Data were analyzed by SPSS.

For the qualitative study, three in-depth interviews were conducted using a biographical narrative enquiry approach in which participants are active interpreters and reporters and share their genuine construction and interpretation of their stories (Kim 2016b). The ethical approval of the qualitative study was obtained by the Human Subjects Ethics Sub-committee of Hong Kong Polytechnic University and AWDHK. Participants were referred by AWDHK and its network partners in China.

Biographical narrative enquiry invites participants to share their stories during which researchers could understand their lived experience related to interpersonal violence and their perceptions of their life and prominent factors affecting their decisions of seeking help or not. Clandinin and Rosiek (2007) have highlighted that narrative enquiry not only focuses on the personal experience, but also on how the experience is being "constituted, shaped, expressed, and enacted" in social and cultural contexts. Narrative enquiry allows researchers to understand the experience and behaviours of individuals, how they face

life challenges, and their solutions, as well as how they respond differently from time to time. Through storytelling, participants share their experiences, emotions, perceptions, and beliefs, and project their reality to researchers (Kim 2016a).

The interviews were conducted in Cantonese or Putonghua (Mandarin), audiotaped with permission from participants, and transcribed verbatim. The duration of the interview was approximately 2 hours. The narrative enquiry consists of two interview phases: 1) Narration Phase: participants have an opportunity to provide full extensive narration of their experience and life stories without interruption from the researchers. The researcher takes notes on the story and the participants' non-verbal expressions, and writes down observations; 2) Conversation Phase: an in-depth semi-structured interview with the researcher. The researcher co-constructs the experience with participants by using narrative questions (Kim 2016a). Transcripts were then analyzed and coded using thematic content analysis (Saldaña 2016). Some quotes were selected to translate into English and included in the article bearing in mind carefully the meaning of the quotes and the values they reflect in Chinese culture (Wong and Poon 2010).

#### **11.4 Limitations**

The study has its limitations in many ways. First, the online survey was limited to a small group of women with disabilities who can access the internet. They are more educated with higher technology literacy. Data from the online survey cannot illustrate the detailed picture of gender-based violence against women with disabilities. We can only see the findings as a preliminary outline of this topic concerning the Chinese community. Furthermore, the interviews were limited to partner violence against women with disabilities. These findings may not apply to other forms of interpersonal violence such as violence by parents, family members, and paid caregivers.

#### **11.5 Results**

##### *11.5.1 Demographics of participants*

Eighty women with disabilities participated in the online survey. Among the 80 respondents, about 34% are 21–30 years old; over 98% reported having received secondary education or above; 68% were living with family members at the time of the research; 96.25% have indicated that they have physical disabilities; 68% are wheelchair users while nearly 24% use walking aids (Table 11.1).

Three participants for the qualitative research were Penny, Hung, and Yan, respectively 60, 58, and 34 years old. All of them were physically disabled and were divorced by the time of the study. Penny and Hung have to raise their children by themselves. Yan lived in mainland China, and the other two lived



*Table 11.1* Characteristics of the survey participants (N=80)

<i>Background Characteristics</i>	<i>Frequency %</i>	
Age		
18–20	3	3.75
21–30	27	33.75
31–40	26	32.5
41–50	15	18.75
51 and above	22	27.5
Type of Disability*		
Physical disability	77	96.25
Visual impairment	2	2.5
Hearing impairment	7	8.75
Mental illness	16	20
Use of Aids*		
Power wheelchair/wheelchair	55	68.75
Walking aids	19	23.75
Hearing aids	4	5
Do not need aids	23	28.75
Highest Education Level		
Primary education	1	1.25
Secondary education	37	46.25
Tertiary education and above	42	52.5
Monthly Income and Subsidies (USD)		
No income/subsidies	12	15
\$1,000 or below	16	20
\$1,001–\$2,000	15	18.75
\$2,000–\$3,000	10	12.5
\$3,001 or above	17	21.25
Living Environment		
Living in institution	2	2.5
Living with family	55	68.75
Living with friend	3	3.75
Living with caregiver	1	1.25
Living alone	19	23.75
N	80	

\*Participants can have multiple choices if applicable to their profile.

in Hong Kong at the time of research. Penny has heart problems since childhood and acquired physical disability and depression when she reached middle age. Both Hung and Yan are physically disabled and have used walking aids from a young age.

### *11.5.2 Overview of the prevalence of interpersonal violence among participants*

Among 80 respondents in the online survey, 24 respondents (30%) reported having experienced domestic violence. Among the 24 respondents, over 80%

Table 11.2 Frequency and prevalence of interpersonal violence

<i>Frequency and Prevalence of Interpersonal Violence</i>	<i>Domestic Violence (N=24)</i>		<i>Sexual Harassment (N=27)</i>		<i>Sexual Violence (N=4)</i>	
	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
1–3 times	4	17	9	33	2	50
4–6 times	4	17	12	12	0	0
7–9 times	2	2	2	2	1	25
10 times or more	14	58	3	3	1	25

have experienced domestic violence at least once. Twenty-seven respondents (34%) reported having experienced sexual harassment, and four respondents indicated the experience of sexual violence. Among those respondents who reported sexual harassment, 45% of them experienced this at least once in their lifetime. Table 11.2 covers the prevalence of interpersonal violence among participants.

“Home” is the most common place where violence incidents take place according to the research. Out of the 24 participants who reported domestic violence, 96% indicated that violence took place at home; 2 among the 4 participants who reported sexual violence indicated that violence occurred at home.

In terms of perpetrators, 11 out of 24 (46%) who reported domestic violence were abused by their mothers, 9 (38%) reported being abused by their fathers, and 33% by other family members. For sexual violence, two out of the four respondents reported being abused by intimate partners and spouses and one by family members. The majority (70%) of participants who reported sexual harassment indicated being harassed by strangers.

Among the three interview participants, two informants reported having experienced domestic violence for over a decade. Penny reviewed her experience with her ex-husband and said, “I always felt threatened over the thirty years of our marriage. He wanted me to compromise by threatening me.”

Both Hung and Yan have mobility impairments, and they shared their urges to search for a non-disabled partner. Yan said:

when I was 25 years old, I was in an urge to find a partner and get married as soon as possible. Because of the impairment with my leg, I felt insecure and anxious about intimate relationship and marriage. The social norm taught me that girls with disabilities like me should put all her efforts into searching for a partner. If I couldn’t find a partner before I reached a specific age, I would become a “left-over” woman. The most important is that he needs to be a non-disabled person. I believe dating a non-disabled person can compensate for my flaws and disabilities on my body.

*11.5.3 Nature of interpersonal violence*

Among the 24 respondents reporting domestic violence, over 90% experienced verbal violence. Over half of them experienced physical violence such as spanking and hitting. Among 27 respondents who reported sexual harassment, about 66% experienced physical harassment; over 50% were harassed by indecent jokes and abusive speeches related to sex. Over one third received sex-related comments. Among the four respondents who reported sexual violence, two experienced combined forms of sexual abuse from unwanted touching and forced oral sex to forced intercourse (Table 11.3).

Women with disabilities often find it challenging to identify their experience as violence for several reasons. Firstly, they have low awareness of interpersonal violence. They usually interpret the experience as disputes and fights that are common in ordinary families (Brownridge 2006). Copel (2006) attributes such lack of awareness to their low self-esteem, sense of shame for their disabilities, and devaluing themselves to be “deserved” for mistreatment. “I did not see it as a violence issue in the first incident. After numerous times of being dragged to the street corner and beaten, I realized it was violence when I saw my head bleeding,” said Yan.

Secondly, their experience of violence often is closely connected to their disabilities. Disability-specific abuse can be restraining the use of needed medical equipment (e.g., wheelchairs) or essential communication aids, or withdrawing necessary help with daily chores (e.g., dressing, toileting, and bathing) (Nosek et al. 2001; Saxton et al. 2001). Yan shared:

*Table 11.3* Types of interpersonal violence

<i>Types of Interpersonal Violence</i>	<i>Frequency</i>	<i>%</i>
Domestic Violence		
Prevalence	24/80	30
Verbal insult/threats	22/24	92
Physical violence	14/24	58
Surveillance/stalking	7/24	29
Prohibition of contacting others	6/24	25
Sexual Harassment		
Prevalence	27/80	
Harassing your body	18/27	66
Indecent or abusive speech or jokes	15/27	56
Allusions/comments related to sex	9/27	33
Acts of indecency or exposure in front of you	8/27	30
Sexual Violence		
Prevalence	4/80	
Harassing your body	2/4	50
Forced intercourse against your will	2/4	50
Forced oral sex	2/4	50

he said marrying me was a remarkable thing for me because no one would be willing to marry a disabled person like me. However, disability is part of me. If he looks down on me due to my disabilities and considers that I should be grateful for being married to him, I feel I am being demeaned in this relationship.

