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ENDING STIGMA

**ASSESSMENT FROM THE PERSPECTIVES
OF PEOPLE WITH DISABILITIES**

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RAISING THE VOICES
OF THE PEOPLE
WITH DISABILITIES

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CONTENTS

LIST OF ACRONYMS

CRPD: Convention on People with Disability
ICF: International Classification of Functioning, Disability and Health
ILO: International Labour Organization
ISDS: Institute for Social Development Studies
iSEE: Institute for Studies of Society, Economy and Environment
MOLISA: Ministry of Labour, Invalids and Social Affairs
NGO: Non-governmental organization
PwD: People with disabilities
UN: United Nations
UNDP: United Nations Development Programme
UNFPA: United Nations Population Fund
USAID: United States Agency for International Development
WERS: Workplace Employment Relations Study
WG: Washington Group on Disability Statistics
WHO: World Health Organization
WHODAS II: WHO Disability Assessment Schedule 2.0

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EXECUTIVE SUMMARY

According to the World Health Organization (WHO), it was estimated that about 15% of the world's population, or more than one billion people, are living with at least one type of disability. A report by WHO and the World Bank (2011) showed that people with disabilities had lower development indicators than those without disabilities, due to their inability to access public services and the stigma they faced. In Vietnam, in accordance with current (disputed) data, 7.8 to 15% of Vietnam's population comprises people with disabilities. The stigma that they face is still widespread. The definition of people with disabilities in Vietnam, according to the Law on Persons with Disabilities, is limited to health deficiencies. The difficulties that these people encounter because of their disabilities to participate equally and fully in the society are not yet included in the definition. Meanwhile, disability-related stigma and discrimination have been demonstrated in other studies to be one of the causes of poverty, lack of employment opportunities and limited access to healthcare and education for people with disabilities in Vietnam. Nevertheless, the stigma that people with disabilities perceive when participating in economic and social activities are still not well documented in Vietnam. This highlights the necessity of a study focused on the stigma that people with disabilities see and feel.

This report is an attempt to provide more information on the stigma that people with disabilities perceive in Vietnam. In doing so, it aims to promote the voices of people with disabilities, build capacity for organizations and networks representing

people with disabilities, and provide policy makers with useful information. The report presents findings from a quantitative and qualitative study conducted in Hanoi, Thai Nguyen province, Nghe An province, Ho Chi Minh City and Da Nang city from August to November 2017, with the participation of 574 individuals from disability groups of visual, hearing, mobility, communication and cognition people. The study was conducted in consultation with experts on and people with different types of disabilities. Following their recommendations, the research focused on four topics that were of great concern to people with disabilities, namely disability assessment, education and employment, healthcare (concentrating on mental, reproductive and sexual health), and participation of people with disabilities in organizations, associations and groups.

The majority of participants were in the age group of 18 to 38 years old, and unmarried. The proportion of disability groups in the quantitative study was as follows: blind/visually impaired: 36%; mobility impaired: 34%; deaf/hearing impaired; self-care disabled and communication impaired: 13% each; and cognitively disabled: 9%. Among participants of the qualitative study, 73% had at least two types of disabilities, and 20% had only one type. In terms of education, 28% of the participants had completed vocational training, university or higher-level courses; 48% had completed middle school or high school education; 16% had completed primary school education; and 10% had either not completed or never been to primary school.

The proportion of people with disabilities involved in organizations, associations and groups was relatively high. Of the participants in the quantitative study who answered questions on this topic (n=413), 72% (more female than male) reported participating in at least one organization. For the qualitative research, of the interviewees who responded to this

question (n=58), 64% participated in at least one organization. According to Pretty's classification of participation, however, participants of both quantitative and qualitative studies still took part in these organizations symbolically, mostly as information receivers. Their participation in planning and decision-making was rarely reported. The organizations most commonly joined by interviewees were ones established and run by people with disabilities. Such organizations as the Farmer's Association, Youth Union, or Veterans' Association are not yet seen as attractive by people with disabilities. Interviewees talked of social interactions with peers as their motivation to take part in these organisations.

Findings on stigma were presented as those for perceived stigma, self-stigma and public stigma. Results on perceived stigma came from analysing responses to two questions, used in the WHODAS II scale on perceived stigma, on embarrassment and discrimination that disabled people perceived when interacting with people around them during the last year. Of the participants in the quantitative study who answered this question (n=481), 43% of respondents reported experiencing perceived stigma. Reports of perceived stigma mainly came from groups of young men, and those with multiple disabilities, visual and mobility impairment. Perceived stigma, according to the interviewees of the qualitative research, often appeared when they lacked opportunities to interact with the outside world, especially with peers. Stigma existed but were not clearly recognized by participants in in-depth interviews in the fields of education and employment.

Rates of reporting self-stigma, a form of perceived stigma, by questionnaire respondents varied by subject. Regarding access to healthcare services, education or social interaction, the proportion of people reporting self-stigma ranged from 2 to 8%. Yet, reports of self-stigma were much higher (60 to 70% of respondents)

with regard to causes of their disability and their worth in life. Regarding love and marriage, self-stigma was reported by both men and women (with a higher rate among women). Explaining the reasons for self-stigma in the latter subjects, interviewees mentioned perceptions of gender roles for men and women in family life as the main cause.

Participants in the study reported that public stigma against people with disabilities was rather common in education and employment. Regarding education, 46% of respondents in the quantitative research (n=347) disagreed that they had sufficient support, such as tools and teaching methods corresponding to their disability (in comparison, 40% agreed). Also, 45% of respondents (n=345) disagreed that schools strictly handled discriminatory behaviour (in comparison, 57% agreed). Some people with disabilities participating in the study had never been to school or went to school very late (usually from 10 years old). Some vocational training courses were stereotyped for certain groups of people with disabilities, thus restricting their occupational choices while career guidance was almost unavailable. Reasons given for people with disabilities not going to school, or not continuing with higher education or vocational training, included that many poor families could not afford to send their children to school, and that families overprotected their children due to concerns about harm or discrimination from society. Meanwhile, schools did not have facilities to address needs of disabled people, especially in rural and remote areas.

The results also show that discrimination against people with disabilities in employment is widespread. Although 66% of respondents (n=389) in the quantitative research had never attended a job interview, 53% of those who had believed they were rejected because of their disability. At work, participants in the qualitative research said they were not treated the same as

or equal to non-disabled colleagues, such as being paid less, not being contracted, not receiving on-the-job training, or working longer hours. This resulted in many interviewees facing job insecurity, instable income and inability to save for unexpected situations. Among those surveyed, the deaf/hearing-impaired group earned the highest average income (approximately VND 3 million per month). Still, this amount was still much lower compared to the national average income of VND 5.4 million per month at the time of the study.

Regarding healthcare, study results indicated that people with disabilities had limited access to healthcare services. Although health insurance coverage was high among participants in the quantitative research (93% of respondents, n=441), 15% of those who had health insurance could not use their insurance because they were outside of the catchment area for their insurance. Most of the interviewees in the qualitative research did not arrange regular health examinations, despite having health problems. As for reproductive and sexual health, the findings from the questionnaire survey showed that only few accessed reproductive and sexual healthcare. Interviews with both men and women showed that men were often excluded from awareness-raising programmes on these subjects, since such programmes often focused on women. Meanwhile, visually impaired people had the fewest opportunities to access information on reproductive and sexual health, partly because most of them never went to school or had not completed primary school, where others typically accessed these kinds of information. Information provided for cognitively disabled people mostly concerned how to use contraception rather than why it was needed. Prenatal healthcare for mothers with disabilities was not sufficient when specialized support, like sign language translation and disability-friendly documents, were not available.

As for mental health, the study found that 53% of respondents (n=457) had poor mental health, particularly among those with perceived stigma, communication impairment and self-care disability. Men were more likely to have mental health problems than women. When discussing what made them worried, thus influencing their mental health, job and income insecurity, job dissatisfaction and worries about their future once their health degraded were mentioned as the causes. In addition, their mental health could be affected badly by the inability by family members to communicate and understand each other, caused by being unable to use a common language (e.g. sign language among deaf children and their parents), lack of parental skills, or hiding concerns out of consideration for their parents. These did not help parents to understand, encourage and support their children in studying, choosing occupations and overcoming stigma.

Concerning the disability assessment, 78% of the respondents (n=440) got their disability assessed. During the assessment, 6% of respondents (n=346) reported stigma and discrimination from the public sector. In-depth interviews with people with disabilities indicated that a current shortcoming in disability assessment was that the assessment only viewed disability from medical perspectives and how disability affected mobility and self-care. This perspective was suitable for people with mobility impairments but not for other disability groups. Besides, the assessment of the severity of disability was reportedly influenced by the sentiment of the assessors, objectively. In regard to the group with cognitive difficulties, the disability assessment was almost unknown to parents.

The above findings help formulate the following recommendations for policy makers and organizations working for the rights of people with disabilities:

1. Enhance studies of perceived stigma:
a. Review different terminologies and concepts of stigma and their equivalents in Vietnamese. This will help avoid confusion in interventions to eliminate stigma, since different types of stigma require different groups of people as subjects of the interventions;
b. Study solutions at institutional and systematic levels to address root causes of disability-related stigma. This can be approached from (i) 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 the multidimensionality of disability in these policies and programmes; and (ii) reviewing and looking for good or not good practices against stigma and/or discrimination.
2. Build the capacity for the associations, groups and clubs of people with disabilities, so that these organizations play active roles in encouraging the participation of parents/family members of people with disabilities and people with disability themselves in tackling stigma and discrimination.
3. Policy advocacy should focus on the right to equal and full participation in society of people with disabilities:
a. Advocate for the application of disability assessment that combines the evaluation of health conditions of disabilities related to six basic functions (listening, seeing, mobility, thinking, communicating and self-care), and their influence on the participation of people with disabilities in social and economic activities;
b. Advocate for the expansion (or inclusion) of sign language and Braille in inclusive schools, 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 used right from the beginning, at nurseries and pre-schools;

c. Advocate for the establishment of a mechanism to monitor and eliminate discrimination in recruitment and benefit packages for people with disabilities. This mechanism requires employers to apply reasonable accommodations in the process of recruiting and employing workers with disabilities;

d. Provide vocational guidance and diversify high quality vocational training for people with disabilities at both specialized and inclusive vocational training centres;

e. Enhance and reinforce a disability-friendly education environment, featuring training for teachers, capacity building to identify and handle stigma in school settings for teachers and administrators, provision of opportunities for parents with disabilities to actively participate in educating their children, and provision of appropriate facilities for people with disabilities;

f. Advocate for making adjustments to regulations on the use of health insurance for people with disabilities who do not have permanent residence status in the areas where they live and work;

g. Advocate for the development of a set of materials (with appropriate communication channels) on reproductive and sexual health for both men and women (especially pregnant women) with disabilities. These materials should be responsive to types of disability and educational levels of material users;

h. Advocate for integration of mental healthcare and mental health awareness raising programmes into medical

centres for people with disabilities or through activities with associations, clubs and groups with suitable communication channels and appropriate guidance materials for each type of disability.

4. The abovementioned proposed policies or activities to abolish stigma and discrimination should focus on groups with a higher tendency to perceive stigma, such as men aged 18 to 38, people with multiple disabilities, and those with visual and mobility impairment.

INTRODUCING DISABILITY AND STIGMA

<div style="text-align:right">1</div>

1. Overview of People with Disabilities and Changes in Approaches to Disability in the World

According to the World Health Organization (WHO), it is estimated that about 15% of the world's population, or more than 1 billion people, are living with at least one type of disability (WHO, 2017). Among people with disabilities, nearly 200 million people aged 15 and over have many difficulties in doing basic tasks. Also, according to the WHO, in coming years, the number of people with disability will increase, partly because world's population is aging and the number of people with chronic diseases is increasing. As a result, disability has become a global problem and requires thorough understanding for comprehensive solutions.

Research by the WHO and the World Bank (2011) showed that people with disabilities have lower development indicators than people without disabilities. Approximately 80% of disabled people are living in developing countries and most of them have not yet benefited from achievement of the Millennium Development Goals (United Nation Development Programme (UNDP), 2017). This group of people also has worse health, lower educational achievements and fewer economic opportunities compared to those without disabilities (World Bank, 2011). One of the reasons for the above-mentioned inequality is that people with disabilities do not have access to public services, such as access to information, healthcare, education, employment

opportunities and transportation, which many people without disabilities have by default. However, stigma against people with disability is seen as the most significant reason obstructing their access to health, education and employment services.

In recent years, disability has been incorporated into global development agendas from human rights and development perspectives (World Bank, 2011). The Convention on the Rights of Persons with Disabilities (CRPD) was adopted in 2006. The Convention aims to *"promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity"* (Article 1). The Convention also states that *"persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others"* (Article 1) (United Nations (UN), 2006). This is the perspective on disability that this study applies.

Apart from the CRPD, development programmes have started to address disability. The Millennium Development Goals (MDG) Report published in 2010 (UN, 2010) linked disability to a lack of access to education. With that perception, in 2010, the United Nations General Assembly (UN, 2011) included education for children with disabilities in Goal 2 of Millennium Development Goals. Specific issues and goals for people with disabilities were also mentioned in the document titled "Realizing Millennium Development Goals for persons with disabilities towards 2015 and beyond" with the aim to help people with disabilities enjoy benefits from the achievements of MDGs. Up to now, 5 MDGs and sustainable development goals have directly addressed issues of disability in education (Goal 4), economic development (Goal 8), the participation in socioeconomic and political issues (Goal 10), the rights to access to public transport and public spaces (Goal

11), and disability-focus data for monitoring progress towards sustainable development goals (Goal 17) (see UN, 2017).

The changes in approaches to people with disabilities indicate a shift towards a rights-based approach that ensures their rights to services or support needed for their life. This approach has replaced the old one that considered people with disabilities as recipients of benefits, medical treatment or social protection. Under the right-based approach, people with disabilities are seen as subjects of development who must have same rights as other citizens in society. As a result, their rights must be respected. Policies and programmes need to be developed in ways that allow people with disabilities to participate fairly and fully in society.

2. Definitions and Overview of Disability and Stigma in Vietnam

Before looking into the current situation of people with disabilities in Vietnam, this report introduces the concepts of disability and stigma, so that common understanding can be built.

2.1. Definitions

Unlike the definition introduced in the CRPD, Vietnam's government still focuses more on medical conditions in its definition of and approaches to disability. 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 many organs or functionality, which are manifested in the form of disabilities that cause difficulties to work, live and learn. Compared to the CRPD's definition, Vietnam's terminology is still attached to the old approach of medical deficiencies and forgoing difficulties facing people with disabilities while accessing public services and social activities.

Stigma is a complicated concept that has multiple definitions and different measuring scales[1] (Link and Phelan, 2001; Alson *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).

There are several types of stigma that this report will refer to, thus definitions of different types of stigma are provided here. Public stigma (thereafter called stigma) is a (negative) reaction by society towards stigmatized individuals. The reaction is based on attitudes or beliefs toward 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 on gender, social classes or ethnicity. Stigma can be seen in the views and/or behaviours of one or more individuals or organizations.

Disability-related discrimination is a form of stigma. According to Article 2 of the CRPD, discrimination on the basis of disability is any distinction, exclusion or restriction on the basis of disability that has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms

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1   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.

in the political, economic, social, cultural, civil or any other field. Discrimination includes the failure to make reasonable accommodation. Reasonable accommodation, where needed in a particular case, means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden to ensure to persons with disabilities the enjoyment or exercise on an equal basis of all human rights and fundamental freedoms with other people without disability.

Perceived stigma is the results of the inference or perception by people with disabilities on a specific behaviour or attitude directed at them (Corrian and Watson, 2002). Persons with disabilities express effects of perceived stigmas differently. These effects may include anger, ignorance, embarrassment, or self-stigma (Corrian and Watson, 2002; Corrian *et al.*, 2006; Alson *et al.*, 2011).

Self-stigma (within the scope of research on people with disabilities) is the prejudice that people with disabilities internalize into their thinking and these thoughts come back against themselves. In this process of internalization, people with disabilities believe in stereotypes (or stigmas) that society labels them, which leads to a lack of confidence in their ability and self-worth (Corigan and Watson, 2002). Self-stigma may be manifested in the form of hiding conditions and difficulties related to disability, non-involvement in social activities, refusal to access disability services, or keeping distance from stigmatized people (see Hing *et al.*, 2015).

2.2. Overview on Disability and Disability Related Stigma in Vietnam

After the introduction of different concepts, this section focuses on analysing status of people with disabilities in Vietnam. In this country, 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 5 and above (approximately 7.8% of the total population) (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 has 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).

The social and economic conditions of people with disabilities in Vietnam are not good. 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 from their families (see Le Bach Duong *et al.*, 2008). According to a study conducted in six economic zones plus Hanoi and Ho Chi Minh City, 25% of respondents with disabilities do not have health insurance. Twenty percent of disabled people aged between 18 and 60 are out of work, mainly due to their poor health. Seventy-six percent of people with disabilities are illiterate, compared to 95% of literate people without disabilities (ILO, 2013) (see Le Bach Duong *et al.*, 2008).

Recognizing the inequality facing them, 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 "handicapped" to "disabilities" (Article 59) (Ministry of Justice, 2001), which demonstrated a new approach to people with disabilities. Vietnam also had 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 Disability (National Assembly, 2010). This was the first comprehensive legal document to ensure the rights of persons with disabilities. If the 2001 Revised Constitution only replaced the term "handicapped children" with "disabled children", in the Law on Persons with Disability 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 disability 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 in accordance with the type of disability and level of disability. In addition, people with disabilities receive social protection, such as a monthly disability stipend or health insurance (free of charge for poor households, under Article 12).

3. Studies on Stigma and People with Disabilities in Vietnam

After analysing the situation that people with disabilities must face in Vietnam, this section reviews some forms of stigma that people with disabilities in Vietnam often encounter.

3.1. Identifying Stigma against People with Disabilities in Vietnam's Society

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 (ISDS, 2008). Stigma against people with disabilities varies, depending on the type of disability, age, gender and education. People with intellectual disabilities, communication impairment 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).

Regarding education, 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 provides 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 considered based on their capacity rather than a universal right for all children as defined by law. Moreover, although enabling all children with disabilities to attend inclusive education has been regulated since 2006 (see Ministry of Education, 2006), assessments show that implementation of this programme is still limited. Teachers are not professionally trained in delivering inclusive education. Schools lack specialized equipment and instructional materials, such as sign language or Braille, to meet the requirements of inclusive teaching for students who have hearing impairments, visually impairments, or autism (Lynch and Pham, 2013). This leads to the fact that schools usually only admit 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 special disabilities such as deaf or blind cannot follow curriculum designed for children without disabilities, thus often dropping out of school (Le Xuan, 2016). In terms of gender, boys with disabilities are often sent to schools to socialise, while girls with disability do not tend to receive the same treatment (Nguyen and Mitchell, 2014).