Both Hung and Penny shared how their ex-husbands mocked about their body shapes. Penny looked back to the old days when they were dating:

women are unfairly treated by men since they were born. He could do whatever he wanted as I had no choice. He raped me at his sister's empty home during a date. I did not know how to respond. I just forced him to be responsible and marry me. Since then, he forced me to cooperate in rough sex. He then started to complain that I couldn't satisfy him sexually...he said I was like a corpse in bed. He said he felt like necrophilia. These words were very hurtful, but I couldn't tell my friends and family members.

Thirdly, due to their disabilities, they often depend on their ex-spouses to work and handle their financial matters. Yan made and sold handicrafts at home, and her ex-husband was the breadwinner. Penny was financially dependent on her ex-husband, who was a businessman. But in many cases, they needed to help their ex-husbands with their financial issues. Besides not paying off their debts, they also both reported that their ex-spouses withdrew their bank savings without their consent. Such a situation may be attributed to their trust in their ex-spouses but is also due to their physical disabilities since they depended on their spouses to visit banks and monitor their accounts. Hung said:

Since 1989, he started to borrow money from me and everyone. We used to have a joint bank account to save money to pay for our taxes. I have a habit of saving money as it is part of my personality. However, he was a big spender and left nothing by the end of the month...but in 2000, he asked for my tax records for loans. At that time, I realized that our joint bank account had no money left.

Penny depended on her ex-husband to manage her bank savings as long as he brought cash home for her daily living. While he no longer did so, she took the effort to check her bank account and was shocked because her account had only a few cents left in it.

Another commonly identified form of violence by the interviewees is social isolation. Penny shared how she was confined at home after major surgery on her leg. Her ex-husband unwelcomed her children, siblings, or friends to visit her. She was also not allowed to leave home and was dependent on the guard in the community to purchase food and daily supplies. She further shared, "I started to use Facebook and add new friends. When he found out my

Facebook, he accused me of searching for compensated dating.” Both Penny and Hung found out that their ex-husbands tried to create tension between them and their children. At first, they thought it was a parenting issue, but soon they found out that their ex-husbands’ intention was to create disagreements between them and the children.

My ex-husband thought that his son would bring him luck. When I asked my son to do his homework, he came to tear off his homework paper and said, “my son doesn’t need to learn, he just needs to bring me luck.” In the beginning, I thought he had his own parenting style, but I realized that he intentionally did so to spoil our son to create a sense of competition between mom and dad. He always described me as a tough commander who ruled the family and offered no room for negotiation. He always warned my children saying that “your mother is hiding a lot of money and one day, she will leave us.”

Penny no longer contacted her youngest son after she had a big fight with her ex-husband. After the fight, her son followed his father’s instructions to slap her in public. Penny realized that her younger son had much misunderstanding about her and she could hardly rebuild their relationship.

In general, the three interviewees reported a pattern of mixed forms of violence. Hung shared how violence escalated from time to time:

he used to asked me for money and argued with me. After several times, he started to shout at me and called me names. When he found that these tactics did not work, he would throw and tear things at home. I got so scared, so I gave him money again. Then, he started to be violent to my children. Sometimes he made them in between of our arguments and would scold them if they did not support him.

#### *11.5.4 Challenges in seeking help and escaping abusive relationships*

According to the online survey, 66% of the respondents who experienced domestic violence reported that they did not seek help, and 85% of the respondents who experienced sexual harassment did not seek help. For those who experienced sexual violence, none of them sought help. The majority explained that they “did not know how to respond” and were “forced to accept” what happened. Some of them even “pretended as if nothing happened.” Very few of them chose to express their fear and anger. They were reluctant to seek help from significant others, helping professionals, or police. Table 11.4 covers an overview of their responses. The main reasons for not seeking help include that they thought “seeking help is useless,” they “did not want to make it more complicated,” “did not want others to know,” and they “worried that it would affect the current relationship” (see Table 11.5).

Table 11.4 Response to interpersonal violence

<i>Response to Interpersonal Violence</i>	<i>Domestic Violence (N=24)</i>		<i>Sexual Violence (N=4)</i>		<i>Sexual Harassment (N=27)</i>	
	<i>%</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>
Forced to accept	46	11	100	4	41	11
Do not know how to respond	38	9	25	2	37	10
Pretend nothing happened	25	6	50	2	37	10
Stare with anger	17	4	0	0	7	2
Escape	8	2	25	1	11	3
Scream	4	1	0	0	7	2
Fight back	13	3	0	0	0	0
Tell family and friends	8	2	0	0	19	5
Seek help from organizations	17	4	0	0	4	1
Call police	8	2	0	0	0	0

Table 11.5 Reasons for not seeking help

<i>Reasons for Not Seeking Help</i>	<i>Domestic Violence (N=24)</i>		<i>Sexual Violence (N=4)</i>		<i>Sexual Harassment (N=27)</i>	
	<i>%</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>
Seeking help is useless	38	9	50	2	33	9
Do not want to make it more complicated	21	5	25	1	30	8
Do not want others to know	33	8	25	1	30	8
Feel shameful	8	2	75	3	26	7
Worry will affect relationship	29	7	50	2	1	5
Worry others will blame me	21	5	25	1	19	5
Abuser/predator escape	0	0	0	0	19	5
Do not know how to seek help	8	2	25	1	15	4
Afraid of troubles	13	3	25	1	15	4
Uncertain if it should be defined as violence	17	4	25	1	11	3
Worry abuser will be harmful to me	13	3	25	1	4	1
Worry that people will not believe me	21	5	25	1	4	1
I already seek help	17	4	0	0	11	3

All interviewees' experiences on violence basically can fit into the model of "Cycle of Violence," a commonly used framework describing abusive patterns in heterosexual relationships (Fisher and Lab 2010). The model contains three main phases: 1) Tension-building phase: stress (e.g., a tough day at work, personal issues, etc.) creates constant discord, impatience, and anger in relationship; 2) Acute battering phase: as tension in the relationship explodes, abusers conduct verbal, physical, or psychological violence to the other to gain the power to control the relationship; 3) "Honeymoon" phase: both parties make apologies for reconciliation, but they tend to deny the severity and occurrence of violence instead of solving problems and tensions in the relationship. For instance, Hung described financial issues as the trigger of their tension and how she tried to give him money to calm the tension. She shared:

I thought as long as I helped him to pay the debt this time, he may finally stop making the same mistake and affect our children and me. I just hoped he would change for the family. I did not think of divorce because I wanted a happy family. I granted an opportunity for us to get rid of the debts together. However, he could hardly stop for a few months, and a similar argument happened again and again.

Yan identified how she noticed the pattern: "once he felt upset, he would beat me... Every time after beating me, he would apologise and bought me new dresses. No matter how I felt, I was forced to have sex with him as reconciliation."

The interviewees shared how they tried to sacrifice for the marriage and family by rationalizing their experiences as part of the social norms in Chinese communities. Their gender role as wives and mothers is socially constructed as a sacrificing one in the family. For women with disabilities, they have to work even harder to earn recognition as a wife/ mother in the family. Hung recalled:

I knew that my mother-in-law was not happy that her son married a disabled person. I had no idea how to be a daughter-in-law nor gaining acceptance from my mother-in-law. However, my mother taught me to be obedient and hard-working on the housework. I never gave myself any time to relax.

Hung continued:

my mother repeatedly told me that I had to bear the hardness for my children. I had to suck it up as traditionally, women had to suffer and bear the pain to keep the family as a whole. I must accept it as part of motherhood. She walked through the path by accepting it.

Penny's narrative echoed Hung's:

my mother warned me that there were no better options in such an unpleasant marriage. She simply said, "never mention the word [divorce] with me..." I thought of the senior family members and two young children, so I decided not to talk to anyone. It is so common that men are tempered and swear with anger. But he acted so "normal" in our social gatherings. What can I say? I am the only person who knows I'm not happy in the marriage.

All interviewees shared their unpleasant experiences in seeking help. They rarely earn the recognition of their sufferings from significant others, if not getting blamed. Penny shared with her sisters her intention to divorce after her son's wedding: "my sisters strongly disagreed. They asked me not to make a scene after these many years of marriage. Moreover, my son just got married, how would my daughter-in-law and her family see me? They said I was too capricious." Yan recalled her experience in seeking help from her parents:

I hate them for all of my life. I called them when I was beaten half to death. They refused to come and see me. They said that I was now over 18 years old, this was my family issues which had nothing to do with them. I felt so hopeless. I had no one to turn to.

The interviewees not only sought help from significant others but also approached formal support such as social workers, lawyers, and the police. Hung approached social workers for help, but she recalled why she withdrew at the end:

the social worker said if my ex-husband was violent, I could apply for a safe house. However, since my elder child reached the age of 15, I could only bring my youngest child with me. I didn't want to separate from him, so I decided not to go.

Yan also described the re-traumatizing experience of seeking help from the police:

there was a time I called the police for help. When police arrived, they were not helpful and blamed me for doing something wrong as if I deserved it. Since then, my ex-husband became more violent as he knew that the police would not take care of these issues. I lived in fear and tension at home.

Interviewees also shared their feelings of helplessness, despair, depression, and anxiety. Although their experiences of violence were from decades ago, both Hung and Penny still required psychiatrist counselling and medication.



Their situation echoes Walker's concept of "learned helplessness" and "battered woman syndrome," which describe the psychology of battered women being chained in the cycle of violence (Fisher and Lab 2010). According to the "learned helplessness" theory, battered women tend to learn to give up making any efforts to escape from abusive relationships since repetitive, abusive experience has presented a distorted reality that they have no opportunities to escape. However, the interviewees consistently reflected on the situation and explored ways out. Hung described, "I was so disappointed. There was no more love in our marital relationship. I just couldn't bear it anymore. I was determined to end this relationship."

### *11.5.5 Getting out of the abusive relationship*

Although quantitative data did not provide details on how respondents sought to get out of the abusive relationship, the interviews have provided detailed descriptions of how they navigate for more recognition and support from others and their hopes for a new life. Yan shared:

in the beginning, I thought I was wrong, but I no longer felt that way later. I just felt I couldn't continue living my life this way. During my childhood, my mother got beaten by my father, and they still stuck together all of their lives. However, I didn't want to live my life like her. I had no more feelings of hope for him. I just thought I should leave if I didn't want to live my life this way.

All interviewees shared that the turning point in their abusive relationship was the recognition of the severity and consequences of such a relationship. Hung described the sudden drop in her son's academic performance as a wake-up call:

I was not a tough person, but I was forced to be tough to protect my two children. My elder child was a top student in school. He always got the highest score in mathematics, but he failed that year. I was so surprised to find out that he was under great stress and anxiety. It turned out that he had to see a psychiatrist.

Yan echoes how her ex-husband finally became aware of the consequence of such an abusive relationship. She said:

I started to doubt my life, thinking why I was living in hell. I had no more feelings for him. All I wanted is to leave, but he didn't want to divorce. One day, he beat me again, and I accidentally cut his hand by waving a knife to protect myself. He called the police, and this time, the police convinced him to divorce. The parents of my ex-husband worried that similar situation would occur again. Therefore, he agreed to divorce.

All interviewees shared their experience in seeking help and support from others to escape from or terminate the relationship. Penny's social worker provided her with a legitimate reason for divorce: "when I found that I had no more money, my social worker said you could apply for Comprehensive Social Security Assistance (CSSA) Scheme, but you need to divorce. I was so relieved as I could finally terminate this marriage and get help to live independently." Hung shared her experience in getting help from her sister and friends:

my sister came to pick us up at my home at midnight. My ex-husband didn't dare to open his door to face my sister. I asked my children's opinion as I explained, "once we step out of the door, we will never return." My children supported my decision to follow my sister. She provided a bedroom at her home as a temporary shelter. Also, I had a friend, who was a parent of my children's schoolmate, to help me to pack up our stuff from my home.

Penny explained that although her sisters did not support her decision to divorce, she had a group of friends who sympathized with the situation. Although she felt disappointed about the dispute with her sisters, she decided to take her sisters' opinions less seriously.

In general, their narratives fit in Kearney's (2001) "4 stages to step out of abusive relationship": stage 1, "this is what I wanted": women usually choose to see early violence as self-sacrifices for their loving relationship; stage 2, "the more I do, the worse I am": women realize their self-sacrifices and temporary solutions are no longer useful to pacify the constant tension in the relationship; stage 3, "I've had enough": women reach a turning point when they find it challenging to tolerate violence in the decayed intimacy; stage 4, "I have found myself": women rebuild a life with new life goals, new homes, and new relationships with others. Despite facing grief and traumatic feelings from past relationships, they often identify significant personal growth with better self-efficacy.

## **11.6 Discussion**

As shown, women with disabilities faced all sorts of violence for long durations. Such violence is strongly correlated to their disabilities and gender. They have been taught to be dependent on others to navigate their daily lives and were rarely aware that they have a choice to reject unequal abusive relationships. Triggers of the violence can be caregiving stress, financial issues, as well as unsatisfactory interpersonal relationships. A core issue here is their belief that they could only count on their significant others although they were the perpetrators. According to the questionnaire, they tend not to take any actions to fight against violence due to lack of planning and awareness. According to our interviewees' sharing, they faced challenges in reporting violence in fear that they would not be treated seriously by their significant others and

helping professionals. “Blaming the victim” also has made them less willing to denounce the violence.

Social discourses on disability and gender have a significant impact on women with disabilities in terms of their self-esteem and beliefs on their roles in a relationship. Since women with disabilities are strongly stereotyped as “damaged goods,” they are mistreated by their significant others, and as a result, they see themselves as less worthwhile and powerless in a relationship (Ballan and Freyer 2012). For example, Hung was taught by her mother that she had to work harder at home to earn the acceptance of her mother-in-law. She was frustrated that giving birth to two children and helping her husband’s debts did not gain approval from her mother-in-law.

Goldstein and Johnson (1997) point out that partners of people with disabilities are also being stigmatized due to their association with disabilities. According to Yan, her ex-husband considered himself as “kind enough” to marry her despite her disability and thought that she should be grateful. Wisseman (2000) has also reported the myth among people that anyone willing to be a partner of a woman with disabilities is kind-hearted and even a “saint.” For this reason, women with disabilities have been discouraged from complaining or will be seen as being “too capricious” if they do, as described by Penny. Such biases affected how Yan found seeking help from police a re-traumatizing experience as she got blamed by the police. In sum, women with disabilities tend to feel they are less valuable and powerful in marriage. They usually do not know how to navigate the power relationship with their partners and find it very challenging to deal with domestic violence.

One of the core factors behind women with disabilities’ vulnerability for interpersonal violence is that the social structure has hindered their opportunities to be physically and financially independent. Yoshida et al. (2011) found that low household incomes have strong correlation with interpersonal violence for two main reasons. Firstly, women with disabilities are financially dependent on their spouse and family members. Secondly, lack of social support and resources lead to poverty among families of people with disabilities. For example, the government provides limited allowance for caregivers. Our online survey has revealed that the majority of respondents completed secondary education and may earn a reasonable income. However, according to our interviews, despite the fact that they were able to earn enough money for living, they still considered their ex-husbands as the core breadwinners. Besides financial dependence, the interviewees shared their expectations of having a non-disabled spouse and getting support for daily activities. Penny depended on her ex-husband to visit the bank. Yan considered herself a housewife and spent most of her time at home. Hung decided to withdraw from the disabled community because of her marriage. Social isolation is also the main barrier for them to engage with society and others.

Our online survey has shown that very few women with disabilities sought help to fight against interpersonal violence, but our interviews demonstrated more agency. Women with disabilities constantly face a lot of discouragements

and challenges when they seek help from significant others. However, rejection and blame from others did not stop the interviewees from seeking acceptance and support from others. Hung did not leave the apartment until her sister came to assist her departure and, most importantly, offering her bedroom as a temporary shelter. Penny and Yan did not have much support from their families, but they valued the emotional and practical support from their friends. They reported a lack of support from helping professionals and agencies. Penny's social worker suggested she apply for social security allowance when she was in need. Hung decided not to go to the safety house not only because she could not bring her teenage child with her, but also because she lacked information about the services. Yan considered that police could not handle violent incidents against people with disabilities.