Regarding employment, people with disabilities face with many shortcomings 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 but rather attended short-term refresher courses. Therefore, their teaching skills for this group of students are limited, so people with disabilities are not trained as well as expected. In addition,

many enterprises are not enthusiastic about employing disabled people due to a lack of confidence in their ability (such as worries of their ability to follow production lines) or resistance to change (see USAID, 2005; Nguyen and Mitchel, 2014; Nhan Dan Online, 2017). If employed, they 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).

Regarding institutional settings, people with disabilities are still simply considered as having physical or functional deficiencies that affect their ability to work, learn or live their daily life, as defined in the Law of Persons with Disability. Therefore, the government still uses medical conditions as institutional requirements in providing social services for people with disabilities. This indicates that disability is still considered as a lack of capacity or inability to meet requirements to join the workforce, which highlights the issues of exclusion of disabled people in economic, social, cultural, and social activities (see Dingo, 2007). This totally contrast to the rights-based approach embodied in the CRPD that emphasizes policy barriers (hence the necessity of appropriate social policies) for people with disabilities to fully and equally participate in society. Moreover, current policies on providing support to people with disability, such as legal aid, are still unclear. When the government issued Decree 28/2012/ND-CP detailing and guiding the implementation of several articles of the Law on People with Disabilities, it did not include regulations specifying which types of disability and which level of disability were entitled to legal aid. 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 (Pham Thi Hong Dao, 2016).

Regarding access to healthcare services, according to a report by USAID (Lynch and Pham, 2013), although rights to health rehabilitation services are included in the Law on People with Disabilities, their application is still deficient. Many of these service providers whose mandates are to serve disabled patients are primarily focused on physical therapy for people with mobility impairments and occasional therapies to help patients recover their speech. However, poor infrastructure and limited professional training, especially at 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 in Chapter 4), is not available. The abovementioned shortcomings reduce the practicality of medical centres to provide necessary healthcare to people with disability.

3.2. Studies on Stigma and Disability in Vietnam

After identifying the major stigmas that people with disabilities encounter in various fields, this section continues by exploring studies on stigma in Vietnam. Research on stigma and people with disabilities is a rather new topic in Vietnam. National censuses do not always include information on various types of disability and stigma. For example, in the 2006 Living Standards Survey (General Statistic Office, 2006) and the 2009 Population Census (UNFPA, 2011), information on disability was collected. However, the survey data did not contain information on stigma related to disability. MOLISA's annual statistics on people with disabilities only focus on severe forms of disability (to provide public services), while ignoring many people with milder forms of disabilities as well as issues related to stigma.

In smaller surveys conducted by ISDS (a leading research institution) on people with disabilities in Vietnam, in 2003 in

Hai Duong, information on stigma was not included. Since 2006, ISDS has begun to research on stigma and discrimination against people with disabilities. In a report published in 2008 on people with disabilities in Dong Nai, Quang Nam, Da Nang and Thai Binh provinces, stigma against people with disabilities was studied in terms of forms and locations of stigma. However, the study approached disability principally from the angle of socioeconomic difficulties and hindrances facing people with disabilities, and how they overcame these obstacles. In addition, the study investigated their awareness and understanding of rights and assisting services they were entitled to get.

In a 2011 study on the economic costs of living with disability and stigma in six provinces (namely Lang Son, Thai Binh, Quang Nam, Kon Tum, Dong Nai and Vinh Long) and two cities (namely Hanoi and Ho Chi Minh City), ISDS investigated different forms of stigma against people with disabilities to estimate the economic costs incurred from disability and stigma. The focus of the study was the financial expenses of living with disability. Stigma was evaluated by comparing perceived and experienced stigma in accessing to basic social services between people with and without disabilities.

In their study, Nguyen and Mitchell (2014) examined changes in inclusive education for girls in schools in Vietnam. They looked at how social and educational policies treated this group of children. They found that girls with disabilities who could learn or carry out basic tasks were considered as "valuable", thus being evaluated to attend schools on this basis. Meanwhile, boys with disabilities were given higher priority in access to education. Stigma was analysed by the authors from the angle of gender-based stereotypes and discrimination in institutional settings. Therefore, perceived stigma was not covered by this study.

The review of the above-mentioned studies shows that, in

Vietnam, there is still a large gap in the understanding of perceived stigma from the perspectives of people with disabilities while they engage in economic, politic and social activities. According to a comprehensive assessment of research conducted worldwide on the topic of stigma and disability, assessment of attitudes of people without disabilities towards people with disabilities has so far received the most attention (Grames *et al.*, 2010). This trend has also been observed in Vietnam. The review of the major studies showed that comparison between different types and level of stigma between people with and without disabilities in the fields of education and healthcare. Perceived stigma from the perspectives of people with disabilities has either been visited only briefly or ignored in these studies.

Better understanding perceived stigma in social interactions is of great significance. Studies outside Vietnam prove that it is the perception of discrimination, not the degree of discrimination, that adversely affects the health and mental state of people discriminated against (see Ali *et al.*, 2008). Thus, improving knowledge on perceived stigma from the perspectives of people with disabilities helps people with disabilities to participate in society fully and equally. At the same time, interventions to reduce and eliminate behaviours or policies that cause perceived stigma can be more responsive when they address stigma and discrimination from the perspective and judgment of people with disabilities.

Faced with requirements for improved knowledge and seeking viable solutions to address disability from perspectives of human rights and development issues, UNDP and the Institute for Studies of Society, Economy and Environment conducted a research study to identify stigma that people with disabilities in Vietnam perceived and experienced. In doing so, UNDP and iSEE aimed to promote voices of people with disabilities in

efforts to abolish stigma. This report is the result of the above-mentioned study and focuses on the assessment of stigma that people with disabilities perceived and experienced in areas of disability assessment, education and employment opportunities, healthcare and participation in associations, groups or clubs. Now that Chapter 1 has introduced the situation of people with disabilities, and major policies and shortcomings in policy implementation for people with disabilities in Vietnam, Chapter 2 will introduce the research and research framework as well as research tools. Chapter 3 will analyse the results of the research, before the implication of these results to policy advocacy and activities for people with disabilities are discussed in Chapter 4.

RESEARCH **METHODOLOGY** $\Big|2$

Recognizing the need to improve understanding of stigma through perceptions of people with disabilities, iSEE, with financial support from UNDP Vietnam, conducted this research from August to December 2017. The study focused on the current state of 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 voice of people with disabilities by giving them an opportunity to speak out, so that the outside world can learn about their perspectives on stigma. In doing so, disabled people can contribute to abolishing stigma against their disabilities.

1.   Research Goal and Objectives

The main purpose of this research is to strengthen the voice of people with disabilities in Vietnam to abolish stigma against themselves. In doing so, the research can help people with disabilities, their organizations and networks discuss and identify stigma, thus contributing to build capacity for them. In addition, the findings from the research can also provide policy makers and organizations that support people with disabilities with information necessary to make sound decisions.

To realize this goal, the research has four objectives:

1.   Collect evidence of stigma against people with disabilities;
2.   Analyse the social settings where stigma is present;
3.   Find out the impacts of stigma on the lives of people with disabilities;

4. Make recommendations for policy advocacy to reduce stigma.

2. Scope of the Research

Regarding the subjects of the research, people with difficulties in carrying out one or more of the following functions following the ICF functional classification (explained in detail in Section 4: Research Approach) were included:

- Visual;
- Hearing;
- Mobility;
- Self-care;
- Cognition (in Vietnam, this type of functional difficulties are referred to variously as mental disability, mental retardation, intellectual developmental delay, Down syndrome, autism);
- Communication.

In terms of content, the research focused on stigma that people with disabilities feel and experience in the following four areas:

- Disability assessment;
- Education and employment;
- Healthcare (focusing on mental, reproductive and sexual health);
- Participation in organizations, associations, groups and clubs.

These areas were selected after careful consideration with four research collaborators who being people with disabilities and through discussion with several non-governmental organizations (NGOs) working in the field of people with disabilities in Vietnam, to focus on areas where people with

disabilities are currently faced with a lot of stigma. With the above group of topics, the research team determined that the age of the study subjects should be working age young people, 18 years old and above.

3. Study Sites

To achieve the purpose of the research, the research team identified study sites in two ways. First, the team referred to previous studies to identify areas that were under-researched and/or with a high incidence of disability. Second, the team consulted with the research collaborators and people with expertise on disability to determine where it could receive support from local networks to recruit participants for this study. As a result, the study sites were selected as follows:

- Qualitative research: Hanoi, Ho Chi Minh City and Da Nang city, and Nghe An and Thai Nguyen provinces;
- Quantitative research: at the beginning of the research, the intention was to achieve nationwide coverage using an online questionnaire (namely Survey Monkey). However, after it was brought to the team's attention that some groups of disabled people would not be able to access the online tool, it decided to use paper questionnaires in Hanoi, Ho Chi Minh City, Da Nang and Thai Nguyen, in addition to the online questionnaire.

4. Research Approach

To achieve its objectives above, the research applied both qualitative and quantitative approaches to collect information. These approaches support the research's framework more

effectively. This section presents the research framework before discussing further the specific methods for data collection.

4.1. 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 disability that causes exclusions and limitation in the 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. This approach is clearly expressed in the definition of persons with disability, as reflected in the CRPD, as mentioned above.

The second theoretical strand for this study is to approach stigma through views of sociologists. Accordingly, to understand how stigma is formed, researchers are encouraged to see disability from a social perspective rather than medical one. One prominent representative of this school of thought is Goffman, whose ideas (see Goffman, 1963) were reformulated to explain the theory of social stigma (see Link's and Phelan, 2001). According to the theory of social stigma, stigma is formed through continuous and integral interactions among the components of 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 analyse factors that constituted stigma and affected the lives of people with disabilities.

The third theoretical strand for this research, complementing the first and second, is based on a framework composing of five scales, namely disability scale, perceived stigma scale, mental health scale, job satisfaction scale and participation scale. The

next section explains the five scales, the reasons for selecting these scales and how they were used. Depending on the scale, there are between two and six questions in each, with each question having either 4 or 5 options for measuring disability, stigma, satisfaction, mental health and participation. 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 with advice from people with disabilities who were the research's collaborators and experts working in the fields of disability and development, and with reference to reports on similar topics in Vietnamese. A similar approach was used to develop the questionnaire for the quantitative research. Details of the steps used to ensure the quality and suitability of the scales and the entire questionnaire can be found in Appendix 1.

A. The International Classification of Functioning, Disability and Health (ICF)

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 completing basic tasks and taking part in society.

With the above-mentioned point of view of disability, WG developed the International Classification of Functioning, Disability and Health, also known as the ICF, using six questions to describe and measure the level of difficulty that one individual has in using the six functions of vision, hearing, mobility, cognition, self-care and communication (see WG, 2009). The ICF

questionnaire was translated into Vietnamese and can be found in Table 6 (Appendix 1). In the next sections of the report, the ICF terms for difficulty level with the six functions are used interchangeably when mentioning different 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;
- 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.

This questionnaire was selected because it had been approved by WHO to assess disability level. This framework is recognized and used by all WHO member countries. Using this questionnaire, the results from 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.

The ICF has both advantages and disadvantages. The classification is only focused on one aspect of disability, which is difficulty in performing basic activities in life. This allows the scale users to quickly and rather accurately determine type and degree of disability. However, if this classification is only used to determine difficulties in carrying out activities involving six functions, bigger problems such as how these difficulties relate to stigma people with disability receive, and how stigma impacts their life will be overlooked. Recognizing this limitation, the research team used the ICF in combination with

other scales (to be discussed in the following sections). In doing so, recommendations to reduce stigma can address stigma for specific groups of disabled people on specific areas, not just functional difficulties disabled people facing in their daily life.

B. Perceived Stigma Scale

In Vietnam, a study was conducted by ISDS (2013) to measure stigma. The iSEE research learnt from and, when possible, used the questions used by ISDS to identify stigma. For instance, the research team used some questions related to the seven main factors of ISDS's stigma scale to measure the prevalence of stigma against people with disabilities in the fields of health, education and employment. At the same time, the research team chose a different framework to assess stigma, in response to its specific research objectives. For example, the stigma measurement used by ISDS was intended for both people with and without disabilities (see ISDS, 2013), whereas the iSEE study focused only on people with disabilities. For this reason, the perceived stigma scale (see Epping-Jordan and Ustun, 2000) was selected, which solely focuses on disabled people. More details on this scale can be found in Table 7 of Appendix 1.

Another reason for selecting the perceived stigma scale was that it had been used and tested in other studies (e.g. Alonso *et al.*, 2008 used it for mental health research). In applying this scale, the research team was able to save time and cost while ensuring the suitability of questions used in the study. Also, for questions to be considered as reliable and suitable in a questionnaire, researchers have to test these questions multiple times with studied subjects, which requires time and money (see ISDS, 2013). With limited funding and time, the research team could not meet this requirement. The perceived stigma scale was used in conjunction with the disability assessment scale and the other scales to assess the relations between perceived stigma, mental

health and disabled people's participation in organizations associations and groups.

While ISDS stigma scale used 40 questions to score stigma in each field, the perceived stigma scale used in the iSEE study consists of only two questions to measure the prevalence of perceived stigma among the research population. These two questions are "How much *embarrassment* did you experience because of your disability during the past year?" and "How much *discrimination* or *unfair treatment* did you experience because of your disability during the past year?" For both questions, response options comprised: "none"; "a little"; "some"; "a lot"; and "extreme". If respondents chose at least "a little" for both questions, they were considered to have perceived stigma.

C. Mental Health Scale: Five Well-Being Index

Mental health was included in this research as it was recommended by research collaborators. According to the collaborators, although many people with disabilities had poor mental health, specialised medical services were inaccessible to them. To measure mental health, the research adopted the WHO Five Well-Being Index (1998). More details about this index can be found in Table 8 of Appendix 1. As with the above arguments for the disability and perceived stigma scales, the mental health scale was chosen because it had been recognized and tested by WHO in mental health research.

A drawback of this scale is that it uses a very vague timeframe to measure different feelings and mental states over a timeframe of one year. Phrases indicating time such as "always", "most of the time" or "more than half of the time" can confuse respondents because they are intangible. With the help of research collaborators, the time frame was made more specific, as follows: *Most of the time* is from 7 to 11 months; *More than half the*

time is from 6 to 7 months; *Less than half of the time* is from 3 to 5 months; *Sometimes* is from 1 to 2 months; *Never* is not ever in the past year.

A respondent's mental health status is calculated by summing the scores for all five statements with a total score ranging between 0 and 25. If the total score of the respondent is 0, his/her mental health is at its worst, meanwhile, if the total is 25, his/her mental health is at its best. Total score can be compared against the standard score of 13. If a respondent registers a total score of less than 13, or scores only 0 or 1 for any of the five statements, he/she is considered to have a high level of depression.

D. Job Satisfaction Scale: WERS2011

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 scale to measure job satisfaction (see Table 9 of Appendix 1). This scale was developed for the WERS (Workplace Employment Relations Study), a UK governmental research organization, and widely applied in Britain. Thus, it has been tested for reliability including on the working environment of people with disabilities (see Haile, 2016). For this reason, the study adopted this scale.

When analysing responses to nine statements about five different aspects of work, the satisfaction with each aspect of the respondent's job is assessed by scores from 1 to 5, with 5 representing the most and 1 for the least satisfied for an aspect of work. Overall job satisfaction is assessed by scores ranging between 9 and 45. The higher the score, the more respondents are satisfied with their jobs. Average score for all neutral responses is

27. The threshold for considering that a respondent is satisfied with his/her job was 30 points.

E. Classification of Participation

The study used the classification of participation developed by Pretty (see Jones and Kardan, 2013) to measure the extent to which people with disabilities participate in organizations they are interested in, which, in turn, can indicate the level of integration of persons with disabilities in society. Pretty's classification of participation has been widely applied when it comes to assess the participation of local people in an organization or a development programme. She focuses on motivations for participation. She classifies participation as a continuum, with one end (negative end) being the manipulation by organizers (and thus participation of citizen is only symbolic). The other end of the continuum (positive end) is self-mobilization by citizens in activities, because they take the initiative independently to change systems.

In the participation scale, there are six statements about different levels of participation (see Table 10 of Appendix 1). Respondents can select their answers from one or more of six statements to best reflect the level of their participation in an organization, such as an association, club or group. If a respondent chooses 1, their participation is only symbolic. With choices from 2 to 5, respondents have no decision-making power over activities or organizations they participate in. Option 6 demonstrates a participant's self-mobilization within an organization that he/she takes part in.

4.2. Research Tools

At the selected sites, the study used two approaches to collect data in parallel: quantitative research; and qualitative research. This section discusses the two approaches in turn.

4.2.1 Quantitative Research

Quantitative research was conducted from August to November 2017. The first thing to do when conducting quantitative research is to select the number of people from a specific group to collect data about. The first part of this section discusses the methods applied in this research to select the appropriate participants for the study.

SAMPLE AND SAMPLING STRATEGY

In sampling, the team should decide which groups of people with disabilities in Vietnam will be selected for the study. Based on the study's purpose to have a whole picture of stigma and discrimination that people with disabilities perceive in life, the research team decided to select some people from all disability groups that needed to be included in this study. With limited time and budget, this study does not aim at providing valuable findings to all people with disabilities in Vietnam. Rather, research results focus on identifying problems in the sample and appropriate solutions for the sample. Therefore, the samples for this study were not chosen to be representative.

As discussed in Chapter 1, data on people with disabilities in Vietnam are often inconsistent due to many different classifications of disability and different levels of disability. Therefore, there is in fact no ICF disability checklist in Vietnam including the study sites. Accordingly, random sampling cannot be done. Instead, the research team chose to use multi-stage sampling.

The advantage of multi-stage sampling is that it does not require a sampling frame to base on each member for the entire population of people with disabilities. In addition, the selected sample can be a group rather than an individual in the entire the population of people with disabilities. The major limitation

of this sampling method is that the sample is not likely to be representative (see WHO, 2004). However, as mentioned above, the study did not aim to provide representative findings for the entire population of people with disabilities, so this limitation of using this sampling method did not affect the study.

Since the study required finding out about the stigma that people with disabilities perceive in the fields of education, health, employment, social participation and defining the level of disability, participants had to be of a certain age and to have a certain ability to share their thoughts and feelings. In addition, the research team also wanted to learn about stigma in the three regions of Vietnam (northern, central and southern) to examine differences in the manifestation and form of stigma. Choosing study sites was the first step of the multi-stage sampling strategy.

At the chosen study sites, among those with the above types of disability, the study selected people at 18 years of age and older (both male and female) so that they could directly (and in depth) share the feelings about stigma in their lives. For the cognitive disability group, to be able to know their thoughts and feelings, researchers could consult their family members or caretakers or educate them to get necessary information where appropriate. In this case, participants under the age of 18 were also selected.

In order to ensure diversity in the samples with regard to persons of different economic backgrounds who may, therefore, have different perceptions of stigma, the team used a network of collaborators and looked for websites that were the exchange hubs for people with disabilities (the website managers were asked to publish a recruitment notice for survey participants). This was the source for people who could answer the questionnaire online. For those who did not have access to the internet, the research team went to centres, clubs, or associations of people with disabilities in the selected cities and provinces to spread

information in search of respondents for paper questionnaires. This enabled the sample to include members with a variety of socio-economic conditions and access to the survey in both formats.

QUESTIONNAIRE

Data from the quantitative survey of stigma and discrimination were collected by online questionnaire (using Survey Monkey) and paper questionnaires in Hanoi, Thai Nguyen, Da Nang and Ho Chi Minh City from people with disabilities aged 18 and above. In total, 578 respondents answered the questionnaire. However, only 516 valid responses were received, after excluding those whose respondents were under the age of 18 or provided incomplete information.

The questionnaire used in this survey was developed on the basis of adjusting and localizing the scales described in Section 3.2 and Appendix 1 to the Vietnamese context. Apart from questions or predefined answers on the above scales, the questionnaire also included questions and predefined answers developed at the same time and in the same way as the five-level questionnaire (see Appendix 2 - Questionnaire). The questionnaire consisted of 66 questions, in which there were six open questions (with short answers) and 60 questions with available options including predefined responses and yes or no answers. To complete a questionnaire, respondents needed 30 to 35 minutes with stable internet connection (if done online). For the visually impaired group, the time to complete the questionnaire could last from 1 to 2 hours.

To complete the paper questionnaire (which asked the same questions as the online survey in Survey Monkey), researchers and volunteers selected for the study either supported respondents to fill out the form directly or asked them questions and then

wrote down their answers. Regarding the deaf and hearing impaired group, the respondents were guided by sign language interpreters to fill out the form directly. Filling out the paper form was usually done in conjunction with activities of deaf clubs or the Association of People with Disabilities in the provinces. At the end of the information gathering, the researchers would check each completed questionnaire to ensure the accuracy of the information and to ensure that all questions were answered.

With the visually and cognitive disabled group, information gatherings were organized similarly to that of the deaf/hearing-impaired group. The difference from the deaf/hearing-impaired group was that volunteers and researchers recorded the responses to the questionnaire on behalf of respondents. By doing so, the information was checked on the spot with the respondents. Thus, the accuracy and completeness of the questionnaire were also guaranteed.

Before the questionnaire was put into use, the lead researcher conducted a training session for volunteers to understand the questionnaire and how to approach people with disabilities. In addition to meetings with the entire research team, face-to-face or interpreted exchange sessions were conducted separately and regularly with each collaborator, who was the bridge between the research and potential respondents, to ensure collaborators understood the method for data collection through questionnaire. Through these training sessions and exchanges, questions and concerns were addressed and the consistency of contents and methodology among those who carried out the data collection was ensured.

4.2.2. Qualitative Research

Qualitative research for the study was conducted from August and November 2017 to contribute to examine the views

and thoughts that quantitative research had overlooked. For this reason, qualitative research used questions outlined by topic in the questionnaire as a basis for discussion with the participants.

SAMPLE AND SAMPLING STRATEGY

Qualitative research was used as part of the sampling strategy, as mentioned in the quantitative research section above. Upon arrival at the chosen sites, researchers used the "snowball" introduction method (see Atkinson and Flint, 2001) to approach the members for this study. This method was used because the population of people with disabilities were often not listed separately and people with disabilities were usually hidden because the families were ashamed of having members with disabilities, as discussed in Chapters 1 and 2.

Research collaborators first introduced some people with disabilities to the researchers, who then invited them to participate. Collaborators introduced people with disabilities with differences in gender, employment, education and living area (urban and rural). From these introduced people, the researchers then asked for introductions and, thereby, expanded the number of people who could be accessed to invite to join the research.

The biggest difficulty of using the "snowball" introduction method is that it may skip people having useful information because they are not known to the research collaborators or people introduced to the collaborators. To avoid this and increase the diversity in the samples, apart from the network of collaborators, researchers (through friends) found more clues from representatives of associations and unions in the studied provinces to see if they had people with disabilities among their members and ask them to refer these people. By doing so, the

research team was able to interview 58 people with disabilities with various functional difficulties.

TOPICS OF QUALITATIVE RESEARCH

The topics of the qualitative research were in accordance with the topics stated in the questionnaire. The topics are focused on four main thematic groups:

- General information about the interviewees;
- Sharing of perceptions of disability related stigma and discrimination;
- Experiences on stigma and discrimination (in the areas of mental health and health services, disability assessment, education and employment opportunities, participation in groups, associations and clubs);
- Changes in the future.

Details of the topics used for discussion can be found in Appendix 3.

QUALITATIVE RESEARCH TOOLS

Qualitative research was conducted with two major tools: in-depth interviews and group discussions based on the above topic groups. In-depth interviews were conducted at all study sites, including Hanoi, Ho Chi Minh City, Da Nang, Thai Nguyen and Nghe An. Group discussions were only conducted in Hanoi and Ho Chi Minh City due to the difficulty of arranging a discussion among people with from different disability groups at the same time.

In support of in-depth interviews and group interviews, a set of four assisting tools was prepared as options to facilitate discussion between the researchers and the interviewees. Support tools included "Naming Stigma through Pictures", "Talking Mats", "Historical Diagram" and "Income and Expenditure

Matrix". Details on how this toolkit was used can be found in Appendix 4.

Both in-depth and group interviews were conducted with an audio recorder (with the consent of the interviewees; see Section 4.5 on Research Ethics for more information). The recordings were transcribed by a team of transcription experts. The interview contents were then written into a Word document that was used for analysis. The use of audio recordings enabled the research team to focus on the discussion with the interviewees without having to spend time taking notes during the interview. However, using audio recordings in interviews could create anxiety and discomfort for the interviewees, thus reducing the quality of the interview. To limit this, the researchers explained from the beginning that the use of an audio recorder was not compulsory. During the interview, the researchers always observed the mood and responses of the interviewees and suggested stopping recording while discussing personal matters with interviewees.

4.3. Data Processing and Analysis

4.3.1. Data Entry and Cleaning

Data collected online via Survey Monkey were exported in Excel format for analysis. The paper questionnaires were entered into the online survey on Survey Monkey after the end of each offline survey. Once all the data had been gathered into a single file, the data were cleaned up to eliminate invalid questionnaires, whose respondents were less than 18 years old or did not answer questions on disability (to identify them as people with disabilities), and those that had given only one or two answers.

4.3.2. Data Analysis

RESPONSE RATE

A total of 574 questionnaires were collected for the quantitative research. This was less than the initial target of 900 set before the study was implemented. Some of the reasons for the low response rate for online data collection on Survey Monkey were:

- The number of people with disabilities who have access to the internet was still low;
- Regarding the visually impaired group, the amount of time they spent to answer online survey was longer compared to that of other disability groups, hence the low online response rate for this group;
- Regarding hearing impaired people, their vocabulary learned in school and literacy skills were limited, as they did not use much writing, they were not willing to read texts such as a questionnaire.

To deal with this situation, the team actively used paper forms to reach people who did not have computers or smart phones or did not use information technology in general, especially people aged 50 years or older. In order to reach the targets, the team contacted clubs, associations and schools for people with disabilities to organize paper-based survey sessions (i.e. offline surveys) instead of online surveys. For cognitively and visually impaired groups, the research team had volunteers to help fill in the form. In addition, for the deaf/hearing impaired group, the research team arranged sign language interpreters to translate each question in the survey to increase the accuracy of the information received.

DATA ANALYSIS

The cleaned-up quantitative data were entered the SPSS software for analysis. The main results were put into Excel

to draw tables for the results. The results of the questionnaire were analysed according to the survey queries based on the four topics selected for the study. These results were analysed to see the popularity of the answers to the questions posed among the respondents.

Not all valid questionnaires collected as part of the quantitative study had answers to all questions. Nevertheless, the research team retained all eligible questionnaires and analysed answers suitable for the research purposes when the questions had a high response rate. Thus, when analysing data on each topic, the number of respondents on that topic was noted, so that the readers can estimate the reliability of the answers in comparison with the total number of participants in the study.

The data in the qualitative research was mainly collected from the interview material. This content was then filtered and arranged into four main topic groups as developed prior to the interview.

- General information about the interviewees;
- Sharing of perceptions related to stigma and discrimination;
- Experiences on stigma and discrimination (in the areas of mental health and health services, disability level assessment, education and employment opportunities, participation in groups, associations and clubs);
- Changes in the future.

This information was entered into the Excel file to analyse the outstanding common features in all interviews. Besides the quantitative information extracted from Excel, such as the number of interviewees with any type of disability, qualitative information explaining a perceived or experienced stigma was compared to the quantitative data with similar content to further enrich the analysis.

4.4. Difficulties Encountered during the Research

In terms of methodology, beyond the strength of providing large-scale information, difficulties with using survey questionnaires in the quantitative research were also inevitable. In addition to the stated reasons for the low response rate to the online questionnaire, other challenges also appeared in aspects beyond the control of the research team. For example, appointments with organizations, associations, groups of people with disabilities depended on the timing of monthly or annual activities to reach more members. In addition, 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 introductory meetings. Appointments with associations and groups of people with disabilities usually had to wait two to four weeks before coming to a settlement.

In the qualitative research, access to people with disabilities in provinces was also very difficult. In the provinces outside of Hanoi and Ho Chi Minh City, the biggest obstacle of approaching people with disabilities to participate in interviews was the suspicion of people with disabilities themselves. This hesitation was because of their limited contact with strangers. In Nghe An province, for example, many interviews were cancelled or refused to participate by respondents, especially people in older age groups. As for Hanoi and Ho Chi Minh City, one difficulty in accessing people with disabilities was fear of boredom, since they had been invited to many interviews by government offices, Associations of People with Disabilities and NGOs during the previous two years.

For both the quantitative research (to reach people with disabilities to collect paper surveys) and the qualitative research

to overcome obstacles of approaching study subjects, the researchers used the networks of the collaborators to contact suitable participants in the study provinces. The involvement of clubs' management boards, as in the case of clubs for deaf people in the targeted provinces, help build bridges and create trust with potential participants.

4.5. Ethical Considerations

While this report, from Chapter 1 to this point, has approached research issues primarily from a technical perspective, to ensure the quality of the research, another important factor was the need for the research to be highly humane, particularly in its approach to people with disabilities. To this end, the researchers took measures to ensure compliance with research ethics.

First, before each interview, the research team spent time explaining to the interviewees about the research and the purpose of the research and how the collected information from the interview would be used. The researchers also provided information on their names and emails/telephone numbers for the interviewees to ask questions after the interviews, if they had any.

Second, the assurance of non-disclosure of the interviewees' identities when using the information obtained from the interview was shared with the participants (for both the qualitative and quantitative research). To comply with this principle, when the data were cleaned, the names and locations of the study participants were encoded into letters and numbers. In the report, anonymous names and locations were used.

Third, after explaining the purpose of the study, the interviewees were counselled, and the voluntary nature of the assessment was explained. It was made to clear to interviewees that they could withdraw from the interview, if they wanted.

The use of audio recorders to record the content of interviews was also checked with the interviewees to ensure that they were informed and could either agree or decline to participate.

Fourth, during the interviews, the interviewers always explained the questions for the interviewees to understand, if they did not want to answer any question, they were not obliged to do so. If they wanted to stop the audio recording, the researchers would stop.

RESEARCH **RESULTS** $\big|$3

This chapter presents key characteristics of persons with disabilities participating in the research, which lay the foundation for presenting findings of this study. In doing so, the authors wish to prepare readers for discussion of implications of the research to policy makers and organizations who work to promote rights of people with disabilities in Chapter 4.

Chapter 3 consists of six parts. Part 1 introduces the general picture of people with disabilities, such as information on demography, education, disability level and disability types, and the participation of people with disabilities in different organizations. Part 2 presents research results on perceived stigma towards people with disabilities and factors that influence stigma. Part 3 focuses on perceived stigma in education and employment. Part 4 discusses perceived stigma in healthcare, focusing on access to reproductive health and sexual health. Part 5 examines the mental health of people with disabilities participating in this study through mental health scale, job satisfaction scale, self-stigma in love and life of people with disabilities. Part 6 concludes the Chapter with a presentation of findings about experience of disability assessment.

1. General Picture of People with Disabilities

1.1. Demographic Information

In the quantitative study, there were 516 participants, of which 269 (52%) were male, 237 (46%) were female, six people (aged 18 - 38) identified themselves as "Other" for gender and four

people did not answer the question about gender. The majority of participants were from 18 to 38 years old (67% of total participants) (see Chart 1). People between 39 and 58 years of age made up 17% and the rest were above 59 years old (not including four respondents who did not provide age information). Unmarried people accounted for 49% of the respondents, married people 38%, and divorced people 6%.

Chart 1: Total number of the participants taking part in the quantitative research by gender and age

	Other	Male	Female	Not available
■ Not available	0	8	5	4
■ 59 years old and above	0	35	26	0
■ From 39 - 58 years old	0	44	46	0
■ From 18 - 38 years old	6	182	160	0
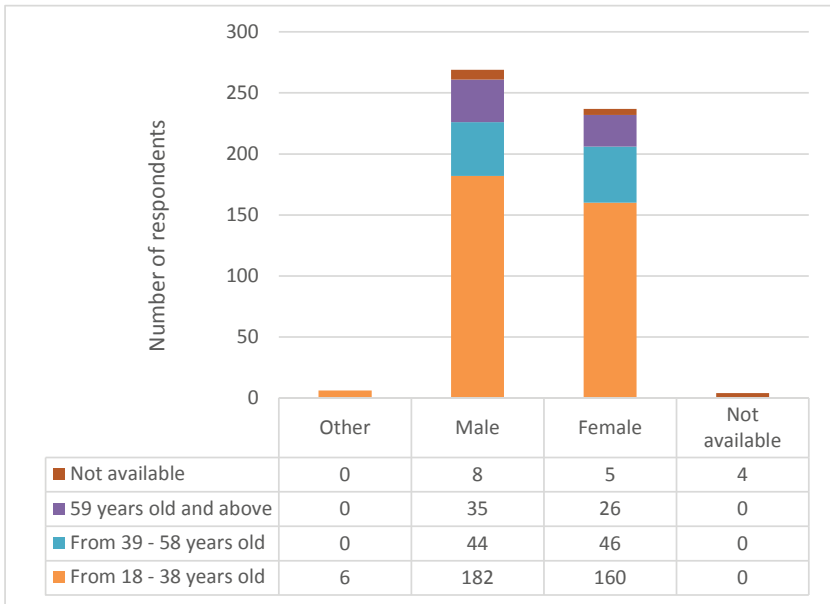
In general, visually impaired people had the highest quantitative research participation rate (36%), followed by mobility-impaired people (34%). People with hearing, self-care and communication difficulties had similar participation rates (13%). Cognitively disabled people had the lowest participation rate, accounting for 9% of the total number of participants. Among those listed as "Other" for the gender category, there

were two people with disabilities within six types of functional impairment (at different levels) and three people with more than one difficulty related to intellect and self-care.

Regarding the area distribution of participants in the quantitative research, the highest regional participation rate was in the northern region of Vietnam (including Hanoi, Thai Nguyen), followed by the southern (Ho Chi Minh City) and central regions (Da Nang) (see Chart 2).

Chart 2: Classification of disability of the participants of the quantitative research by region
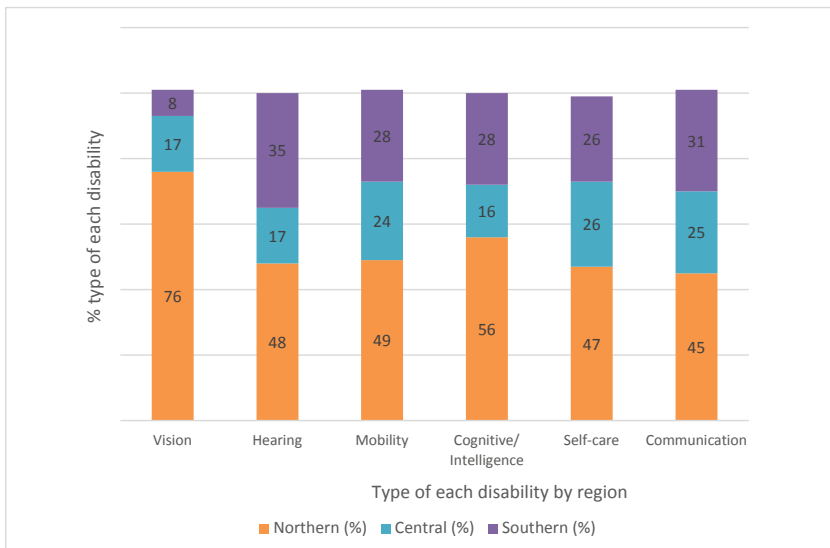
The number of participants in the qualitative study was 58 (29 males and 28 females and one self-identifying as other gender) from six functional disability groups, interviewed in five areas (see Chart 3). There were 44 participants between the ages of 18 and 38. The highest number of participants in the qualitative research came from the hearing-impaired group. Among the respondents, 69% of interviewees were unmarried and 15% were married.

Chart 3: Number of the participants of the qualitative research by gender and area
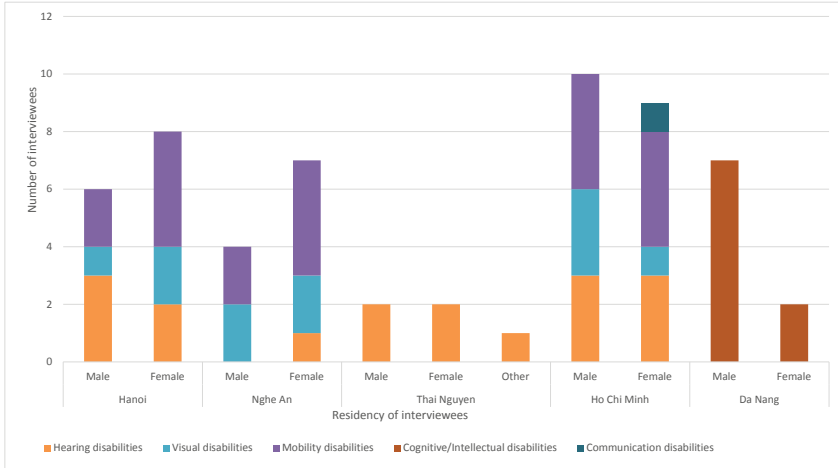
> *Notes*: Disability related to self-care was included in the same category with mobility impairment because all people with self-care disability were people with mobility impairment and nearly half of the people with mobility impairment were those who could not take care of themselves and needed assistance.
>
> The communication-impaired group in the interview were mostly people with hearing difficulties, who were thus listed in the same group as deaf/hearing-impaired people. There was one person interviewed in Ho Chi Minh City (via text message) who classified as communication impaired because the person could hear and understand very well but did not speak or speak very little (mostly yes/no).
>
> Three of the interviewed cognitively disabled participants were aged 15. The qualitative research retained these participants in the sample, since it was difficult to find people with cognitive disability to interview.