### 11.7 Implications

The findings of this research provide some insights for policymakers and service providers. Firstly, it is essential to further develop research and collect statistics and data related to interpersonal violence against women with disabilities. Such information will facilitate strategic planning and policymaking to build support networks for battered women with disabilities.

Secondly, it is essential to promote the independence of women with disabilities. To be more specific, a barrier-free social environment is critical so that they can engage with society. Policymakers should also provide support to family members of women with disabilities.

Thirdly, it is important to raise awareness of individuals with disabilities, their family members, and friends as well as helping professionals. This article has illustrated the power of informal support networks as the resources for help among women with disabilities. For service providers and helping professionals, it is vital to enhance their capacity to address violence against women with disabilities.

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## 12 Voice and empowerment

### Addressing and preventing domestic violence against women with disabilities

*Yuan Feng and Yang Hao*

#### 12.1 Introduction

Women with disabilities experience various types of domestic violence, and the forms of violence often intersect with one another. Women with disabilities often encounter challenges from both their families and the society, which are based on multiple gender- and disability- related discrimination and stigma. Women with disabilities often need support from their communities and their needs are often not responded to efficiently or effectively. There are still gaps in enforcing China's Anti Domestic Violence Law. Recommendations are given to address and prevent domestic violence against women with disabilities, including popularizing China's Anti Domestic Violence Law, building the capacity of stakeholders, identifying and fulfilling the needs of women with disabilities from a rights-based perspective, effectively implementing China's Anti Domestic Violence Law, and empowering women with disabilities by improving their access to education.

#### 12.2 Background information

##### *12.2.1 International framework*

Both experience and research have shown that women have multiple vulnerabilities when encountering disability. According to the World Disability Report, about 15% of the world's population experience certain forms of disabilities and the disability prevalence is higher with women (19%) than men (12%). Between 65% and 70% of women with disabilities in low- or middle-income countries live in rural areas (WHO and WB 2011).

Women and girls with disabilities experience disproportionately high rates of violence, and the perpetrators may be their family members, caregivers, or strangers. A study from the United Nations Population Fund (UNFPA 2018) reveals that girls and young women with disabilities are subject to ten times more gender-based violence than those without disabilities. Overall, the rate of sexual abuse against people with disabilities is higher than against those without disabilities (WHO and WB 2011). Girls with intellectual disabilities are



particularly vulnerable to sexual violence (UNFPA 2018). However, women and girls with disabilities that experience gender-based violence often have limited access to services and justice (UN General Assembly 2017). Adolescents and adults with disabilities are also much more likely to be excluded from sex education programmes and sexual and reproductive health care services (WHO and WB 2011).

Under the UN Convention on the Rights of Persons with Disabilities (CRPD), Article 16 on “freedom from exploitation, violence and abuse” refers explicitly to the issue of gender-based crimes. It stipulates that legislative, administrative, social, educational, and other measures should be taken by the State Parties to protect persons with disabilities, both within and outside the home, from all forms of violence including gender-based violence. Forms of gender- and age-sensitive supports and services should be provided for persons with disabilities, their families, and caregivers, and the assistance programmes should be effectively monitored by independent authorities. Legislation and policies need to be in place to ensure that cases of violence against persons with disabilities are identified, investigated, and prosecuted. It also highlights the development of preventive strategies and recovery, rehabilitation, and social reintegration of persons with disabilities suffering from gender-based violence. Article 25 clearly states that the State Parties shall provide persons with disabilities with quality and affordable gender-sensitive health care and rehabilitation programmes, including sexual and reproductive health services without discrimination against disability.

In 2012, the UN Special Rapporteur (2012) on Violence against Women, its Causes and Consequences submitted a report on Violence against Women with Disabilities to the UN General Assembly, which emphasized a social model of understanding violence against women with disabilities. The social model challenges the physical and social environments, and the legal frameworks that negatively affect persons with disabilities. The Special Rapporteur concluded that the CRPD, the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), and other international legal instruments had been widely ratified; however, it remained difficult to assess whether these instruments were effectively implemented to prevent and respond to violence against women with disabilities. Up to now, most countries lack specific or general laws and policies for protecting persons with disabilities from violence, especially for women with disabilities.

### *12.2.2 China's legal framework*

Official statistics from the *Third Wave Survey on the Social Status of Women of 2011* show that 24.7% of all married women in China have suffered at least one form of domestic violence from their husbands (ACWF 2011). However, China lacks national statistics concerning gender-based violence or domestic violence against persons with disabilities. According to a study carried out in Hei Longjiang province in 2011, 21% of disabled women in rural areas

have experienced at least one type of domestic violence in their marriage (Xin 2013). A small-scale focus group study conducted by Disability Associated Women Support Group (DAWS) in 2017 showed that domestic violence is a severe issue for women with disabilities in mainland China. The most common form is psychological violence, followed by physical violence.<sup>1</sup>

China's Anti Domestic Violence Law (Anti-DV Law) was enacted in 2016 and as of March 1, 2021, 12 out of 31 provinces, autonomous regions, and municipalities had promulgated their provincial regulations to facilitate local implementation of the Anti-DV Law (Equality 2021). The Law defines domestic violence<sup>2</sup> as the "infringing of physical, psychological or other harm by a family member on another by beating, tying, injury, restraint and forcible limits on personal freedom, recurring verbal abuse, threats and other means." The definition covers not only relations within marriage, but also cohabitating partners and family members. For people with disabilities, other than violence from intimate partners, parents, and children, it is also within the scope of the Anti-DV Law if the perpetrator is a caregiver or guardian living with them.

The Law highlights the special protection for disabled persons, minors, the elderly, seriously ill persons, and women in pregnancy and breastfeeding (Article 5).<sup>3</sup> The Anti-DV Law has created a system of mandatory reporting for persons with no civil capacity or limited civil capacity who have suffered or are suspected of suffering from domestic violence. As far as the disabled persons are concerned, in practice, except for minors under the age of 18, persons with no or limited capacity for civil conduct generally only include persons with intellectual disabilities and mental disabilities. In some provincial-level anti-DV legislation, the scope of mandatory reporting has been expanded. For example, in the anti-DV regulations of Shandong province and Inner Mongolia, the compulsory reporting not only covers persons with no capacity or limited capacity for civil conduct, but also includes "people who have suffered or are suspected of having suffered domestic violence but cannot report the crime due to old age, disability, serious illness, coercion, intimidation, etc."

Other important measures stemming from the Anti-DV Law include warning letters and protection orders. The Law stipulates public security agencies

1 Two focus group discussions with a total of 33 women and two men with physical or intellectual disabilities, visual or hearing impairment. Study results were shared by DAWS in a UN workshop on Elimination of Gender Based Violence through Legal and Policy Advocacy held in Beijing in January 2018.

2 [Anti-Domestic Violence Law of the People's Republic of China] (promulgated by the Standing Committee of the National People's Congress, December 27, 2015, effective March 1, 2016), <[www.lawinfochina.com/display.aspx?id=20841&lib=law&EncodingName=big5](http://www.lawinfochina.com/display.aspx?id=20841&lib=law&EncodingName=big5)> (China), visited 9 October 2020.

3 Article 5: The minors, the elderly, the disabled, pregnant and lactating women, and seriously ill patients suffering domestic violence shall be given special protection.

must issue warning letters to minor offenders (Article 16)<sup>4</sup> and anyone who is suffering from domestic violence or is facing a real danger of domestic violence can seek personal safety protection orders from the people's court (Article 23).<sup>5</sup> The provincial anti-DV regulations in Hubei also specifically stipulate that as one of the special groups protected by the Anti-DV Law, when people with disabilities suffer domestic violence, the public security organ shall issue a warning letter to perpetrators.

According to the Anti-DV Law,<sup>6</sup> for persons with no or limited capacity for civil conduct, or those who are unable to apply in person due to coercion, intimidation, etc., the victim's close relatives and key responsible agencies may apply on their behalf for protection orders. In 2018, the local District Disabled Persons' Federation in Putian city of Fujian province applied for a personal safety protection order to the court on behalf of domestic violence victim Lu who has intellectual disability, on the grounds that she is in danger of domestic violence and could not submit an application as a result of being threatened.<sup>7</sup> The local court thereafter granted a protection order for Lu and prohibited the perpetrator from committing domestic violence and moving within 200 metres of Lu's work unit. This was the first case in China in which the Disabled Persons' Federation submitted a protection order application on behalf of the disabled domestic violence victim.

In addition, the Anti-DV Law provides measures of revocation or transfer of guardianship (Article 21)<sup>8</sup> as well as temporary shelter and short-term

4 Article 16: Where the domestic violence is not serious enough for public security administration punishment in accordance with the law, the public security organ shall criticize and educate the inflicter or issue a caution letter.

The caution letter shall cover the inflicter's identity information, statements of facts of domestic violence, and content of prohibiting the inflicter from committing domestic violence, among others.

5 Article 23: Where a party concerned applies to the people's court for personal safety protective order due to suffering domestic violence or facing real danger of domestic violence, the people's court shall accept the application.

6 Article 23: Where the party concerned is unable to apply for personal safety protective order because he or she is a person with no or limited capacity for civil conduct, or is coerced or threatened, his or her close relatives, the public security organ, women's federation, residents' committee, villagers' committee, or relief management institution may apply on his or her behalf.

7 <http://jfy.chinacourt.gov.cn/article/detail/2021/12/id/6455306.shtml>

8 Article 21: Where a guardian commits domestic violence which has seriously infringed the lawful rights and interests of the ward, the people's court may, upon the application of the relevant person or entity such as a close relative of the ward, residents' committee, villagers' committee, and the civil affairs department of the people's government at the county level, disqualify the guardian in accordance with the law, and designate a new guardian.

The inflicter whose guardianship is revoked shall continue to burden the appropriate alimony for the spouse or the costs for supporting the aging parents or children.

living assistance (Article 15)<sup>9</sup> to enable a better protection for persons with disabilities.

Despite the considerable progress since 2016, there are still many challenges and gaps in the implementation of the Anti-DV Law in protecting the rights of women with disabilities.

There are no comprehensive judicial interpretations for providing specific guidance in implementing the Anti-DV Law which is urgently needed to address uncertainties such as refining the definition and scope of domestic violence and clarifying the evidentiary standards, obligations of non-compliance with mandatory reporting obligations, as well as the issuance standards for personal safety protection orders, etc.

There are inadequate implementation measures from the responsible departments. Except for the Women's Federation, other responsible departments with specific responsibilities clearly specified in the Anti-DV Law, including the Ministry of Justice, the Ministry of Public Security, the procuratorate, the courts, and the Disabled Persons' Federation have not yet issued specific requirements and guidelines for their front-line staff to carry out anti-domestic violence work. There is a lack of data and information from the Disabled Persons' Federation regarding their implementation of the Anti-DV Law.

The mechanisms of mandatory reporting are still unclear, and the mandate has been applied mostly to minors. In legal practice so far, the mandatory reporting has not been seen to cover other vulnerable groups that are specially protected by the Anti-DV Law including people with disabilities, especially those with intellectual and mental disabilities. Protection orders and warning letters are also underutilized. Data on the number of warning letters issued in each province and their effectiveness is fragmented and incomplete and the approval rate of protection orders was 71% by February 2020 (Wumei Law Firm 2020).

By exploring the current status of women with disabilities suffering from domestic violence in China, this article aims to provide policy recommendations to improve their situation. Data and excerpts presented in the following sections are mainly from a published report, which introduced stories of 15 disabled women who have experienced domestic violence (henceforth "15 stories"). These women have diverse backgrounds in age, geographic locations, and social class. DAWS collected their stories from in-depth interviews with these women from 2016 to 2018. The stories reflected a range of living situations of disabled women under domestic violence: some successfully escaped; some were still trapped; others were in the process of seeking support

9 Article 15: Where persons with no or limited capacity for civil conduct are suffering grievous bodily injury, facing personal safety threats, unattended, or under any other dangerous state due to domestic violence, public security organs shall notify civil affairs departments, and assist the departments in relocating such persons to temporary shelters, relief management institutions, or welfare institutions.

(Feng, Xiong, and Ma 2018). All names in these stories have been replaced with pseudonyms.

### **12.3 Manifestations of domestic violence against women and girls with disabilities**

Women with disabilities experience various types of domestic violence, and the forms of violence often intersect with one another. In one of the 15 stories, Liu Ping was born with congenital diseases, and abandoned by her grandfather when she was a little girl. She has experienced both physical and psychological abuse from her adopted daughter, including being forced to do things and being scolded or threatened frequently. Her adopted daughter also controlled her economically by continuously asking for money.

Women with disabilities experience various gender-based discrimination and violence from a young age. Among the 15 stories, there were cases in which disabled women were abandoned, and others were prevented from leaving home or from going to school during their childhood. Adolescent girls with disabilities had fewer opportunities to complete secondary education and they were hidden by their families or subjected to limited mobility. For those who had jobs, their income tended to be controlled by their families. Women with intellectual disabilities in the stories were highly vulnerable to sexual violence, while disabled adolescents were often regarded as asexual and had no access to sexual and reproductive health information and services.

For adult women with disabilities in the stories, violence occurred in different forms. Some women were not allowed to obtain further study or employment, to handle their income, and were deprived of ownership of property. Some women were forced to date, marry, or separate from their loved ones. Stories also showed that disabled women were beaten or threatened by their husbands. They cannot seek divorce or see their children, while being sexually abused or treated as a reproductive tool. Sexual violence such as forced marriage or remarriage, forced pregnancy, abortion, and sterilization all occurred in the stories, among which sterilization was regarded as a common issue in China. The Concluding Observations issued by the Committee on the Rights of Persons with Disabilities to China's initial report in 2012 raised the concerns of forced sterilization and abortion for women with disabilities (UN 2006). The 15 stories also indicated that elderly disabled women were more vulnerable to economic exploitation and physical or emotional abuse by their family members due to lack of financial independence.

Nearly half of respondents with disabilities experienced some form of violence during the COVID-19 pandemic, the highest among any given group (nearly 54% experienced no violence of any kind, the lowest among any given group).<sup>10</sup>

10 Data from a presentation by Dr Yuan He at a seminar at University of Hong Kong on February 2, 2021, based on 11,204 questionnaires with a completion rate of over 96%. These

Table 12.1 Gender-based violence within different groups

	<i>Disabled persons</i>	<i>Migrant business women</i>	<i>LGBTIQ</i>	<i>Ethnic minority women</i>	<i>People living with HIV/AIDS</i>	<i>People over 60 years old</i>	<i>Cisgender woman</i>
Abused	32.8%	21.2%	32.7%	22.5%	22.8%	8.0%	19.2%
Beaten	5.6%	2.3%	4.6%	2.5%	2.3%	0.0%	2.0%
Denied to medical service	5.3%	1.5%	2.3%	1.8%	1.5%	4.0%	1.4%
Economic control	16.9%	9.3%	12.7%	10.1%	10.0%	4.0%	7.1%
Sexually harassed	10.9%	8.2%	12.7%	7.6%	7.6%	4.0%	7.3%
Sexually assaulted	2.1%	1.0%	1.0%	1.0%	1.1%	4.0%	0.6%
Others	5.3%	4.3%	3.5%	3.6%	3.4%	16.0%	3.5%
No above experience	53.8%	70.4%	60.5%	70.0%	69.6%	92.0%	73.2%

Source: Dr. Yuan He

Looking at the result of this survey from an intersectionality perspective, women with disabilities, especially non-heterosexual women with disabilities and non-binary women with disabilities, had the highest rates of experiencing gender-based violence (Feng 2021).

## 12.4 Challenges for women with disabilities who experience domestic violence

### 12.4.1 *Gender stereotype and social norms on disability*

The 15 stories showed that women with disabilities often encounter challenges from both their families and society, which are based on multiple gender- and disability-related discrimination and stigma. For example, Chinese parents often see children as their property. In one of the stories, the parents were reluctant to support their daughter to complete compulsory education. Families in the stories denied the decision-making rights of women with disabilities because they were regarded as incapable of taking charge of their bodies or lives. Women in the 15 stories had experienced discrimination and violence particularly targeting their status of disabilities. They were insulted for their physical disabilities, starved or neglected by their caregivers, restricted of liberty, forced to have sex in exchange for help, and so on. Due to their disabilities and dependence on assistance from inside or outside of their families, women with disabilities tend to be more submissive to the abuse and domestic violence they have experienced.

Domestic violence is often in the name of love, yet originated from the deep-rooted gender stereotype and bias against disability. Two women with disabilities in the stories (Lu Ming and Yue Ya) were not allowed by their parents to seek a divorce, although they suffer frequent domestic violence from their husbands. In another story, Xiaohe was sent back to her ex-husband by her parents after the divorce, and was forced to remarry him because her parents think marriage is the most important guarantee for a disabled woman. Weiwei was not allowed to go to work by her parents-in-law as they think it is not convenient for a woman with visual impairments to move around and she should just stay at home after marriage. Studies also show that women with intellectual disabilities are forced by their families to stay in psychiatric hospitals (Ma 2014).