Regarding difficulty levels related to the six functions (upon ICF scale), "having some difficulties" was chosen by the greatest number of participants in the quantitative study. The level of "unable to do this task" had the highest rate in the visually impaired group, followed by the mobility-impaired group (see Chart 4). The analysis of answers to the questionnaire shows that 73% of the respondents (in total n=448) had at least two

disabilities, and 20% had only one functional disability. The remaining 7% did not have any functional difficulties were likely because they were those with limited height caused by lack of growth hormone as seen in qualitative research.

Chart 4: Difficulty levels in performing six basic functions by the participants of the quantitative research
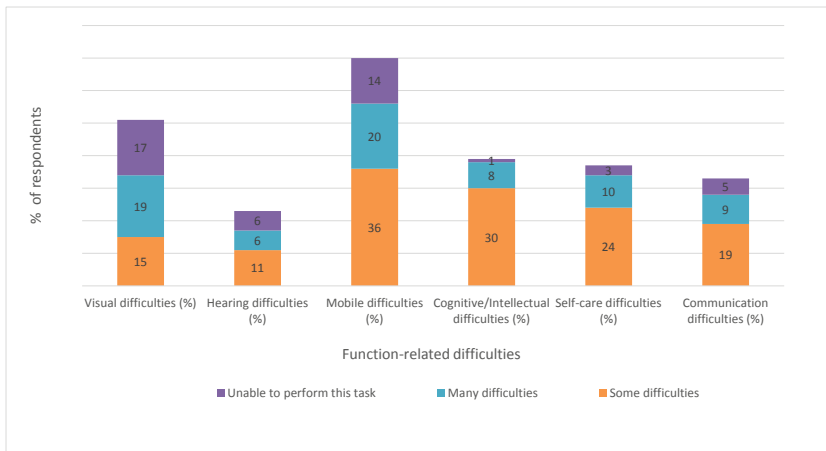
Regarding education, 48% of quantitative research participants had completed secondary school and high school. Ten percent of the research participants had not had the opportunity to attend school or had not finished primary school (see Table 1).

Table 1: Academic levels of the participants of the quantitative research

Highest academic level	n	%
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

In the quantitative study, people with self-care disability had the highest rate of not going to school or not finishing primary school. In terms of middle and high school level, the communication-impaired group had the highest completion rate (see Table 2). On the other hand, regarding undergraduate and graduate education, the visually impaired group had the highest percentage of people who had finished these levels, higher than that of the mobility-impaired group (see Table 2).

Table 2: Types of disability and academic achievement by the participants of the quantitative research

	Vision		Hearing		Mobility		Intelligence		Self-care		Communication	
	n	%	n	%	n	%	n	%	n	%	n	%
Never been to/not completed primary school	16	11	1	2	23	16	5	13	12	22	6	11
Completed primary schools	19	13	13	27	27	19	11	29	10	19	13	25
Completed middle schools	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 colleges	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

From a gender perspective, the proportion of females at undergraduate and graduate level was higher than that of males. At other levels of education, the difference between men and women was not that great (see Chart 5).

Chart 5: Percentage of people completing different levels of education by gender in the quantitative research (n=224 males and 200 females)
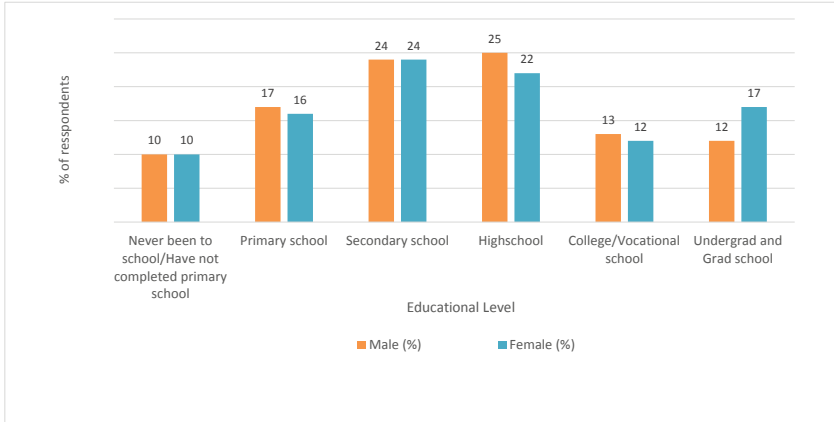
Regarding the education of qualitative research's participants, most of the 58 interviewees had completed primary school (see Chart 6). However, only six had completed a university degree; these comprised two females and four males, who belonged to the mobility-impaired, visually impaired and dwarfism groups. Five of the interviewees (two females and three males) had never been to school, among which four had visual impairment and one had mobility impairment.

Chart 6: Number of the interviewees and academic level (n=58) in the qualitative research
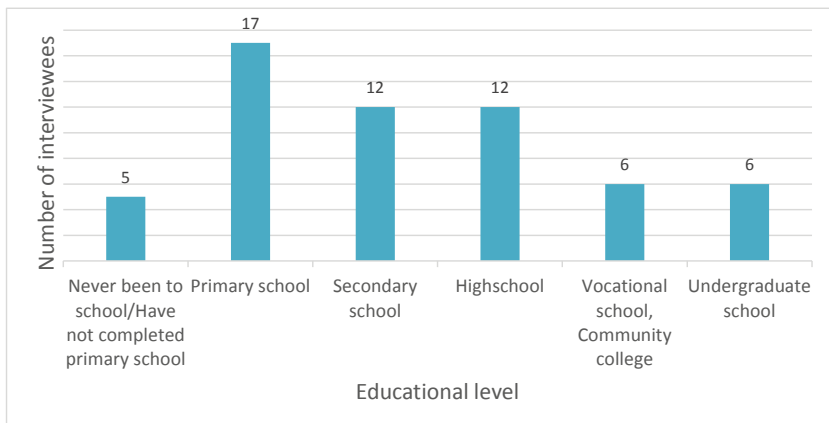
1.2. Participation in Organizations, Associations and Groups

In the quantitative study, 72% of respondents (n=413) reported having participated in one or more organization, association or group. Among participants in organizations, associations and groups, the percentage of male participants (70%) was lower than the percentage of female participants (74%). Among respondents who did not participate in any organization, association or group (n=115), the percentage of respondents giving the reason for non-participation as being busy was the highest (35%), followed by those responding that they did not know the groups to participate in (27%). The number of people who reported perceived stigma (n=178) had a lower participation rate in organizations, associations and groups (67%) than those who did not (n=234) (76%).

In comparison between different forms of disability and their involvement in organizations, associations and groups (Chart 7), hearing impaired people (n=52) were more likely to participate in organizations than all other disability groups, with the rate of respondents participating in organizations, associations and groups being 92%. The response of visually impaired people (n=145) to questions on participation revealed that their participation rate was 91%. People with cognitive disabilities tended to be less extroverted, with the lowest participation rate (61%) (see Chart 7). Among those listed as "Other" were four people who did not participate in any organization, association or group and one participant who had joined a hobby club. The higher rate of deaf and hearing-impaired people participating in organizations, associations and groups might be influenced by the fact that these people had their own disability groups (i.e. organizations established by themselves not by the government), while others did not. However, participation queries also list

mass organizations alongside self-organised clubs/organizations by people with disabilities and those by the government.

Chart 7: Percentage of people taking part in organizations, associations and groups by types of disability in the quantitative research
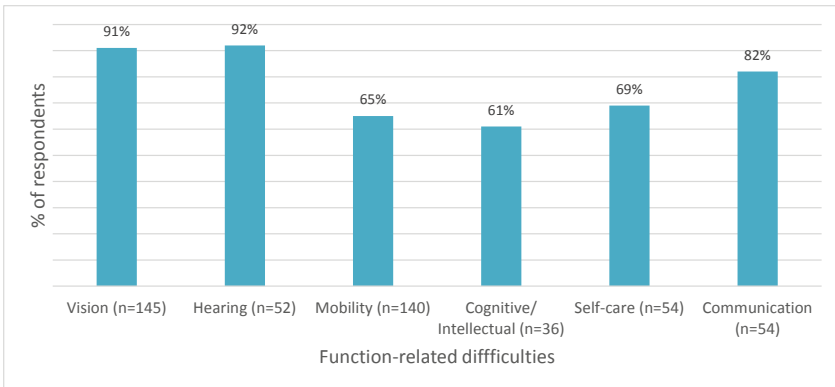
Among participants in organizations, associations and groups, 46% of respondents (n=298) in the quantitative study participated in associations, groups and clubs established by people with disabilities, while 44% participated in the Association of People with Disabilities established by the government. Rates of participation in mass organizations, such as the Farmers Union, Youth Union and Veterans Association, were relatively low, ranging from 3% to 5%. Rates of participation in the Women Union and the Association of the Elderly were rather higher, at 11% and 8% respectively. The participation of people with disabilities in organizations, associations and groups was mostly symbolic when their role was only to listening to information. Sixty percent of respondents (n=298) were involved in organizations at this level. Participation with the highest level of engagement (i.e., engaging in planning *and* decision making for activities) was reported by only 24% of respondents (see Chart 8).

Chart 8: Percentage of the respondents with participation levels in organizations, associations and groups in the quantitative research
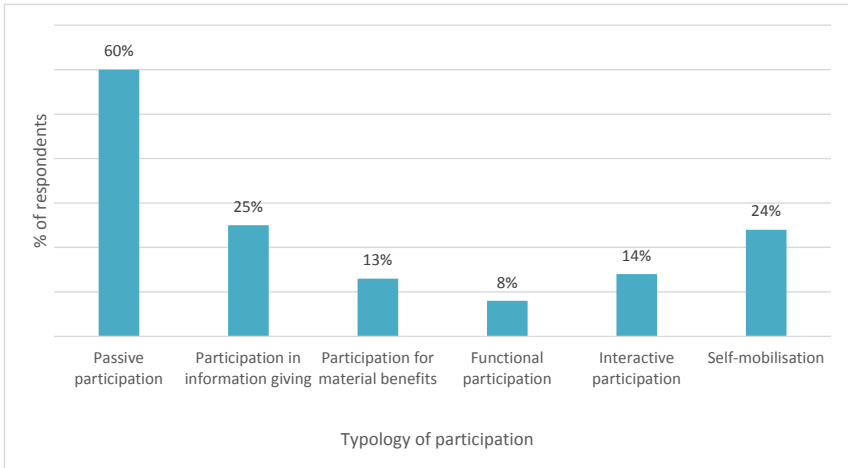
The reasons people with disabilities gave for joining organizations, associations and groups varied among respondents (n=298) as follows: keeping relationship with peers (73%); sharing difficulties; learning experiences (62%); being vocationally trained and learning to read/write/use sign language (58%); and information exchange on employment (31%).

In the qualitative study, 37 (out of 58) interviewees participated in associations (state-established associations), clubs or groups (established by people with a disability), or both. What was remarkable about interviewees from the northern and southern regions is that, regardless of disability type, they were mainly involved in clubs or groups established by people with disabilities (see Chart 9). Social organizations, such as the Women's Union or Farmer's Union, were not likely to reach out to people with disabilities. Interviewees in the qualitative research shared that they participated in clubs or hobby groups because they liked to meet and help each other when possible. When participating in clubs or groups founded by people with disabilities, the

interviewees said that they could contribute to decision-making regarding activity selection and organizing, so they could be beneficial or responsive to the demands of members. This is also understandable because clubs or groups had more flexible organizing than other state-established associations or unions.

Chart 9: The number of the participants taking part in associations/ groups/clubs by region in the qualitative research
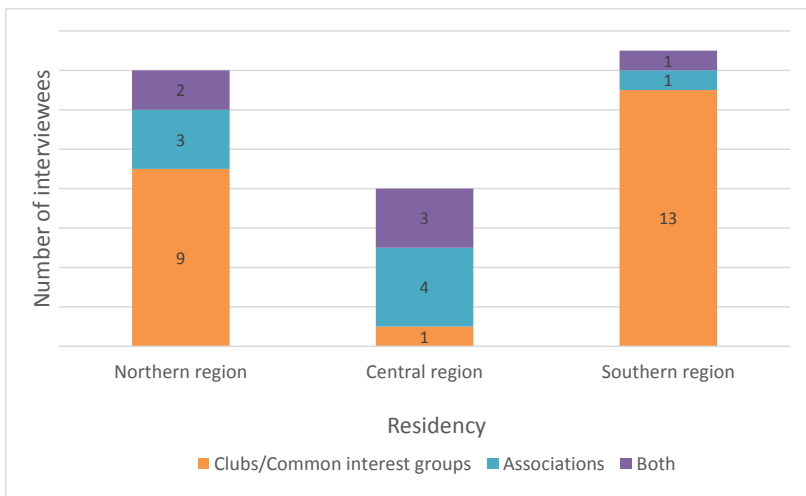
In the qualitative study, the main reasons people gave for not joining any organization, association or group were "not having time", because they were busy working or taking care of their families, or "not finding an interesting organization" in the area they lived in. A woman with mobility impairment in Nghe An province shared that she did not want to participate in associations because she did not want to communicate with people in her area.

Among the clubs or groups mentioned by the interviewers, the deaf clubs seemed to be the largest and best organized. The clubs held their regular activities once a month. After a playing session, the members learned sign language and exchanged new

information. Self-motivation in decision-making and planning was mainly concentrated in the leadership groups of these clubs. These clubs had been supported by a capacity-building project for the management boards of the clubs, which ran for three years since 2013.

2. Perceived Stigma from the Perspective of People with Disabilities

Having presented basic information about people with disabilities in the previous section, the report continues by presenting findings on perceived stigma and influencing factors, before sharing findings on self-stigma and ability to recognize stigma against people with disabilities.

2.1. Perceived Stigma and Influencing Factors

In the quantitative research, perceived stigma was determined by analysing the responses to two questions used in the stigma measuring scale (see Chapter 2) about levels of embarrassment and discrimination that research participants had experienced during the previous year. Those who answered, "a little" (or more) to both questions were considered to have perceived stigma.

The results from the analysis show that 43% of respondents (n=481) had perceived stigma during the previous year. The proportion of people who perceived stigma varied according to subject. The data from the questionnaire revealed that, in general, gender, age, type of and multidimensionality of disability seemed to contribute to perceived stigma rather than education level. However, this may have been different if the sample had been conducted in another location or expanded to a nationwide scale.

• The percentage of young people who perceived stigma was higher than that of older people (see Chart 10).

Chart 10: Percentage of people who perceived stigma by age group (n=262)
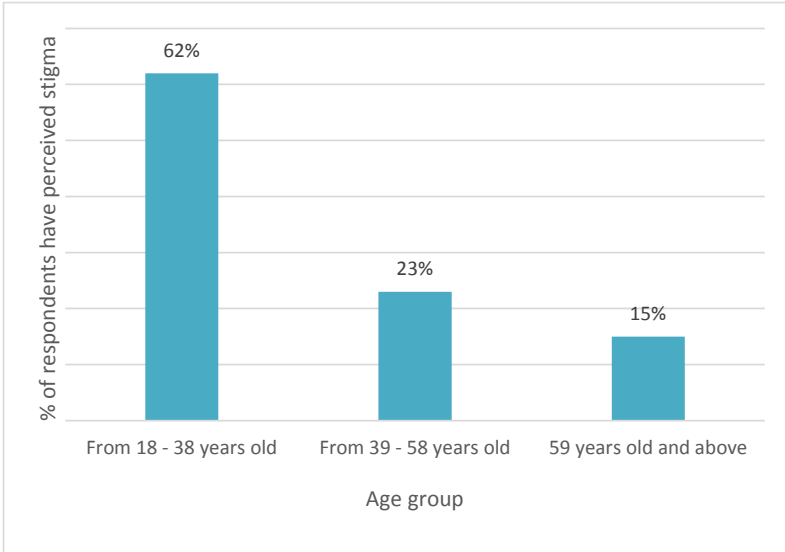
- The percentage of men who perceived stigma was higher than that of women (see Chart 11)

Chart 11: Percentage of people who perceived stigma by gender
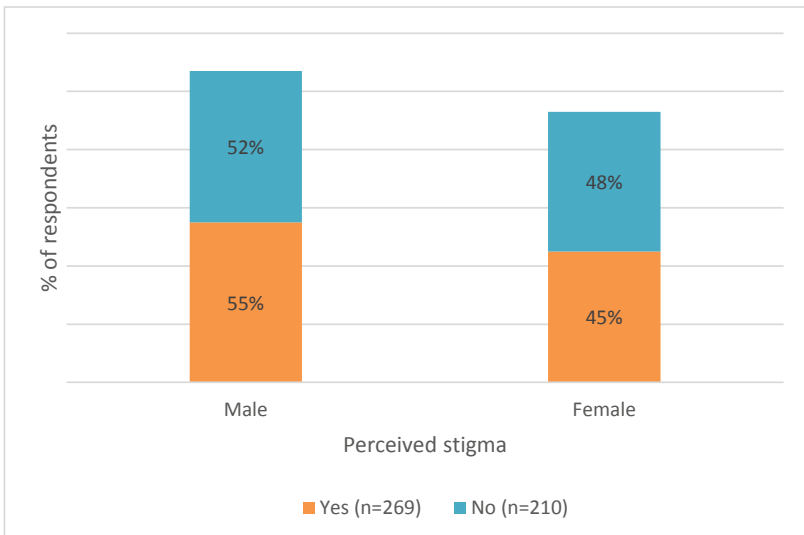
- People with visual impairment had the highest percentage of perceived stigma among the different types of disability. This group was followed by people with mobility impairment. The percentage of people with self-care disability who perceived stigma was the least among the groups with different types of disability (see Chart 12).