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11,204 respondents came from 31 provinces, autonomous regions, and municipalities in mainland China, including a small number of compatriots currently living overseas, covering a total of 43 ethnic groups. Among them, 90% were (cisgender) females, 6% were (cisgender) males, and 4% were non-conventional genders (people who thought they did not belong to the existing gender category). Respondents under the age of 40 accounted for 96% of the total; those with a college degree, bachelor degree, or above accounted for 85% of the overall respondents.

Due to discrimination, family members tend to isolate disabled women from society. In order to control women victims of domestic violence, perpetrators often block them from their social connections, including their parents and close relatives. The Chinese custom of living with the husband's family after marriage causes many disabled women, especially those from rural areas, to be separated from their original families and communities. As "outsiders," women with disabilities often find it difficult to get effective support from the governing body in the village (such as village committees) or neighbourhoods. Insufficient social support makes women with disabilities dependent on their families or perpetrators emotionally, financially, and physically, which results in significant difficulties for them to escape from violent relationships.

The 15 stories also indicated that it is hard for women with disabilities to be independent of their intimate relationships, marriage, sexuality, and reproduction. The parents or other family members usually make decisions for disabled women. They either prefer to marry their disabled daughter to someone also with disabilities and make sure they are "the same" and "equal," or to "sound people" as they regard their daughter's disability as incompetent and need a "competent" husband to take care of their daughter. The existing gender norms on marriage are considered essential for women with disabilities and even if they experienced domestic violence, maintaining a family is better than being alone.

A focus group study with 32 women with disabilities in Beijing and Yunnan province<sup>11</sup> shows that women with disabilities, especially those living in rural areas and those with intellectual disabilities, are likely to be treated as mere reproductive tools. They are subject to sexual assault or marital rape. One extreme case stood out in the study where a woman with mild intellectual and language disabilities was used as a tool for reproduction by her husband. The intervals between her births were short without any consideration of her body conditions, and her husband sold her children for money.

Furthermore, the sexual and reproductive rights of women with disabilities are often ignored or denied because they are seen as sexually unattractive or asexual, without reproductive ability (Ma 2014). Therefore, they are prevented from gaining knowledge about their body, information and services on family planning, sexually transmitted diseases including HIV/AIDS, or maternal health care. In some cases, they are not allowed to have intimate relationships, get married, or get pregnant. Women with functional limitations were less likely to be offered information on contraception (WHO and WB 2011). Women with intellectual impairments in minority ethnic communities

11 The study was carried out by Handicapped International for four focus group discussions with 32 women with different types of disabilities (physical disabilities, mental disorders, and visual impairments) in Beijing and Yunnan in 2018; Handicapped International has authorized the use of data in this chapter.



have even less access to such health care information and services (WHO and WB 2011).

#### *12.4.2 Limited access to services and justice*

Women with disabilities often need support from their communities such as local women's federations, disabled people's federations, and community committees. However, their needs are often not responded to efficiently or effectively. The enforcement of the Anti-DV Law from the public security department is not in place, either. In the 15 stories, when the disabled victims of domestic violence called 110 – the public emergency hotline – the police often refused to intervene because domestic violence is still taken as a private matter and thus not under their responsibility. Despite six years of implementation of China's Anti-DV Law since 2016, there is still a huge gap in the awareness and capacity for the police to respond to domestic violence complaints, for instance, keeping quality records when managing domestic violence cases, taking evidence seriously, not blaming domestic violence victims, and issuing warning letters to perpetrators in accordance with the law.

The court also often failed to act according to the law. Domestic violence is one of the circumstances that can be judged for divorce under the Marriage Law and the Anti-DV Law in China, which requires the court to file applications for protection orders and to verify domestic violence in the trial. However, due to gender bias and lack of training and awareness among the judges, it is difficult for disabled women who suffered from domestic violence to obtain such judgement from the court for protection orders or divorce (Zhang and Feng 2019). In divorce mediation, the consideration of domestic violence is even more invisible. The 15 stories showed the court did not offer favourable consideration to domestic violence victims in the division of property, and compensation for domestic violence victims is seldom implemented. According to a study of 560 court judgements between 2016 and 2018, only four applicants seeking protection orders were disabled persons (Zhang and Feng 2019). Two of the applicants had repeatedly contacted government agencies, women's federations, village committees, and other government agencies for help but failed to get their assistance. In terms of seeking help from non-government bodies, a study shows that there are few NGOs capable of providing service for disabled women victims in China, especially in rural areas (Xia 2018). The lack of formal and informal supporting systems leads some disabled women to use violence as the last resort against domestic violence, which often results in double tragedy (Feng 2013). The perpetrators pay the price of health and life and domestic violence victims often end up with legal punishment.

On the other hand, it is also worth noticing that the 15 stories revealed significant changes in those women with disabilities. The interviewees insisting on getting a divorce after experiencing domestic violence have started a new life, continued further studies, pursued new jobs, and become financially independent.

## **12.5 Policy recommendations**

Although it is impossible to present a full picture of domestic violence faced by disabled women in China, based on the 15 stories and limited research, analysis in this study can help to discover some of the current status and unmet needs of disabled women under domestic violence, thus to propose recommendations to improve the enforcement of the Anti-DV Law.

In order to better protect women and girls' rights stipulated under the Constitution of the People's Republic of China and relevant laws, especially the Anti-DV Law, and to fulfil China's obligations in international conventions such as CRPD, CEDAW, and the Convention on the Rights of Children (CRC), the study has proposed the following policy recommendations.

### *12.5.1 Popularize the Anti-DV Law*

Government and social organizations should promote activities to popularize the Anti-DV Law among women and girls with disabilities to help them fully understand their rights and access to services and support. It is also urgent to raise the awareness of their parents, spouses, and other caregivers in domestic violence and Anti-DV Law to prevent the use of violence, and foster respect for disabled persons' choices of education, work, mobility, personal life, sexuality, and reproduction.

### *12.5.2 Build the capacity of stakeholders*

The 15 stories and other studies show there is a significant capacity gap among individuals and public agencies to provide effective support and assistance for women with disabilities experiencing domestic violence. According to Articles 4 and 6 to 14 of the Anti-DV Law, agencies responsible for anti-DV include the People's Court and the Procuratorate, the Working Committee on Children and Women of all levels of government, bureaus of public security, justice, civil affairs, education, health, news and publishing, township governments and sub-district offices, federations of workers, youth, women, and disabled persons, social organizations, residents' committees, villagers' committees, corporates, guardians, and individual citizens. Accordingly, the responsible parties of state organs and social organizations should strengthen the capacity of their personnel to provide quality support and service for domestic violence victims and also deal with perpetrators. It is also important to raise the awareness of guardians on domestic violence and redress their violent behaviour.

### *12.5.3 Identify and fulfil the needs of women with disabilities from a rights-based perspective*

In addition to the general service to respond to domestic violence, it is necessary to take into account the individual needs of women with disabilities and provide reasonable accommodations.

To achieve this, the government is supposed to conduct data collection and research, encourage and support social organizations, especially Disabled People's Organizations (DPO) for women, and enhance their capabilities. The government should effectively cooperate with social organizations to develop and disseminate publicity materials and improve the accessibility of anti-DV services for people with disabilities, especially those with visual or hearing impairments. For example, 110 or other hotline services should be accessible to hearing impaired people; shelters and service centres should adjust their services to meet the needs of women and children with different disabilities. Therapists and psychiatrists should be trained with basic skills to identify and deal with domestic violence cases.

#### *12.5.4 Effective implementation of the Anti-DV Law*

The capacity of legal workers, including lawyers, police officers, prosecutors, and judges, should be enhanced to effectively implement the Anti-DV Law, such as mandatory reporting, temporary shelter, warning letters, protection orders, and the withdrawal of custody. For example, educational institutions, welfare agencies, and community-based organizations should be supported to fulfil their mandatory reporting obligations and responsibilities.