Chart 12: Percentage of people who perceived stigma by types of disabilities
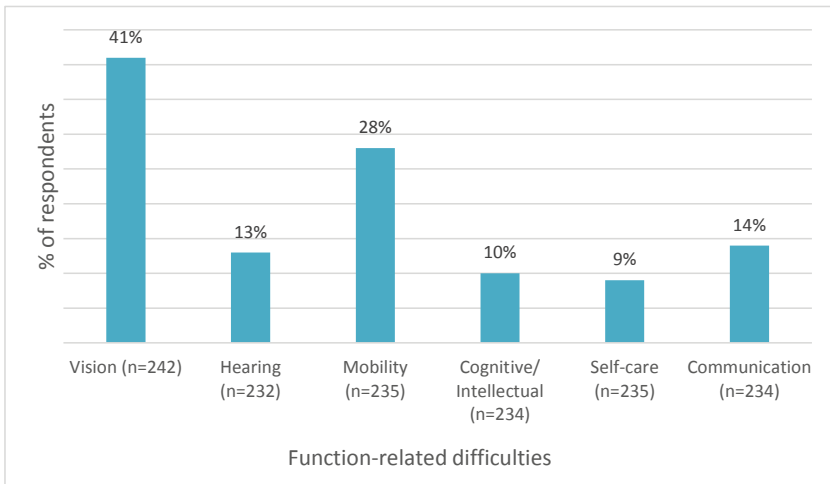
- Educational level did not seem to affect the perception of stigma. People who had never attended school or had not completed primary school had the lowest response rate of stigma perception. The percentage of people who finished high school had the highest rate of stigma perception at 23%, followed by those who had completed primary school, middle school and undergraduate education (see Chart 13).

Chart 13: Percentage of people who perceived stigma by academic levels (n=238)
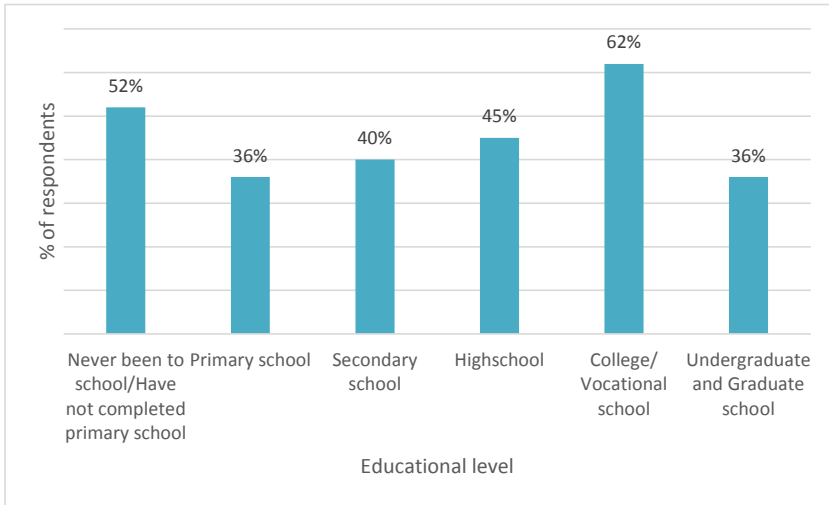
- Persons with disabilities in more than two functional areas had a higher rate of perceived stigma than those with one disability. Sixty-eight percent of people with multiple disabilities (n=222) reported having perceived stigma, compared to 27% of those with one disability.

For interviewees in the qualitative research, just more than half (21 out of 40 people) felt embarrassed by their disability; more males were embarrassed (13) than females (eight). The following quotes illustrate some situations that made interviewed people feel embarrassed. In the story told by a deaf man (through an interpreter) living in Hanoi about his childhood experience:

"When I was little, my mother was often insulted by our relatives because of having me 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. It was the fault of my mother that I was born with a disability like that."

Embarrassment also came up when the families hid their disabled members from surrounding people, as told by a visually impaired woman in Hanoi:

"People think that, when a child with disability is born, the whole extended family is not blessed. So, if a family line has a person with disability, it is difficult for even 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, the interviewees shared that embarrassment lessened as they were growing up. This explained why people were embarrassed when they were young. Many mentioned the lack of opportunities to share difficulties and discuss how to overcome them with people from outside, especially peers in similar situations, as one main reason for their embarrassment about their own disabilities. In addition, the absence of respect from surrounding people was another reason for people to feel they were the target of criticism or teasing by others.

As grown-ups, 37 people (out of 40 respondents[1]) did not feel embarrassed because of their disability. To explain this, interviewees said 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 influencing 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

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1   9 people with cognitive disability did not discuss this question because they did not considered themselves as people with disabilities; they were just slower than others.

decreased thanks to propaganda programmes by the press and mass media. The above explanation of reduced stigma was well described in the words of a man with mobility disabilities in Nghe An:

> *"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 behaviours. 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."*

Among the 37 people who said they had no embarrassment about their disability, 18 people (seven men and 11 women) actually had expressed their experience with perceived stigma in different ways. Responding to stigma and discrimination, they no longer felt embarrassed. Instead, those people learnt to ignore or accept these behaviours as part of their lives being people with disability, or felt sad, angry, annoyed, and frustrated by these behaviours. According to definition of perceived stigma as stated in Chapter 1, embarrassment is only a part of the perceived stigma. The feelings and reactions that more than half of the respondents mentioned above are also considered as perceived stigma.

Although perceived stigma has decreased as participants of qualitative research reported, incidents of discrimination were

still abundant. When asked about discrimination, 45 (26 men and 19 women; including those with cognitive difficulties) out of 49 respondents reported having been discriminated against in the past. At the time of the interviews, 34 people (18 males and 16 females) out of 49 related that they were still discriminated against because of their disability. This discrimination was often related to employment, school and travelling around (e.g. shopping, bus ride). The nine respondents who had cognitive disability (developmental delay, Down syndrome, mild psychiatric illness, depression) had encountered frequent cases of ridicule at school before moving to a specialized school environment.

2.2. Self-stigma

A manifestation of perceived stigma by people with disabilities, as discussed in Chapter 2, is self-stigmatization. Self-stigma was not encountered frequently among the quantitative study participants. Different forms of self-stigma were listed in a number of options available for questions related to access to education, health, participation in organizations, and love. When encountering stigma and discrimination, 15% of respondents (n=315) felt embarrassed. However, the percentage of respondents reporting self-stigma varied by subject. Regarding accessing health services, the percentage was relatively low (ranging from 2 to 3% of respondents). This rate increased slightly in education and social interactions but tended to increase rapidly when facing relatives and families in discussions about self-worth. Concerning love and marriage, in the quantitative study, the rate of people reporting self-stigma was high too (see Table 3).

Table 3: Different types of self-stigma among the participants of the quantitative research

Types of self-stigma	Areas	Response rate
Don't want to be identified as a person with disability so do not	use Healthcare Insurance	1,8% (n=56)
	go to sexual health check-up/counselling	1,9% (n=316)
	go to reproductive health check-up/counselling	2,6% (n=11.)
	do disability assessment	3% (n=94)
	want to engage in social activities	7,9% (n=15)
Assume that a person with disability don't need to learn or learn much	Education	5% (n=509)
Self-blame for their disabilities	In relationship with family	69% (n=94)
Agree with the statement that people with disabilities are useless	In 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)

Gender differences existed in self-stigma in love and marriage topics. The percentage of male respondents who never thought that a person with disability should not love, marry or have children was higher than the percentage of female respondents. In addition, the percentage of male respondents who did not have self-stigma was much higher than the percentage of male respondents who had self-stigma in the three areas. As for females, the percentage of respondents who reported not having self-stigma was not much higher than the number of respondents who had self-stigma. However, the difference was

clearly expressed in the percentage of women who did not have self-stigma and the percentage of women who had self-stigma in having children when they were disabled (see Chart 14).

Chart 14: Percentage of people by gender who had self-stigma in love and marriage in the quantitative research
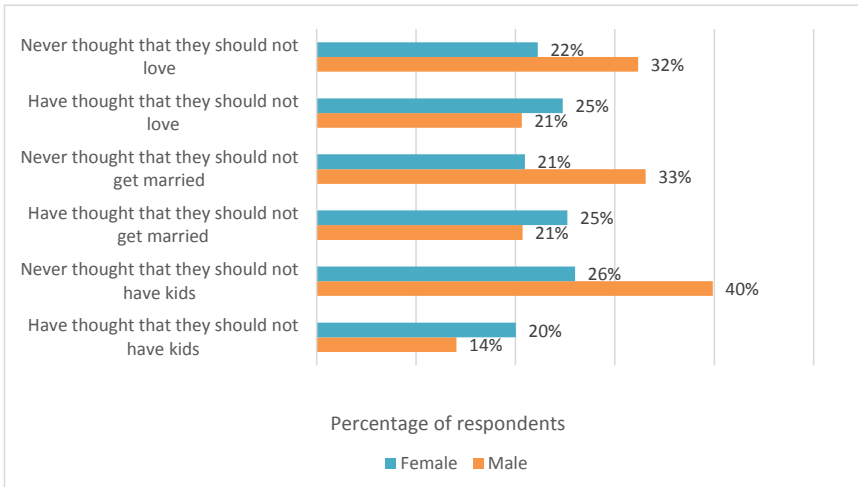
In the qualitative study, self-stigma about matters of love, marriage and having children was discussed with interviewees at all sites but discussions on these topics with cognitive difficulties group were not in-depth[1]. For both men and women interviewed in other disability groups, the issue of marriage and family was a relatively serious problem for all groups with disabilities, particularly mobility and visual impairment.

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1   The discussions on this topic with people with cognitive disability were not deep due to several reasons. First, people with this type of disability were not encouraged to love by families and schools. Second, since it was only possible to interview people with cognitive disability in school, the authors asked permission to interview people with cognitive disability in a school for children with learning difficulties in Da Nang. In the school, interviewees were 15 years old and had little life experience. As the result, discussion on this topic only limited to the question "do you love or like anyone?".

However, interviewed participants did not think they should not love because of their disability. Instead, the decision about not yet loving somebody was influenced by whether they had a stable job (in order to have a stable income to cover the costs) and good health (to be able to have children and take care of them).

Relating to employment and health, gender differences were clearly shown in interviews. For men, the concept of being the head of the family weighed on the mind of men with disabilities. This was a common self-stigma in men with disabilities. In their mind, they could not support their family (if being married), so they would not move towards love or marriage. When opportunities for education, jobs or stable income were limited, many men chose not to love yet. For women, they thought they could not do household chores such as cooking, cleaning houses, caring for their husbands because of their disability. Therefore, they refrained from starting a loving relationship that might lead to marriage.

Interviewed hearing impaired/deaf people reported not being embarrassed to express their love or their wishes to get married. This was often explained that as their lovers or spouses had the same disability, they did not have any inferior feelings towards each other. In addition, many said that when they could not speak and hear, they did not pay much attention to what the other said about them.

Apart from love, in qualitative research, self-stigma was also discussed when talking about embarrassment in different aspects of life of people with disabilities. In group discussions, the participants also shared that they did not feel embarrassed. This could be explained by the fact that interviewed participants had certain social networks with people in similar situations, which was said to make them more confident. In the words of most interviewees "*I do not do anything wrong, so I do not need to be embarrassed*".

2.3. Perception by Interviewees on Stigma

The prominent situation found in interviews with interviewees was that people with disabilities were not always aware of the discriminatory behaviours directed at them. Awareness of the rights of people with disabilities (i.e. rights to equal treatment and full participation in society, as stated in the CRPD) among those interviewed was still very weak. In matters related to social communication, such as while shopping, travelling on vehicles or accessing buildings, the respondents immediately used the word "discrimination" as they were mentioning cases that had made them upset. However, in relation to work, interviewed people with disabilities did not mention the word "stigma" in difficult situations they encountered (to be discussed in the following section on jobs). The authors often asked them about the topic of employment and identified maltreatments as discrimination. However, the interviewees (regardless of disability type) did not name what they experienced as either stigma or discrimination.

In the school environment, awareness of discriminatory behaviour was not high among respondents. Interviewed people with cognitive disabilities often recounted being teased about their disability while studying in an inclusive school, which led to them transferring to their current school. However, these people were not aware what experiences were called stigma or discrimination. Their parents or carers had often avoid talking about their children's disability, so, according to one teacher at the school, when the interviewees brought up the issues of being teased in school, their parents were reportedly silent and transferred their children to different schools.

For interviewees with limited height, when being at school, they were chased or got hit by children because the children thought they were their age with older faces. As a result, interviewees only thought that being chased or hit by children

was childish ignorance as shared by a man with limited height in Nghe An *"the kids at my school didn't know anything. They are children, so they teased."* Meanwhile, most deaf people, when asked for why they had not furthered their education or studied their favourite vocation, answered that the schools near them did not have interpreters for sign language. As a result, they were unable to understand and follow curricula.

3. Education and Employment Opportunity

After presenting findings on the perception of stigma, this part of the report examines the manifestation of stigma in education and the role of stigma in employment opportunities for people with disabilities participating in this study. This section covers three topics, namely general education, vocational education, and employment. The following sections approach these three topics in turn.

3.1. Formal Education: Reality and Stigma

In the 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 disability, compared to 40% who agreed. Regarding school, 45% of respondents (n = 345) disagreed that the school had strictly handled cases in which children with disabilities had been teased, compared with 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.

In the qualitative research, interviewed hearing impaired/ deaf people had a common characteristic of having been late to attend school. Although there was one case where a 19-year-old studied in the first grade, most of those started to go to school did so at 10 years old on average or studied two years each grade, or teachers did not teach in sign language, which it difficult for them to comprehend the words and concepts introduced by teachers. Even those who reached college also showed their unwillingness to write or speak to people without disabilities 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.

The reasons given by interviewees for not being able to study at a higher level that they desired or having never attended schools can be divided into the four main groups of stigmas. First, poor financial conditions were mentioned as a major factor causing many people to be unable to attend schools. A man with dwarfism who moved to Ho Chi Minh City for more than 10 years shared about his family's economic conditions and how it had influenced his studies as follows:

"I stopped going to school early 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 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."

When financial problems were critical, sending children with disabilities to school was not a high priority. As a mobility-impaired woman 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."

When family conditions were unfavourable, even when interviewees were enrolled in publicly funded educational programmes, the prevailing policy only allowed them to complete primary education and then enter vocational training, because people with disabilities were often late to attend school and had already reached 15 or 16 years old by the time they finished primary school. As a man with mobility impairment who had moved to Ho Chi Minh City 10 years ago said:

"I started school when I was 10 years old. It was a school for children with disabilities. I was a boarder 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, the teaching and training schools that did not have appropriate facilities for teaching people with disabilities did not encourage their parents to have them enrolled in schools. One woman in Nghe An province who was from an ethnic minority and visually impaired shared that:

"When I was little, I followed my friends to go to the nursery near my house. By the time of first grade, they started to learn writing.

However, I could not see, thus not able to learn to write anything. I could not help but stop coming to the school."

There was no higher education or vocational training for hearing impaired people after they finished primary, middle or high school. Many universities and colleges/vocational centres refused to accept deaf people, as shared by many interviewees. A deaf woman who had moved to Thai Nguyen city over seven years ago shared about her study as follows:

"I dropped out of school after finishing middle school because inclusive education was only option for me if I wanted to attend a high school in Thai Nguyen. It meant that I had to study with children without disabilities. I attended an inclusive high school for a month. However, I could not follow curriculum because I could not hear a word, teachers spoke too fast for me to read their lips and there were no interpreters. In the end, I disliked it, so I dropped out."

Even if being admitted, children with disability received no support from their schools (such as the high schools in Thai Nguyen), 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.

Visually impaired interviewees who had never attended school said that primary schools near their homes had been unable to teach them to read and write (because Braille had not been 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, so they did not allow me to attend."

Even when encouraged by their parents, studying higher

than high school or undergraduate level was extremely difficult for visually impaired people, due to the lack of appropriate facilities, as a 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 School for the Blinds. I was sent to normal high school under the inclusive programme from Nguyen Dinh Chieu School. 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 audio tapes. In university, the curricula 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 primary or higher-level schools for children with disabilities were all concentrated in big cities. This meant that children in rural areas far from these centres or lacking sufficient financial conditions were unable to attend school, as told in the above examples.

Fourth, the general trend among those interviewed was that the family's protection for people with disabilities also became a form of stigma, by considering them as useless and dependent on the care of families. They did not need to go to school because they did not have anything to do with the knowledge acquired there. From this point of view, encouraging children with disabilities to go to school was not always the case. A woman with a disability who had moved to Hanoi for more than five years shared her family's response 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 my royalties that day, my dad replied, "Even you can write an article and they even publish 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 the 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 study, 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 arguments about whether she should continue 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 with my mother, uncles and aunts who helped me to enrol there."

3.2. Vocational Training: Reality and Stigma

According to the results from the quantitative study, 59% of the respondents (n = 463) received vocational training. Vocations for people with disabilities participated in this research were not diverse, as listed in Table 8. The occupation commonly trained among the respondents included massage (this partly reflects the high number of blind and visually impaired people who participated in this study), computing and handicrafts. Although some other occupations such as drivers, musicians, waiters and bartenders were also mentioned, these jobs were not popular and not listed more than twice each.

Table 4: Occupations by the participants of the quantitative research

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

During in-depth interviews, the sharing of respondents showed that vocational training for people with disabilities was repetitious and conventional. Among the interviewees, 39 (out of 58) had received vocational training. According to the interviews with these people, training in certain vocations was more likely to be provided for certain types of disability. For example, young people with mobility impairment now have the tendency to learn and do computer-related vocations, such as software design or image editing. Visually impaired people have default occupations, such as massage, and broom and toothpick making. Deaf people are often tailors or barbers[1].

Vocational counselling for people with disabilities was almost unavailable. The above occupational assumptions for each type of disability were imposed on persons with disabilities, who were forced into vocational courses for them. Of the respondents, only four were given career counselling before choosing a vocation, and this counselling came from family members, not specialized

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1   These observations could differ if interviewed group had been extended because the total number of interviewees who had been vocationally trained in this section was low.

counsellors at their schools. The rest could not choose their future career.

In many cases, self-selection by people with disabilities of the vocations they wanted to study was also hindered by stigma that blocked their advancement. This stigma came from both their families and schools. In a group discussion, a woman with mobility impairment who had moved to Ho Chi Minh City seven years ago talked about her parents' obstruction to her study as follows:

"When I expressed my wish to go to a vocational training college, my father said, "My daughter you can just stay at home in my care, why do you want go out there when we don't lack anything for you. Even after your training, who will employ you?" After my father passed away, I resolved to beg my mother and she finally let me go to graphic design college."

A deaf man who was born and grew up in Thai Nguyen city 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 I was not capable of studying, so I should stop dreaming like that."

In addition, vocational schools usually focused on people without disabilities. People with disabilities were assumed to be incapable as examples above showed and, as in the following experience that a deaf man shared in an in-depth interview in Ho Chi Minh City:

"I wanted to study hospitality. I applied to a school in the centre of District 3 that taught hotel management. When I enrolled in the school, the teacher I consulted at the school rejected my application. She said that I would not be able to learn while being deaf, it would be very hard, it would be impossible."