Like other responsible agencies stipulated by the Anti-DV Law, the disabled people's federations should strengthen their awareness of the Law and improve their capacity to provide quality assistance to disabled domestic violence victims, including accepting complaints, fulfilling their responsibilities of mandatory reporting, assisting in requesting warning letters and submitting protection order applications on behalf of the victims, providing anti-domestic violence education and psychological counselling for perpetrators, etc. With reference to the work procedures for the women's federations to handle domestic violence cases, the disabled people's federations should also develop their internal anti-domestic violence work process and guidelines.

#### *12.5.5 Empowering women with disabilities by improving their access to education*

The 15 stories have shown that many women are unable to attend school or complete their studies because of their disabilities. Research also shows that women with disabilities have significantly less access to education compared with normal women or disabled men (Guo et al. 2013). Education is important for women with disabilities to survive, develop, and to prevent violence. Allowing every disabled woman to complete compulsory education and support them to get further education is essential to achieving equal educational opportunities.

In addition, China's Anti-DV Law stipulates that educational institutions should carry out anti-DV education. The UN 2030 Sustainable Development Goals (SDGs) also set a target to ensure all learners acquire human rights, gender equality, and non-violence related knowledge and skills among the

member states, including China. Therefore, education on gender equality and prevention of and response to gender-based violence should be incorporated in all levels of education, especially for women and girls with disabilities.

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# Annex: Relevant international human rights instruments

*River Hustad*

## A.1 From a principle of equality to the right to equality

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UN Charter	<i>Article 1 (2)</i> (“principle of equal rights and self-determination of peoples”); <i>Article 1 (3)</i> (respect for human rights “for all without distinction”); <i>Article 2 (1)</i> (“sovereign equality” of states); <i>Article 8</i> (equality between men and women); <i>Article 13 (1)(b)</i> (General Assembly promotion of human rights); <i>Article 55 (c)</i> (promotion of universal respect for human rights); <i>Article 76 (c)</i> (Trusteeship system respect for human rights); <i>Article 77</i> (“sovereign equality”); <i>Preamble</i> para. 1.
UDHR	<i>Article 1</i>
CESCR	<i>Article 2 (2)</i>
CCPR	<i>Article 2(1)</i> <i>Article 26</i>
CRC	<i>Article 2</i>
CRPD	<i>Article 5</i> – Equality and non-discrimination
CMW	<i>Article 7</i>
The European Convention on Human Rights (ECHR)	<i>Article 6</i> Right to a fair trial
HRC, <i>General Comment 18</i>	para. 4 & 7
HRC, <i>Sandra Lovelace v. Canada</i> (Communication R.6/24, UN Doc. A/36/40, 1981)	paras. 14–15.
Asbjørn Eide, <i>The Right to Food as a Human Right</i> (UN Doc. E/CN.4/Sub.2/1987/23, 7 July 1987)	Like all human rights, the nature of the right to equality has three dimensions of state obligations: the obligation to respect equality, to protect equality, and to fulfil equality.

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## A.2 The nature of human rights obligations towards equality

### A.2.1 *Obligation to respect*

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Treaties	American Convention on Human Rights <i>Article 24</i> . Right to Equal Protection African Convention on Human and Peoples Rights <i>Article 3</i> . European Convention on Human Rights <i>Article 14</i> . Prohibition of discrimination
General comments	HRC, GC 18, para. 12 CESCR, General Comment 12, para. 15
Jurisprudence	HRC, <i>Broeks v. The Netherlands</i> , CCPR/C/OP/2 at 196 (1990) HRC, <i>Waldman v. Canada</i> , CCPR/C/67/D/694/1996 HRC, <i>Garcia Pons v. Spain</i> , CCPR/C/55/D/454/1991 (1995) Inter-American Court of HR; <i>the "Street Children"</i> ( <i>Villagran-Morales et al.</i> ) <i>v. Guatemala</i> , Nov 19, 1999

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### A.2.2 *Obligation to protect*

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Treaties	CERD Article 2, 4 (a) & (b), 7 CEDAW Article 2, 5, 10 CCPR Article 20
General comments, concluding observations, and general recommendations	HRC, <i>General Comment 28</i> (2000), para. 4, 31 HRC, <i>General Comment 31</i> (2004), paras. 7–8 CERD, <i>General Recommendation 26</i> (2000), paras. 1–2 CEDAW, <i>General Recommendation 19</i> (1992), para. 24 HRC, <i>Concluding Observations on Venezuela</i> (UN Doc. CCPR/CO/71/VEN), para. 23 HRC, <i>Concluding Observations on Mauritius</i> (UN Doc. CCPR/C/79/Add.60, 1997), para. 23 HRC, <i>Concluding Observations on Sweden</i> (UN Doc. CCPR/CO/74/SWE, 2002), para. 12 (c) HRC, <i>Concluding Observations on Mauritius</i> (UN Doc. CCPR/C/79/Add.60, 1996), para. 23 HRC, <i>Concluding Observations on Finland</i> (UN Doc. CCPR/C/79/Add.91, 1998), para. 16 HRC, <i>Concluding Observation on Poland</i> (UN Doc. CCPR/C/79/Add.81, 1985), paras. 15–17 HRC, <i>Concluding Observation on Poland</i> (UN Doc. CCPR/C/79/Add.110, 1999), para. 12

Jurisprudence	<p>Inter-American Court of Human Rights, <i>Velasquez-Rodriguez v. Honduras</i> (Series C, No. 4, 29 July 1988), para. 172 (due diligence and human rights).</p> <p>HRC, <i>Franz Nahlík v. Austria</i>, CCPR/C/57/D/608/1995 (1996), para. 8.2</p> <p>European Court of Human Rights, <i>X and Y v. The Netherlands</i>, Application No. 8978/80 (1985), paras. 23 &amp; 30</p> <p>CERD, <i>Yilmaz-Dogan v. The Netherlands</i> CERD/C/36/D/1/1984, para. 9.3</p> <p>CERD, <i>Ahmed Habassi v. Denmark</i>, CERD/C/54/D/10/1997, para. 9.4</p> <p>CAT, <i>K.S.Y. v. The Netherlands</i>, CAT/C/30/D/190/2001, para. 7.5</p>
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### A.2.3 *Obligation to fulfil*

Treaties	<p>UDHR, preambular para. 3</p> <p>CERD <i>Article 5</i></p> <p>CEDAW <i>Article 3</i></p>
General comments	<p>CRPD, <i>Preamble</i>, para. (c), <i>Article 6</i> – Women with disabilities</p> <p>CESCR, <i>General Comment 9</i> (1998), para. 9</p> <p>CRPD, <i>General Comment 1</i> (2014), paras. 35–36</p> <p>CRPD, <i>General Comment 2</i> (2014), para. 14</p> <p>CESCR, <i>General Comment 22</i> (2016), paras. 8–10</p>
Other UN documents	<p>UN General Assembly, <i>Resolution 48/121: Vienna Declaration and Programme of Action</i> (UN Doc. A/CONF 157/23, 25 June 1993), para. 5</p> <p>UN General Assembly, <i>Proclamation of Teheran: Final Act of the International Conference on Human Rights</i> (U.N.Doc. A/CONF. 32/41, 1968), para. 9</p> <p>UN General Assembly, <i>Resolution 32/130: Alternative approaches and ways and means within the United Nations system for improving the effective enjoyment of Human Rights and Fundamental Freedoms</i> (UN Doc. A/RES/32/130, Dec 1977), para. 1 (a) &amp; (b)</p> <p><i>Report on the Draft Guiding Principles on Extreme Poverty and Human Rights</i> (UN Doc. A/HRC/15/41, 6 Aug 2010), p. 4, para. 14.</p> <p>Summary Record of the Thirteenth Meeting of the Commission on Human Rights (UN Doc. E/CN.4/SR.13, 4 Feb 1947), pp. 3–5 (Major Charles Dukes from the United Kingdom)</p>

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**A.3 Prohibition of discrimination****A.3.1 Criteria 1: Distinction**


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Treaties	CERD <i>Article 1 (1)</i> CEDAW <i>Article 1 (1)</i>
General comments	HRC, GC 18, para. 7
Jurisprudence	HRC, <i>Tadman v. Canada</i> , CCPR/C/67/D/816/1998

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**A.3.2 Criteria 2: Membership in a group**