3.3. Employment: Reality and Stigma

Half of the participants in the quantitative research were employed (including self-employed). 27% of respondents answered they were not working. The number of people who were looking for a job and studying made up the remaining 23% of respondents (see Chart 15). Participants in the study did not tend to apply for recruitment tests. Sixty-six percent 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.

Chart 15: Percentage of people with and without work in the quantitative research (n=495)
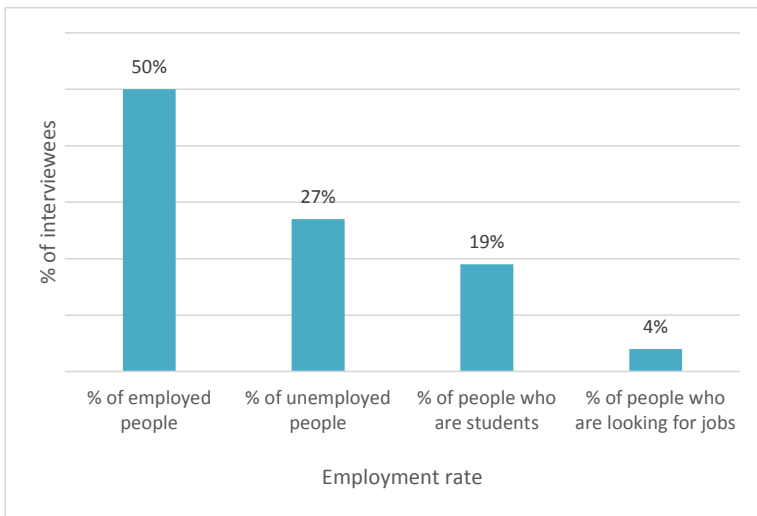
Eighty percent of the study participants received a state allowance. Median monthly income of the participants was very low. The average monthly income of Vietnamese people in the second quarter of 2017 was VND 5.4 million (MOLISA, 2017b). Meanwhile, the highest median income among the disabled groups (the deaf/hearing-impaired group) was VND 3 million

(see Table 5). Income disparity between high income earners and low income earners was very high between the deaf/hearing impaired and the mobility impaired (see Table 5).

Table 5: The monthly income by type of disability among the participants of the quantitative study

Type of disability	N = 308	Median monthly income
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

According to the income standard to classify poor households in the period 2016 to 2020, people with incomes below VND 1.3 million per month, and from VND 1.3 million to 1.9 million are classified as near poor and average, respectively, in urban areas (Law Library, 2017). As most of the respondents lived in urban areas, according to the above income standard, mobility impairment, cognitive and self-care disabled people at the study sites were classified as average (see Table 5). As the difference between being near poor and average is very close, and the study participants did not have secured jobs (to be discussed), the chance that they fall to poverty levels was 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. Of the 44 interviewees who were employed, only 13 reported having sufficient earnings to cover their food and living

expenses. Only three were completely independent of parental support or disability benefits and had money to travel, save or pay for extra tuition for their children.

Out of the 44 interviewees, nine people with cognitive disabilities were not working, 31 reckoned that their incomes were not enough to cover their costs. 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 costs of gasoline, renting house, electricity and water bills for both of us. Therefore, it is sad if on any day we only make VND 100,000. Our business is as street vendors, 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."

With low monthly income while the cost of living in the city is high, 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 borrow the salary for the following month to cover the costs of the previous month. According to a visually impaired man 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 fund 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 42) of the employed interviewees reported having been discriminated against at work because of their disability. These discriminations were often related to recruitments, wages, 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 impairment). 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 interview because of concerns that they could not work because of their mobility impairment. 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 recruitment process but, instead, in pay and working conditions.

In addition to low incomes, people with disabilities also had to deal with 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 an old debt, I've incurred a new debt. Sometimes I got my tickets snatched out of my hands, sometimes someone would pretend to see 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 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 previously, without any compensation partly because they legally have 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 a proper rest. Overtime is also not paid because my wage is calculated based on how many pieces I can make."

Or having to work long working hours, as told by a woman with mobility impairment 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 work 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."

Or not being given the same opportunities for on-job training as colleagues without disabilities, as in a case shared by a deaf male teacher in Hanoi:

"My fellow teachers who are not disabled say that they have coaching and training programmes throughout a school year. However, I (and two other teachers with hearing difficulties cannot enrol because training providers don't have interpreters for deaf people or 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."

4.　Healthcare

The healthcare section of the report presents results from the study in the following areas: access to health services in general; and access to reproductive health and sexual health services.

4.1 Access to Healthcare Services: Health Insurance and the Use of Health Insurance

The number of people covered by health insurance was high among the participants in the quantitative study. Ninety-three percent (n = 441) of the participants in the study had health insurance, in which the proportion of men and women among those having health insurance was almost equal (see Chart 16).

Chart 16: Percentage of the participants having health insurance by gender (n = 441) in the quantitative research
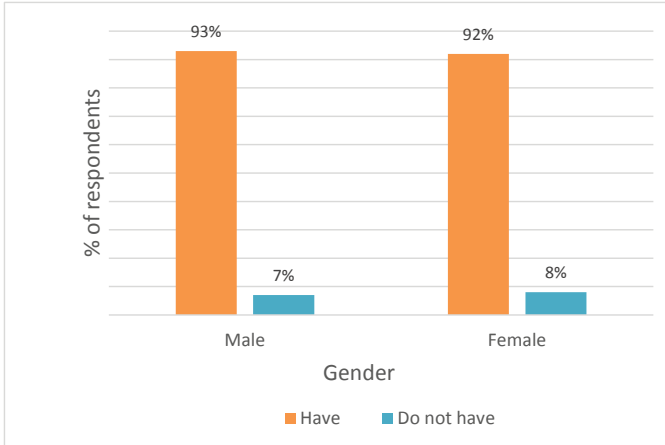
Of those who had health insurance, 96% were given an issued card of their own. Among the uninsured people, the reasons for not having health insurance included lack of money (33% of respondents), not knowing where to buy (21%), not believing in the benefits of health insurance (9%), and not knowing what health insurance is (6%) (see Chart 17).

Chart 17: Percentage and reasons of not having health insurance among the participants of the quantitative research
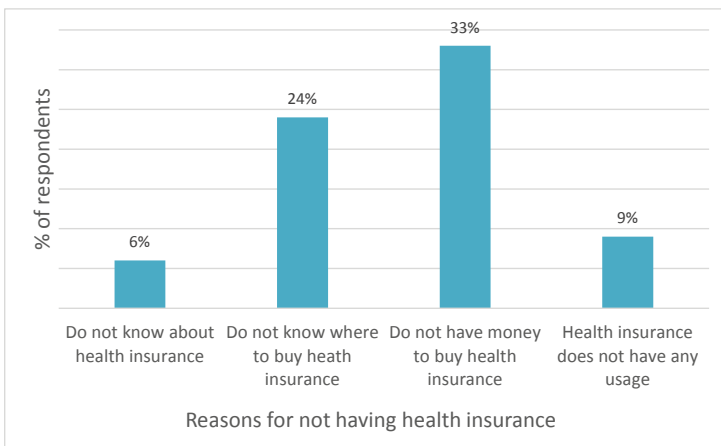
At their most recent check-up, 75% of participants (n = 377) used health insurance. However, 11% of respondents had never used their card (Chart 18). Of those who did not use their health insurance (15%), the most mentioned reason (34%) was that their health insurance was outside of the covered area. Another reason was that their health insurance did not cover or covered only a little of the costs, while the procedures were not convenient (Chart 19).

Chart 18: Percentage of health insurance users in the quantitative research (n=377)
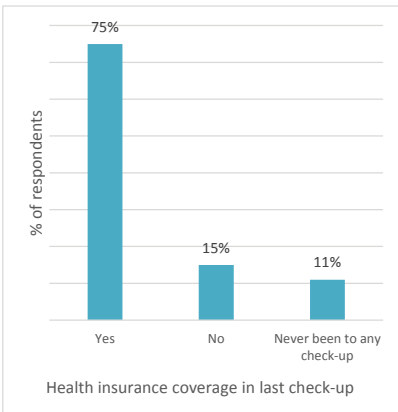
Chart 19: Rate of responses for reasons users not use health insurance in the quantitative research
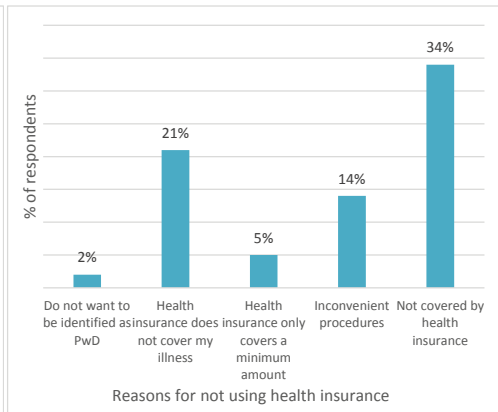
In the qualitative research, eight people (two females and six males) did not have health insurance (out of 58 respondents). Among those who were uninsured, six were deaf. The general situation among these deaf people was that they did not know what health insurance was and what the benefits were.

In addition, the awareness of using public health service in the community of people with disabilities is not high and they do not have sufficient financial resources to access specialized services for their disability. Although being people with disabilities, who are often not as healthy as average people, as proved in the ISDS

study (2013), the interviewees did not register for any routine screening programmes related to their disabilities. The majority of people who were asked about medical care had no habit of going to check-ups. They thought that they should see a doctor only when sick or seriously sick. When feeling unwell, they mostly went to the drugstore and bought medicines themselves, as in the case of a visually impaired woman living in Vinh city:

"I have degenerative spine conditions. I often have headaches, you know. I have all kinds of diseases like that. Also, with colonic disease. The older I get, the worsen these diseases and the worst they hurt me. In the past, I didn't have many headaches but now I constantly feel painful. I only went to check my head, but I have never been for a full body check-up. When it hurts too much, I go to the pharmacy to buy medicines to treat it myself."

Despite the high percentage of health insurance coverage among the interviewees, the rate of using health insurance was low. Of 50 people (27 females, 23 males) who had health insurance, only 25 (14 females and 11 males) used health insurance when going to see doctors. Those who had health insurance did not use it because they never went to see doctors, or their health insurance was outside of the covered area. In the case of the visually impaired person mentioned earlier, the use of health insurance did not mean much for her, she said, because the insurance she got did not provide her with cost for medicines she needed because she lived outside of the insurance coverage. For this reason, many interviewed people with disabilities relied on their income to cover medicine costs, because most interviewed people came from countryside and went to cities to look for work.

4.2. Access to Reproductive and Sexual Health Services

The results of the quantitative study indicate that access to reproductive health and sexual health services for people with

disabilities is very low. Seventy-eight percent of respondents (n=404, of which the number of male respondents was higher than the number of females) answered that they had never been to sexual health examination or counselling. Similarly, the number of people who had never had a reproductive health check-up or counselling was also high (76%, n=400 with more men than women). Among those who had been to an examination, the proportion of female respondents was twice that of men.

The most frequently mentioned reasons among the participants in the qualitative study are *"I am completely normal, so I don't have the need to go to the doctor or consultant"* (accounting for 63% and 64% of the answers) and shyness (accounting for 17% and 18% of the answers) when referring to reasons that prevented them from going to medical facilities. Respondents also mentioned the reason of not having somebody to take them to, or none understanding them when they came to medical facilities (accounting for 11% and 12% of respondents) (see Charts 20 and 21).

Chart 20: Rate of responses and reasons the participants of the quantitative research gave for not using sexual health examination and counselling (n=316)
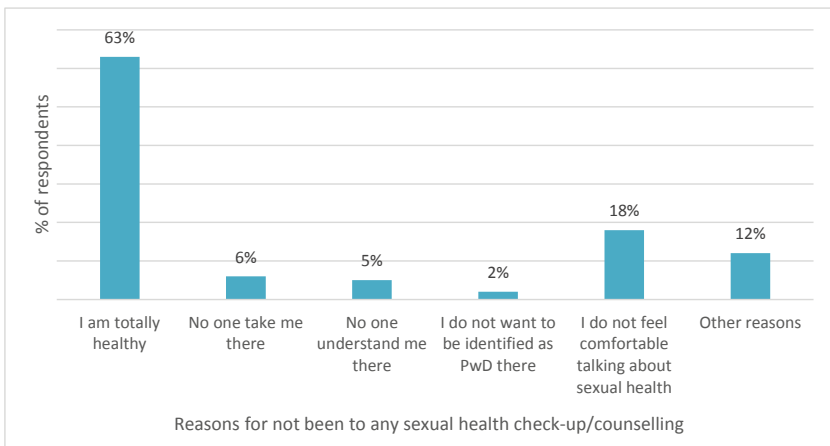
Chart 21: Rate and reasons that the participants of the quantitative research gave to explain why they did not take reproductive health examination and counselling (n=303)
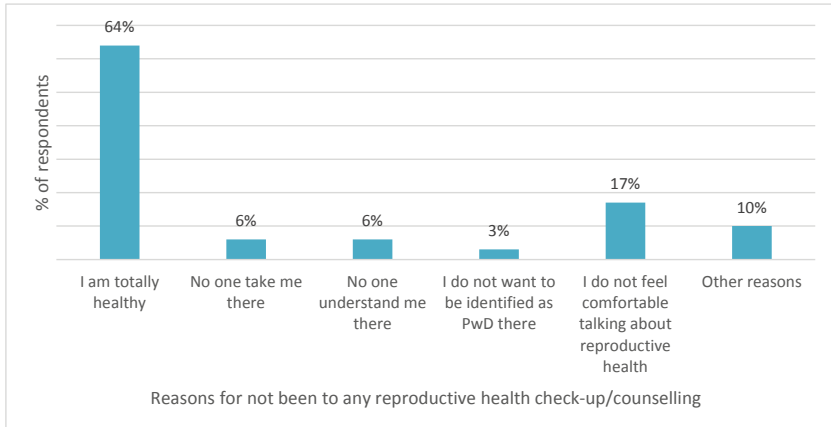
In qualitative research, interviews with research participants revealed that access to information about reproductive health and sexual health was limited, so their knowledge was limited. For unmarried interviewees, awareness of the necessity and importance of having information on reproductive health and sexual health to their lives was very weak, particularly among males. All women who had attended at least primary school had the opportunity to access information related to sex education in schools such as physical development and differences between the bodies of males and females. This was the main source of information on reproductive health and sexual health that they knew. No one in the unmarried group had access to this information through the health system.

Those who never attended school, including both men and women, said that they had no knowledge on reproductive health. These people also did not learn more because there was no need when they had never loved anyone and were not going to get married soon. For them, sexually related diseases would

not affect them because they thought they would not have sex. One woman with mobility impairment in the interviewed group who had never attended school said:

"When I think about getting married, I will go to consult a doctor. I am still young. There's still time. Now I just want to focus on working to make money, so that if I get sick in the future, I at least have the money to take care of myself."

People with disabilities who are men, married or unmarried had limited knowledge of reproductive health. These people shared that they were often not invited to information sharing session on this topic because they were not women. In the view of men with disabilities, this is a kind of discrimination in access to health information as shared by a deaf man in Hanoi:

"Normally, they are more concerned about reproductive health for women, and men do not receive that kind of concern. So, naturally, we boys are dismissed. In our deaf people's community, I have never seen such a project for male audience... And we think that, for example, people who work at centres of reproductive health are almost all women. If we go to those places for sexual health counselling, I'd be very embarrassed. In view of the above, we, men, are now the one at disadvantage than women."

The fact that reproductive health information is only available to women is also common to other groups with disabilities. For example, a blind man in Hanoi said that even when the Blind Association did training on population subjects, only female members were invited.

However, different disability groups had limitations as well as their own information channels to find the information they needed. For the deaf/hearing impaired group, even at the schools for people with disabilities, access to information related to reproductive health and sexual health for deaf people was also restricted, as related by a male in an interview:

"We were introduced to reproductive health and sexual health in a project in school. When listening to the talk, because the interpreter was too slow to keep up with the speech of the speaker, the information we learned was limited. And then, in the middle of the talk, the principal found out that there was a sign language interpreter, and she forbade the interpreter to continue translating for us because according to school regulations, we studied through speaking, writing and lip reading. As a result, we didn't understand the rest of the conversation. In general, although I learnt about reproductive and sexual health in school, I do not know much."

To compensate for the lack of information, deaf males often went to internet sources if they were curious to know more, as was shared by many of the interviewees. However, due to limited vocabulary, these people said that when reading online information, they did not understand much. They shifted to see sex movies to find out more about issues related to sex through images.

For people with dwarfism, both male and female, access to reproductive health was also limited. Many people assumed that they did not need to know that information because there was no prospect of them falling in love or getting married and having children due to their lack of growth hormone, which was the cause of their disability.

People with mobility impairments often had better access to information related to reproductive health and sexual health. Both male and female interviewees of this group had mainly completed undergraduate level, were employed and had financial support from their families; they learned information about reproductive and sexual health through seeing experts, schools or hospitals. Experience of discrimination related to access to health services by this group often involved travelling and moving to and from a medical centre, such as slippery and sloppy wheelchair routes. However, for poor people in this group, the rate of access to health

services in general and to reproductive health information and services in particular was not higher than for those with dwarfism, because of lacking money or family attention to see a specialist.

For the visually impaired group, information on reproductive health was limited. Out of 10 respondents, seven had never been introduced to this subject, four had never attended school so they were not introduced to reproductive health, and six did not use smart phones because they had insufficient money. Therefore, access to information through modern information channels was not available. If they wanted to know related information, they had to wait to listen to the radio when there were appropriate programmes but did not actively seek information as in the case of deaf interviewees.

The matter of sexual health and reproductive health education for people with cognitive disability is a very sensitive issue. Among cognitively disabled people aged 15 to 25, when asked about their lover, the respondents were often embarrassed partly because of little contact with the outside world, and partly because the topic was usually not encouraged at home. A cognitively disabled male in this group shared that he liked a girl but had only told his grandmother, not his parents because his parents forbade him to love. His parents, he said, also had not explained to him why he could not love. According to a teacher at a school for cognitively disabled children, parents of children with cognitive disability thought that having them is a burden for the family. Thus, they did not want their children to love or marry. At school, according to the above teacher, teaching about reproductive health or sexual health for people with cognitive disability began to be recognized as a right of people with disabilities and were integrated into independent living programmes. However, teaching basic knowledge such as using condoms or other forms of contraceptive was primarily due to concerns about cognitively

disabled people having children. Teaching people with cognitive disability about contraceptives mostly focused on methods rather than reasons for using them. Discussion of whether cognitively disabled person should have children had not been included in a reproductive health education programme. Instead, families and society still held preconceptions (for example that they do not need to love and have children) and imposed them on the group of people with this kind of disability.

In addition to the discriminatory concept of love and marriage for people with disabilities, discrimination was reported in healthcare for pregnant women with disabilities. This discrimination usually arose from a failure to provide specialized services for persons with disabilities. For hearing and speech-impaired women, there were no specialized services or information on these subjects at maternity and children hospitals. Three interviewed women, who were deaf and mute and had children in Hanoi, Thai Nguyen and Ho Chi Minh City, shared that they were not provided with any specialized services or documents assisting or providing them with pregnancy care, maternal and new-born care. Although they went for examinations, doctors would talk to family members rather than the pregnant person because there was no translator. As a result, these women had to depend on their family to look after their babies. According to a deaf person who took his wife who was also deaf to pregnancy tests in the past year, the doctor only made signs for them to go home without attempting to communicate with them to let them know about the condition of the mother and foetus. The couple went home assuming the child and mother were in good health.

For mothers who are visually impaired, discrimination occurred when information about child care and nursing was not provided to them. Although they may have heard of maternity information from the advice of doctors, however,

parenting depended entirely on whether the mother found the right information. Without help from her family, a blind mother shared that she had to manage everything on her own to train her child to eat, sleep, defecate and urinate in a timely manner that she can look after as follows:

"When I was raising my child, I did not have any supporting information for the blind. I found things out myself. When preparing milk for the baby, I could not see, so I place the feeding bottle to the side of the child's mouth and he himself learned to push the bottle into the mouth. When he finished eating, he would push the bottle out. At eight to nine-month-old, he could learn to feed himself. And at three years old, he would take me to the market and knew which shop sold vegetables or other things. At about five to six years old, he was able to take a bath by himself and wash small clothes."

When arriving at reproductive health facilities, an initial response to visits of disabled people was usually not friendly. When a woman with mobility impairment, who was paralyzed from the waist down, came to a reproductive facility for examination, she said in an in-depth interview that the doctor's reaction was "*why do you come here*?" and "*why need an examination when you can't give birth?*". Visually impaired people also reported coming across comments from medical workers, as shared by a blind mother:

"When we go to a hospital to give birth or for examination, many women who are doctors or nurses often say something like 'gosh, why do you made your life more difficult when you cannot see already.'"

Regarding families of both hearing and visually impaired groups that the researchers had the chance to interview, the role of fathers in the pregnancy and maternal care or receiving counselling from specialists and childcare (if any) was very insignificant. The fathers often said that their mothers-in-law

and wives did not want or encourage their involvement. These men also excluded themselves, thinking that they did not know anything. In addition, they supposed that their hearing or visual impairments only troubled others more. This is a problem of self-stigma of men with disabilities in accessing reproductive healthcare services.

5. Mental Health

In this section, the research results in the field of mental health are presented. Mental health is affected by many factors; thus, a group of issues are reviewed here to inspect their relationship to mental health. This section consists of three parts: the scale for measuring mental health of people with disabilities in the study; the scale for measuring job satisfaction level; and self-stigma in love and family issues.

5.1. Mental Health

Following the mental health scale discussed in Chapter 2, respondents with a total score less than 13 points or giving answers to any of the questions on the scale of 0 or 1 are considered to have mental health problem. According to data from the questionnaire, 53% of respondents (n=457) had some form of mental health problem, in which more men had mental health problems than women. Among those who had perceived stigma (n=130), 64% also had mental health problems. Disability groups with the highest rate of mental health problems were the communication-impaired and self-care-disabled groups. Cognitively and deaf/hearing impaired groups had the same rate of mental health problems. According to this assessment, the visually impaired group had the lowest rate of mental health problems among the six groups of disabilities (see Chart 22).

Chart 22: Percentage of the respondents with mental health problems by types of disabilities in the quantitative research
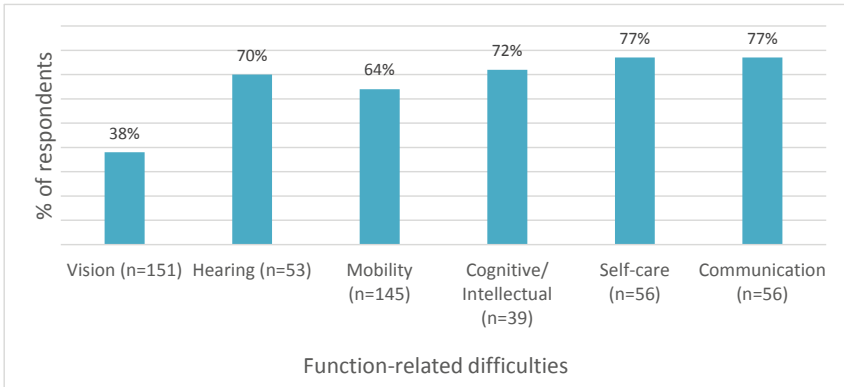
In the qualitative research, factors affecting the mental health of people with disabilities were discussed. Among the interviewees, the number of people with balanced and happy emotion was 31 (out of 49 people sharing about their mental life). However, 42 people believed that they were always concerned about job/income instability (as discussed in the employment section), and this was the main reason contributing to their low morale. Unstable job, insufficient income to live on and the weight of psychological pressure led to a mental life with a lot of worries, as shared by a man who was deaf, married with one child

> *"I am more sad than happy (sad more than half the time) 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."*

The issue of healthcare is an important factor affecting the mental health of people with disabilities. This issue was discussed in a-women-only group discussion in Hanoi. A person with mobility impairment in the group stated the following points, 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 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 visually impaired person in this group added, "such thoughts are always in my head." However, with the same thought, a man with mobility impairment living in Ho Chi Minh City who did not know how long he could live with his illness said that he always found self-motivation 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.

Apart from health problems, the reason many people feel uncomfortable in their mental wellbeing derives from dissatisfaction with their work because of discrimination or limited opportunities for a new job (as discussed in the employment section).

5.2. Job Satisfaction Level

As mentioned above, employment affects the mental wellbeing of humans. Therefore, this study investigated the level of job satisfaction of people with disabilities. On the scale of job satisfaction, the scoring method used here was given in Chapter 2; the average score for choosing all neutral answers was 27 points. The score to be considered as being job satisfied was estimated at 30 points or more. Results from the questionnaire indicate that 62% of respondents (n=246) were satisfied with the job they were doing. Female respondents (n=107) had a higher job satisfaction rate than male respondents (n=138): 63% for females versus 61% for males.

Deaf people had the highest percentage of job satisfaction (72%), followed by members of the mobility-impaired (62%), visually impaired (61%) and cognitively disabled (61%) groups. People with communication impairment had the lowest job satisfaction rate among the groups (52%), which was 3% lower than self-care group (see Chart 23).

Chart 23: Percentage of job satisfaction by types of disability
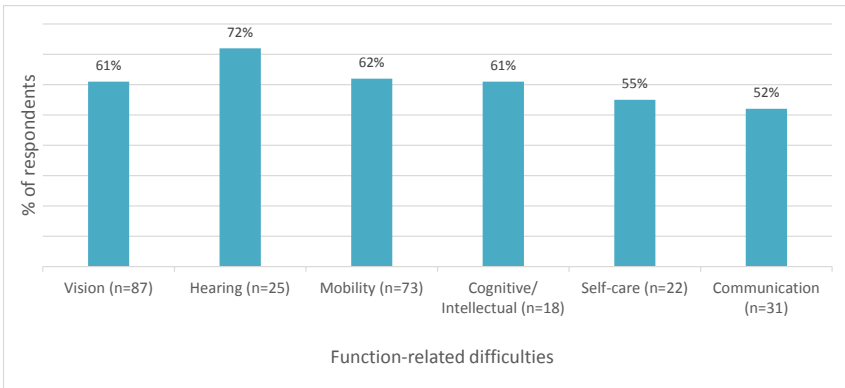
In the qualitative research, like the factors mentioned in the job satisfaction scale, respondents also shared similar factors in the scale that affected their satisfaction with their jobs. Some respondents were satisfied with their jobs because of adequate wages, management methods, opportunities for on-job trainings or the job itself corresponding with their disabilities and health.

Dissatisfaction with their jobs was reported by most interviewees but often overlooked by them because they considered that having a job was already lucky enough for them. Feelings of enduring the dislikes of their jobs were common among interviewees. This was explained by little chance of changing jobs they did not like. The interviewees shared that they did not have many employment options due to limited training, stigma in recruitment and health as discussed in the previous sections. Therefore, although they did not like the work they were doing and felt sad to continue, many interviewees echoed the following sentiment:

"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

three out of the 58 respondents who said that they had enough confidence to provide for their family and for their children to go to school without support from the government or their extended family. This opinion was often given in interviews.

In interviews, there were also people who had been trained at vocational training college or university and were doing things they loved and were passionate about, such as teaching and writing journals for 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 and on-job training or feelings of isolation in the work environment with other colleagues due to the lack of welcome and appreciation were the main reasons given for why job satisfaction was declining, although interviewees loved the jobs they were doing.

In addition to the passion and preference, being able to work with other people with disabilities was reported to be an especially important factor increasing job satisfaction. Working with other people with disabilities was also said to motivate people because they could maintain or expand their social networks. This was shared by all groups of different types of disability. A visually impaired man in Vinh City who worked in a musical 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. Income from playing music is low that can only afford travel expense."

5.3. Communication within family

In addition to love, the mental health of people with disabilities is also affected by their families. This topic appeared while interviewing people with disabilities (not in the quantitative research). Even

among their immediate family (parents and siblings), people with disabilities often feel lonely at their own home. For deaf people, it was rare for parents or family members to know sign language to talk to them. Their parents tended to have their children treated with the hope of curing their deafness and wanted their children to learn to speak or write. A deaf and married person shared in a group discussion as follows (through an interpreter):

"It's hard to be with my extended family when we don't use the same language. My parents can't understand my sign language and I can't talk, so we don't interact much at home. I mostly communicate with my friends from the Club for the Deaf. For my immediate family, I am trying to teach my child (who is not disabled) sign language so we can communicate with each other. If my parents had considered learning sign language (for I could not learn my parents' language because of my deafness and muteness), our family would have had better harmony and I wouldn't have been that lonely. But my parents do not want to learn."

Regarding other types of disability, the concern of making parents or relatives sad was often mentioned as the main reason for the refusal from the interviewees to share their thoughts and feelings with their families and relatives. This could also lead to a situation where parents and children did not exchange thoughts and feelings. Both cases mentioned above pointed to the fact that because parents did not understand aspirations of their children, they prohibited their children from participating in social activities or following career paths of their choices. In many cases in which the interviewees were hearing impaired people, when the fathers or other family members could not communicate with their children, they beat them.

Another topic in the family life of people with disabilities is related to the education of children without disabilities who are the offspring of parents with disabilities. Parents with disabilities were less likely to be involved in child education. Interviewees who were visual impaired had more opportunities to participate

in the child's personality development and learning process than the deaf and mute[1]. With the development and spread of computers in schools, parents who are visually impaired can participate more deeply in their children education such as parent conferences, school-work review and guidance with the available of e-school record and syllabus that they can listen to (instead of looking at in the conventional way). As one father said:

> *"There is now electronic contact between families and schools, so parents with disabilities like us can easily track our child's learning progress because we know how to and can afford use a computer or a smart phone."*

Meanwhile, deaf and mute parents did not have much chance to be involved in their children's education since there was no support service between parents and schools. In these cases, the child's education must rely on grandparents from both sides before and when they go to school. In many cases, anxiety about the safety of the child or lack of confidence of grandparents in the ability of the parents led to deaf parents being eliminated from the process of parenting. According to a deaf father in Thai Nguyen province, he was very sad and disappointed when not being able to raise his daughter.

> *"Both my wife and myself are deaf and mute. Our daughter is nine years old and doesn't have any disability. When my daughter was younger, my parents in law did not allow my wife and I to take my daughter out of the house because they were worried that we could cause accidents to her when we could not hear cars or motorbikes coming. We were also not allowed much time to play with her because they thought we would not be able to teach her to speak and learn. When my daughter started nursery and school, my in-laws*

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1 The groups of parents with visual and hearing impairment were the only two groups that the researchers had the chance to get in touch with to discuss the parenting issues as other disability groups had no parents participating in the interviews

take her to and from school and spend evenings teaching her. As a result, my daughter is closer to my in-laws. As being deaf, I cannot take part in parent's conference. My in-laws do it. I am desperate to be able to take my daughters to places like playgrounds, school and attend parents conference. Not being able to do these makes me really sad and disappointed."

For single mothers, parenting is even more limited. To earn living for all family a blind single mother left her child at home with the grandmother to go to work. Parenting in this case was completely dependent on the grandmother. The mother also shared her worries and sadness about the personality development of her child, but she also said she could not help but go to work because there was no other support for her staying at home or working near home.

6. Assessment of Disability

The final section of this chapter presents the findings from the study regarding the disability assessment. Results from the survey showed that, among the respondents (n=440), 78% had been through disability assessment as the basis for determining whether they would receive disability benefits from the government. Among those who had not been assessed, the main reason for not taking the assessment was not knowing what the disability assessment was, who decided it, and what the benefits were (72% of the answers; see Chart 24). Sixty-five percent of people with disabilities who had had their disability assessed took the measurement at the commune level and 35% at the provincial level. During the assessment process, these people's perception of stigma and discrimination by the public service system was very low (6% of respondents, n=346). The main obstacles encountered during the disability assessment process

included the facts that their trusted examination facilities were far away (20% of the respondents), that the authorities did not explain the results of the assessment to them (16%) or that they did not provide enough information (9%).

In the qualitative research, the interviewees' experience of the process of assessing disability (to receive disability benefits) was varied. Many people were satisfied with the disability assessment process because they received an allowance after the evaluation. The interviewees with mobility impairment had a relatively positive experience according to feedback from the group members as well as those outside of this group. This was because their type of disability was more compatible with the current assessment methodology adopted by the government, in which difficulties related to six basic functions in daily activities of people with disabilities (not restrictions coming from these difficulties when engaging social and economic activities) were focused[1].

Chart 24: Percentage of responses to reasons for not receiving disability assessment among the participants of the quantitative research (n=94)

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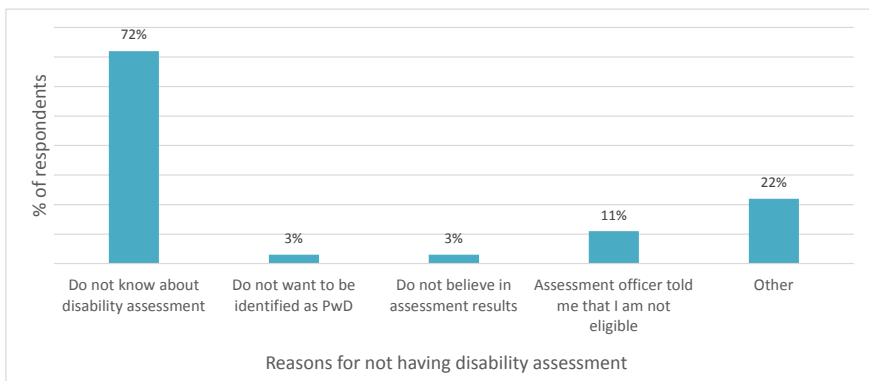
1   For more information, refer to Form 05: Disability Assessment Form for People Aged 6 Years and Above in Joint Circular No. 37/2012/TTLT-BLDTBXH-BYT- BTC-BGDDT (MOLISA, Ministry of Health, Organization Department and Ministry of Education and Training).

However, in addition to the mobility impaired group, other disability groups had highly inadequate experiences in their opinion. According to a female interviewee with blindness in Ho Chi Minh City:

"The inadequacy in disability assessment is that they are not made with an understanding about the life of people with disabilities. Basically, with the current regulations the government do not know how people with disabilities live, hence regulations to determine severity of disabilities are based on whether one can take care of him/herself. We, the blind, for instance, can look after ourselves most of the time, but our blindness very much affects our ability to work and participate in society. Those are not touched upon in the assessment."

In addition to a lack of understanding of the difficulties people with disabilities faced, the assessment was also reported to have shortcomings related to how it was conducted. The assessment of disability levels at the study sites was heavily influenced by the sentiment of local government officers. Among the interviewed groups with disabilities, inconsistency in the assessed disability levels was most clearly shown in the results for deaf people of the same age and health. In the same administrative unit, a deaf man in Hanoi shared (through interpreter's words) that:

"When I went for a disability assessment, I met a deaf couple who also could not talk and hear like myself. I talked to them as they came out. The couple's disability was assessed to be at a severe level, while mine was rated mild. When I asked the examiner, I was told that it must have been harder for a married couple with their disability, hence the severe level. And because I lived alone, it should have been easier, thus my disability was given as mild."

A commonly held view among local government officers was that poverty and pitifulness were still the measures used to determine the severity of disability, and therefore disability

benefits. According to a hearing-impaired man in Hanoi who was assessed for his disability and was advised by his father to impersonate a mentally disturbed man, he was later given a severe disability and received disability allowance. According to his explanation

> *"I had to use that trick. If you appear to be a pitiful looking person, they will evaluate a high level of disability for you, but if you don't look pitiful but decent and courteous, they won't think of you as a person with disability."*

Unfairness and lack of transparency in the assessment method causes misunderstandings or jealousy among people with disabilities, which results in discriminatory behaviours within the community of people with disabilities. For example, question of whether a person should receive disability benefits was raised. Among those interviewed, a woman with congenital paraplegia said that she had been ridiculed by other disabled people at her workplace, who claimed that she had pretended to have a disability in order to receive allowance. This was since this woman was receiving benefits (under regulations for Agent Orange victims) that were much higher than others. This happened, besides the unfairness of the disability assessment, due to people with disabilities not having adequate information on the process and procedures for disability assessment and levels of benefits for different types of disabilities as told by one male interviewee in Nghe An:

> *"I had to go back and forth several times for the disability assessment. It was very difficult as I couldn't see and moving around was very hard. Each time, I was told I lacked some document. I also wasn't explained the whole process at the beginning, so I did not know what documents I should prepare. As a result, I had to go back and forth many times."*

For the interviewed group of people with cognitive

disability, the assessment of the disability levels is often not conducted. In Vietnam, according to Rydstrom (2010), the term "learning difficulties" is understood in many ways from cognitive development delay, cerebral palsy, Down syndrome, and behavioural problems. The term "learning difficulties" used by WHO has not been officially adopted (in writing or in law) in Vietnam. In Da Nang, where researchers were able to have access to people with cognitive disabilities, the term "intellectual disability" is generally often used to imply cognitive disabilities. On this difficulty, a female teacher who taught more than 12 years in a school for children with cognitive disability commented that:

"When departments sat together to evaluate the educational status of people with cognitive disability, they recognized that it was very difficult to identify children with cognitive disability among other children. For deaf or blind children, their disabilities show itself externally, so it is easy to screen these children. However, cognitive disability is difficult to measure. Therefore, now to determine if a child has cognitive disability, we consider a child who does not keep up with his or her school work as one with cognitive disability and have him or her moved into a specialized school."