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Treaties	UN Charter <i>Article 62</i> CCPR <i>Article 17</i>
General comments, concluding observation	CESCR, <i>General Comment 20</i> (2009), para. 32 CRC, <i>General Comment 3</i> (2003), para. 8 CRC, <i>General Comment 4</i> (2003), para. 6 HRC, <i>Concluding Observation on Austria</i> (1999) (“sex or sexual orientation”): <i>Concluding Observation on Trinidad and Tobago</i> (UN Doc. CCPR/CO/70/TTO, 2000), para. 11 HRC, <i>Concluding Observation on Ireland</i> (UN Doc. A/55/40, 2000), paras. 422–451 HRC, <i>Concluding Observation on Trinidad and Tobago</i> (UN Doc. CCPR/CO/70/TTO, 2000), para. 11
Jurisprudence	HRC, <i>Vos v. The Netherlands</i> , CCPR/C/35/D/218/1986 (1989) HRC, <i>Toonen v. Australia</i> , CCPR/C/50/D/488/1992 (1994) HRC, <i>Young v. Australia</i> , CCPR/C/78/D/941/2000 European Court of Human Rights, <i>Rasmussen v. Denmark</i> , 28 November 1984 HRC, <i>Prince v. South Africa</i> , CCPR/C/91/D/1474/2006 HRC, <i>Cziklin v. Canada</i> , CCPR/C/66/D/741/1997 (1999)

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**A.3.2.1 Grounds written in treaties**


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Race	CCPR, Art. 2 (1) & 26; CESCR, Art. 2 (2); CERD, Art. 1 (1); CRC, Art. 2 (1); CMW, Art. 1 (1)
Colour	CCPR, Art. 2 (1) & 26; CESCR, Art. 2 (2); CERD, Art. 1 (1); CRC, Art. 2 (1); CMW, Art. 1 (1)
Sex	CCPR, Art. 2 (1), 3, 23 (4) & 26; CESCR, Art. 2 (2), 3 & 7 (a)(i); CEDAW, Art. 1; CRC, Art. 2 (1); CMW, Art. 1 (1)

Language	CCPR, Art. 2 (1) & 26; CESCRC, Art. 2 (2); CRC, Art. 2 (1); CMW, Art. 1 (1)
Religion	CCPR, Art. 2 (1) & 26; CESCRC, Art. 2 (2); CRC, Art. 2 (1); CMW, Art. 1 (1)
Political or other opinion	CCPR, Art. 2 (1) & 26; CESCRC, Art. 2 (2); CRC, Art. 2 (1); CMW, Art. 1 (1)
National, ethnic, or social origin	CCPR, Art. 2 (1) & 26; CESCRC, Art. 2 (2); CERD, Art. 1 (1); CRC, Art. 2 (1); CMW, Art. 1 (1)
Property	CCPR, Art. 2 (1) & 26; CESCRC, Art. 2 (2); CRC, Art. 2 (1); CMW, Art. 1 (1)
Birth	CCPR, Art. 2 (1) & 26; CESCRC, Art. 2 (2); CRC, Art. 2 (1); CMW, Art. 1 (1)
Descent <sup>a</sup>	CERD, Art. 1 (1).
Nationality	CMW, Art. 1 (1)
Age	CESCRC, Art. 10 (3) (children); CCPR, Art. 24 (children); CMW, Art. 1 (1)
Economic position	CMW, Art. 1 (1)
Disability	CRC, Art. 2 (1); CRPD, Art. 4 (1)
Other status	CESCRC, Art. 2 (2); CCPR, Art. 2 (1) & 26. See also CRC, Art 2 (1)

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<sup>a</sup> See also CERD, General Recommendation 29 (descent includes “discrimination against members of communities based on forms of social stratification such as caste and analogous systems of inherited status”).

### A.3.3 Criteria 3: Purpose

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Treaties	CERD, <i>Article 1 (1)</i> CEDAW, <i>Article 1</i>
General comments	CERD, <i>General Comment 14</i> (1993), para. 1
Jurisprudence	HRC, <i>Simunek v. Czech Republic</i> , CCPR/ C/54/D/516/1992 (1995) HRC, <i>Wackenheim v. France</i> , CCPR/C/75/D/854/1999

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### A.3.4 Criteria 4: Effect

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General comments, general recommendations	HRC <i>General Comment 18</i> (1989), para. 12 CERD, <i>General Recommendations 19</i> (1995), paras. 1–4 CERD, <i>General Recommendation 14</i> (1993), para. 2
Jurisprudence	HRC, <i>Singh Bhinder v. Canada</i> , CCPR/ C/37/D/208/1986 (1989)

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**A.3.5 Criteria 5: Reasonableness**


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General comments	HRC, <i>General Comment 18</i> (1989), para. 13
Jurisprudence	HRC, <i>Toonen v. Australia</i> , CCPR/C/50/D/488/1992 (1994)
	International Court of Justice, <i>Liberia v. South Africa</i> , Second phase, I.C.J. Report, July 18, 1966
	HRC, <i>Van Oord v. The Netherlands</i> , CCPR/C/60/D/658/1995
	European Court of Human Rights, <i>Marckx v. Belgium</i> , 1976
	HRC, <i>Jacobs v. Belgium</i> , CCPR/C/81/D/943/2000 (2004)

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**A.4. Intersectionality**


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Treaties	CRPD, Preamble: [c]oncerned about the difficult conditions faced by persons with disabilities who are subject to <i>multiple or aggravated forms of discrimination</i> on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status
General comments, general recommendations,	CRC <i>Article 23</i>
	CEDAW, <i>General Recommendation 18</i> , Disabled Women, double discrimination, 1991
	CRC, <i>General Comment 8</i> , The Rights of Children with Disabilities, 1994
	CESCR, <i>General Comment 5</i> , Persons with Disabilities, 1994
	HRC; <i>General Comment 28</i> , para. 30: “discrimination against women is often intertwined with discrimination on other grounds,” 2000
	CEDAW, <i>General Recommendation 27</i> , Older Women, paras. 1, 13, 16–17, 2010
	CEDAW, <i>General Recommendation 28</i> , para. 18: States must recognise, prohibit and eliminate intersectional discrimination, 2010
	CEDAW, <i>General Recommendation 30</i> , para. 57 (b): those subjected to multiple and intersecting forms of discrimination, 2013
	CEDAW, <i>General Recommendation 33</i> , Women’s Access to Justice, para. 14 (c): “those who face intersecting or compounded forms of discrimination,” 2015
	CRPD, <i>General Comment 3</i> , Women and Girls with Disabilities, 2016
	CEDAW, <i>General Recommendation 34</i> , Rights of Rural Women, para. 14: rural women are not a homogenous group and often face intersecting discrimination, 2016

## Jurisprudence

CEDAW, *A.T. v. Hungary*, CEDAW/C/32/D/2/2003 (January 26, 2005)

Mother fleeing domestic violence could not be accommodated in safe house because it could not care for a severely handicapped child, thus the family stayed in the abusive home.

CEDAW, *Fatma Yldirim v. Austria*, CEDAW/C/39/D/6/2005 (October 1, 2007)

para. 12.3 (a) – application by wife for protection from spousal abuse failed to consider the precarious migration status of the husband. Because he was subject to deportation if the marriage was dissolved, this added a greater seriousness of the threat to the wife’s safety.

CEDAW, *V.K. v. Bulgaria*, CEDAW/C/49/D/20/2008 para. 9.8: “bilateral violence” of physical and mental or sexual harm

CEDAW, *Cecilia Kell v. Canada*, CEDAW/C/51/D/19/2008 (April 26, 2012)

claim: “As an aboriginal person, she experienced racism, and as a woman, she experienced sexism. Both of these aspects of discrimination contributed to a pattern of behaviour that was ‘at best bullying and at worst abusive’. Poverty, unemployment, dislocation and homelessness resulting from the theft of her home played a role because she could not afford a lawyer of her own choosing, and at times she could not afford the contribution that ...Legal Services ...demanded in order to provide her services.” –Para. 9.3

Para. 10.2: Accordingly, the Committee considered that “intersectional discrimination” had taken place against.

CEDAW, *Isatou Jallow v. Bulgaria*, CEDAW/C/52/D/32/2011 (August 28, 2012)

necessity of an “intersectional reading”

CEDAW, *R.P.B. v. The Philippines*, UN Doc. CEDAW/C/57/D/34/2011 (2014)

para. 9 (b) (iii): In the case of deaf, mute 17-year-old the court applied to her stereotypical norms about how the “ordinary Filipina rape victim” would presumably react. The Committee held that the state must “Ensure that all criminal proceedings involving rape and other sexual offences are conducted in an impartial and fair manner and free from prejudices or stereotypical notions regarding the victim’s gender, age and disability.”

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