In addition, from the perspective of the family of the child with cognitive disability, many parents refuse to accept that their child has a disability (to receive appropriate education or care). This is also a common problem in families with children with other types of disabilities like hearing impairment or deafness.

DISCUSSION OF FINDINGS AND POLICY IMPLICATIONS

4

The study focused on analysing stigma from the perspective of people with disabilities. The objective of this research was to strengthen the voice of people with disabilities in reducing stigma against people with disabilities in Vietnam. To do this, the study collected evidence on stigma that people with disabilities perceive, and analysed social settings where stigma was present at the study sites (Hanoi, Thai Nguyen, Nghe An, Da Nang and Ho Chi Minh City), to identify causes of stigma and its impacts on the lives of people with disabilities. Interventions could, therefore, be identified to promote the voice of people with disabilities through recommendations for policy advocacy to make policies more relevant to their lives and disabilities.

Before discussing the results of the study, several limitations of the research (or the focus of the research) are discussed. The authors were aware that friends and relatives of people with disabilities may 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 stigma that people with disabilities perceived and factors that caused them to happen. In addition, this study did not aim to be a representative evaluation of stigma perceived by all people with disabilities in Vietnam. Rather, it should only be considered as a quick assessment to meet information needs of organizations and policy makers working with people with disabilities and for people with disabilities to have a quick

but sufficiently deep knowledge of issues of importance to people with disabilities (such as in counselling on the focus of the research with professionals and people with disabilities as discussed in Chapter 2).

For the above reasons, the research focused on the following issues: (1) information on people with disability taking part in the research: demography, education and involvement in organizations; (2) stigma perceived by people with disabilities through the stigma assessment framework WHODAS II; (3) realities and stigma faced by people with disabilities in the education and employment settings; (4) stigma encountered by people with disabilities in relation to healthcare, with an emphasis on reproductive and sexual healthcare; (5) mental health of people with disabilities according to the WHO mental health scale, the job satisfaction scale of WER2011 and self-stigma; and (6) disability assessment.

In the quantitative research, for the offline survey, the dependence on available networks of associations for people with disabilities, as well as groups and clubs established by people with disabilities at the study sites, may have affected the samples of study participants, who were mainly introduced to the study team by these organizations. Similarly, the online participants were those who had access to the internet or social networks. Nevertheless, to reach out to less accessible people, the qualitative research sought to find people with disabilities through both the channels of association and groups and also through personal channels of people with disabilities. In doing so, the research strove to approach people with disabilities with a diverse range of life experience, who could be expected to have a diverse experience of stigma and environments in which stigma existed.

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. Stigma against People with Disabilities, Perceived Stigma and Self-Stigma of People with Disabilities: Implications for Organizations and Individuals Working with People with Disabilities

Stigma against people with disabilities in this study appeared in several areas. In education, the fact that schools did not strictly handling bullying towards students with disabilities or teachers did not have appropriate teaching methods for people with disabilities was found to 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 with the same quality that students without disabilities are entitled to. 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, 2014).

The results also showed that discrimination in the education system was relatively systematic. Children with disabilities from poor families dropping out of school or never going to primary school, the compulsory education level in Vietnam, because

they were not taken to school or because there were no teachers or teaching aids, indicated systemic failure 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 in-need 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 the blind, tailoring for the deaf, computer graphics for people with mobility impairment). Those who wanted to follow other occupations outside of the default professions 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 their disability. The absence of adjustments to meet the needs of people with disabilities significantly reduced the chance of living and choosing a profession according to the wishes of people with disabilities.

Discrimination related to education for people with disabilities also occurred within the family. Whether due to being worried about difficulties facing their children, not giving priority to education of children with disabilities, or hoping to cure their children's disabilities, parents (who were not disabled) of children with disabilities demonstrated a lack of parenting skills. The lack of these skills kept the parents from encouraging or teaching their children to learn the skills and gain the confidence necessary to live independent lives. A lack of encouragement from their families contributed to the fact that people with disabilities often went to school late, dropped out of school, and were not motivated to learn. Training on parenting skills, especially skills in communicating with children or relatives with disabilities, should help to reduce the self-stigma that research participants reported when facing their families and friends. This

skills training should focus on repelling popular stereotypes that people with disabilities are useless and they are the cause or the embodiment of bad luck.

Findings from the research in the area of education indicate some urgent actions to help reduce stigma in this area. Training on parenting skills for parents of children with disabilities will help them to become a primary source of encouragement to help their children to access education. At the same time, the education system at all levels, including vocational training, must provide teachers with skills to teach and work with people with disabilities. Thus, people with disabilities 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 sign language for deaf people or people with hearing impairments who want to study in that language. Moreover, opportunities for parents with disabilities who have children without disabilities to participate in parenting activities in and outside of schools need to be increased. The education system for students without disabilities needs to have specific services to enable parents with disabilities to participate fully and equally in the parenting process as parents without disabilities.

Closely associated with the issue of education is employment. The findings from the research pointed out that discrimination in education occurring at schools and families contributed to poor employment opportunities for people with disabilities. People with disabilities who participated in this research tended to have below average income and job security. However, they rarely dared to change jobs because they believed that they had a limited chance of finding a better job. The quality of vocational guidance and training for young people with disabilities failed to prepare them effectively to enter labour market. This did not help people

with disabilities to fight against unfair working conditions, such as no labour contract, lower wages, and longer working hours.

The findings of the research showed that perceived stigma, while not the experience of the majority, was still rather common, with 43% of the participants experiencing perceived stigma. The results also revealed that perceived stigma was related to gender, age, type of disability and the multidimensionality of disability but did not tend to be influenced by the educational level of the research participants. In this study, perceived stigma in social interactions was more pronounced among men, those in the 18-38 age group, and the visually and mobility impaired. In addition, people with perceived stigma were less likely to engage in organizations than those without perceived stigma. These populations should be the primary focus of efforts or programmes aimed at reducing perceived stigma.

The findings of the research also showed that participants identified stigma and discrimination in their everyday social interactions, such as shopping, and travelling on the road or by bus. In interactions related to work and study, people with disabilities had weak capacity to identify disability-related stigma. When discussing work and study situations, people with disabilities participating in this study could name the effects of stigma, such as feelings of sadness, anger or embarrassment. However, they failed to link these feelings as being the result of stigma and discrimination against them in work and study situations. This means that people with disabilities need training to identify stigma in employment and education, so that they can recognize barriers to improving their lives. 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 eliminating it. In the views of the research participants, raising

awareness for children in school settings is seen as an early intervention, so that, when growing up, they will not discriminate against people with disabilities.

The research results also showed that, in the environment where the mentioned stigma existed, fighting against stigma created willpower or life experiences for people with disabilities to urge them to improve and help free themselves from self-stigma that negatively affected their lives. To reduce perceived stigma, the study also pointed out 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 with same situations, so that they can share and learn from each other on how to overcome adversity caused by disability. 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. Programmes of working skills (including negotiation skills, interviewing skills, as well as basic information on the rights of labourers, and the right to equal treatment under the Law on Persons with Disabilities or in the spirit of the CRPD) should be integrated in programmes of general and vocational education at specialized schools for persons with disabilities or in activities organized by associations, groups, clubs of people with disabilities.

The findings from the research also showed that research participants had poor mental health, with more than half of the respondents having a score signifying they have mental health problems. The reasons for poor mental health were often attributed to concerns about job insecurity, low income and job satisfaction. Since the employment of people with disabilities also encompasses a wide range of disability related stigma, interventions in employment can address two issues, namely

reducing stigma and improving mental health for people with disabilities. Groups of respondents having scores that indicated poor mental health tended to be those that had perceived stigma and males. This indicates that mental health programmes for people with disabilities should focus on these groups. Mental health programmes should incorporate activities that provide vocational training opportunities, or/and ensure equal working conditions, to create a higher level of job satisfaction.

The results indicate that, despite the high proportion of government-sponsored health insurance coverage, awareness on the need for routine medical check-ups among the research participants was low, even though they were a group in society who needed more medical care. In addition, concern for healthcare services in old age was common among the participants in the study. This was due to lack of information on access to health services in general and medical programmes for people with disabilities in particular. These are areas in which disability related healthcare interventions should focus. These areas can be integrated into training activities of raising awareness for people with disabilities through clubs or associations of people with disabilities, so that they can learn about the importance of regular medical check-ups and possible access to medical services and healthcare planning for when they are out of working age.

The results of this study show that, even though health insurance coverage among people with disabilities was high, being outside of the coverage area was one of the main reasons preventing people with disabilities from accessing healthcare services. Therefore, access to medical services for people with disabilities who are not registered as permanent residents in urban centres, such as Hanoi and Ho Chi Minh City, should be included in the advocacy programmes. In doing so, healthcare for the more disadvantaged groups of people with disabilities

can be improved and the pressure of medical expenses on this low-income population would be lessened.

Regarding reproductive and sexual health, the research revealed that both men and women seldom used healthcare services. Because of self-stigma in marriage and having their own families, in which men with disabilities were concerned about being unable to be the breadwinner and woman with disabilities of being unable to take care of their own families and their in-laws, having a lover, being married or having children was not considered by them as a top priority. This was often the case among all disability groups except the deaf/hearing-impaired people. This was one of the reasons why people with disabilities refrained from seeking information related to reproductive and sexual health. The study also found out that men with disabilities were less likely to use these services than women. In addition, men reported experiencing discrimination in seminars or awareness sessions on reproductive health education programmes. People who had never attended school or completed primary education had very limited knowledge about reproductive and sexual health, since school was reportedly a main information channel for reproductive and sexual health for all disability groups.

Discussions on reproductive and sexual health showed that reproductive and sexual health educational programmes for people with disabilities need to be promoted to equip them with the necessary knowledge, so that they can decide their own health plan. These programmes need to pay attention to men and those who never go to school or have not completed primary school. Educational materials for this topic should correspond to the type of disabilities and financial conditions of their target audiences, to ensure that the information is accessible to all. For example, smart-phone or computer-based materials can be too

expensive for many people with disabilities. Visual materials accompanied by sign language are important for deaf/hearing-impaired people, while those with sound are more accessible to the visually impaired. Materials should be vivid and simple languages for other groups. Specialized materials and services for each type of disability should be designed for mothers with disabilities, to ensure equal access to health services for pregnancy and prenatal care. By doing so, the benefits from the Millennium Development Goal achievements that Vietnam has attained during recent decades can reach people with disabilities.

Having fair disability assessment is a right of people with disabilities, especially when the outcome of the assessment determines their eligibility for disability benefits and allowances. Although the percentage of people reporting disability-related perceived stigma in the assessment process is low, removing barriers to complete and accurate information for people with disabilities during the assessment process can help ensure their rights and benefits.

The results of this study pointed out shortcomings in disability assessment, such as bias (in spite of good intentions in many cases), lack of transparency in information on the assessment, and lack of understanding about the life of the disabled. These shortcomings implied a need for changes in the assessment method to ensure equality in policy implementation. Vietnam's current disability assessment methodology is based solely on functional difficulties under the ICF framework. However, determination of the severity of a disability should also consider the implications of the disability for a person's ability to participate in economic and social activities. Incorporating this criterion into disability assessment would surmount the shortcomings in the current framework that Vietnam's government employs. In doing so, rights-based and equal-participation approaches to disability

can be institutionalized. For this reason, advocacy efforts by organizations working for the rights of people with disabilities should focus on the disability assessment methodology.

2. Key Recommendations for Policy Makers and Organizations Working for the Benefit of People with Disabilities

1. Enhance studies 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 that eliminate stigma, since different types of stigma have different subjects;

- 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 on eliminating or causing stigma and discrimination towards people with disabilities, paying attention to factors such as age, gender, type of disability and multidimensionality of disability 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.

2. Direct activities with people with disabilities to eliminate stigma: build capacity for associations, groups and clubs of people with disabilities so that these organizations can help people with disabilities and their families to participate effectively in social activities. The activities should focus on the following areas:

- Increasing opportunities for social interactions and peer networking for people with disabilities and their relatives (parents and/or children of people with disabilities);
- Raising awareness and knowledge of labour rights and rights of people with disabilities;
- Improving parenting skills for parents of children with disabilities. For parents with deaf children, understanding of the importance of communication in sign language with their children and teaching of sign language should be included;
- Improving ability to identify stigma for both people with disabilities and their parents and skills or measures to deal with these stigma, particularly in the areas of employment and education;
- Providing information on health services, for example on where and who can support which types of health services for people with disabilities;
- Providing information on reproductive and sexual health for both men and women with disabilities, especially for those who have either never attended school or not completed primary school.

By enhancing participation in social activities, people with disabilities can improve their self-confidence, organizational skills

and ability at teamwork. For parents, participating in activities with people with disabilities help them to understand and have knowledge about the stigma that their children may encounter. As the capacity of both parents and children is strengthened, they can together build an image of people with disabilities as independent people trying their best to improve their lives. Thus, people with disabilities will be the ones active in abolishing stigma against them. In addition, with improved understanding about people with disabilities by their parents and relatives, self-stigma originating within the family environment can be reduced.

3. 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 requirements of people with disabilities:

- Adjustment of disability assessment policy to include in the assessment process abilities or limitations to participate in social and economic activities. This can be carried out at the same time as advocacy for full implementation of the CRPD, of which Vietnam is a full member;

- 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;

- Establishment of a mechanism to monitor equality in recruitment of people with disabilities, and the implementation of stipulations on their working conditions. Following the CRPD, it is important to have a legal document to make sure companies apply reasonable

accommodation when recruiting and employing people with disabilities;

- 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 different types of disabilities;

- Enhancement and reinforcement of a disability-friendly environment at formal and vocational educational centres, for example by increasing training opportunities in teaching people with disabilities for teachers, building capacity to identify and handle stigma among teachers and administrators, and providing opportunities for parents with disabilities to participate in school activities;

- Changing the conditions for using health insurance for people with disabilities who do not have permanent residence registration in the area where they live;

- Design of materials (with appropriate communication channels) on reproductive and sexual healthcare for both men and women (especially pregnant women) with disabilities. Reproductive health and sexual health programmes need to pay more attention to those who have never attended school or have not completed primary school;

- Integration of mental health and awareness raising programmes, such as counselling psychology, into healthcare centres or facilities for people with disabilities or through associations, clubs and groups with suitable communication channels and appropriate guidance materials for each type of disability.

4. The above intervention activities and policies should

consider disability groups with a higher tendency to perceive stigma, like men aged 18 to 38, people with multiple disabilities and those with visual and mobility impairment.

3. Conclusion

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 these 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, policy makers and organizations working for the rights of people with disabilities.

The desire to end stigma is the concern of many people involved in this research. *"Raising awareness for children and young people without disabilities at a young age on treatments to people with disabilities to create a friendlier environment for people with disabilities when these children grow up"* was one of suggestions by people with disabilities to eliminate stigma. The wish of people who lost

their hearing is to be called deaf (as this report has adopted), so that they can have access to a better education that allows them to use sign language during their study, during their study. As a result, they can improve their vocabulary and knowledge. The aspirations and wishes of different disability groups are also the goals and wishes of iSEE and UNDP in conducting this study that include the creation of a medium for people with disabilities to speak out and to be heard in efforts to eliminate stigma against them. In doing so, people with disability can gradually play greater roles in the country's development.

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APPENDIX 1: Scales used in the research

The following scales are the products of researches outside Vietnam and are written in English. The research team, therefore, emphasizes the importance of translating the questionnaires used in these frameworks into Vietnamese to ensure the language smoothness and its relevance to the conditions and circumstances of people with disabilities in Vietnam. In addition, in order to ensure the questionnaire was used in a highly practical manner, the research team also consulted persons with disabilities working on development issues, experts or organizations supporting people with disabilities with the deep and wide participation in social activities. To do this, the team has undertaken the following steps:

- Step 1: The research team read and studied these scales and searched for similar studies in Vietnam in Vietnamese or English with or without the same scales to choose the most appropriate words;

- Step 2: Created a collaborative group consisting of 4 members who were people with mobility impairment, visually impairment, dwarfism and deafness. Members of the group were asked to propose topics related to stigma and discrimination that they found outstanding and widely concerned in their community. After members proposed the topics, the group would discuss to agree on the topic. When the topic was approved, a member of the research team would collect questions that have been used in similar studies

in Vietnam and abroad. These questions were translated into Vietnamese;

- Step 3: Completion of the questionnaire for these scales was conducted with the participation of both the research team and the collaborator group. The questionnaire was revised and finalized four times through four counselling sessions with the collaborators: three face-to-face group direct meetings (that have interpreter for deaf collaborators) and one personal counselling session with each member of the collaborator group by phone, Skype or email;

- Step 4: The questionnaire was tested in two phases. Phase 1 was with the same team of collaborators by phone and computer of each member after the 3rd version had been completed. The second trial was conducted with three randomly selected disabled people when the fourth version had been completed;

- Step 5: After the second trial, the questionnaire was last modified and put into use on the Survey Monkey in October 2017.

Throughout the above process, the research team also advised with the programme officer responsible for UNDP's disability-related activities for further consultation to ensure the quality of the research.

In consultation to develop the questionnaire, members of the collaborator group and randomly selected disabled members were asked:

- Do you understand the question or the statement in the frame?

- Have you ever felt or experienced the situation mentioned in the question or statement?

- Do you think that every question or sentence in the frame is appropriate and provides enough information?

- Your opinion on the format of the answer (yes or no or on a 3 or 5 scale).
- Your opinion on the font and font size to make the question easy to read.

Table 6: The International Classification of Functioning, Disability and Health (ICF)

	No difficulty	Some difficulties	A lot of difficulties	Cannot do
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 down stairs?				
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)?				

Table 7: Scale of Perceived Stigma by People with Disabilities
(in the last 12 months)

	None	A little	Some	A lot	Extreme
1. How much *embarrassment* did you experience because of your disability for the past year?					
2. How much *discrimination* or *unfair treatment* did you experience because of your disability for the past year?					

Table 8: Mental Health Scale: Five Well-Being Index
(in the past 12 months)

	Always (5 points)	Most of the time (4 points)	More than half the time (3 points)	Less than half the time (2 points)	From time to time (1 point)	Never (0 point)
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						

Table 9: Job Satisfaction Scale: WERS2011

	Very satisfied	Satisfied	Neutral	Unsatisfied	Very unsatisfied
Please indicate how satisfied you are with the following aspects of your job:					
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					

Table 10: Classification of Participation

Select one ore more of the following statements, which best reflects your participation in civil society organizations	
1.	I am informed of decisions approved by the organization
2.	I am consulted on the organization's decisions but having no say in whether these decisions are approved or not
3.	I participate in the organization because I get paid or receive other benefits
4.	I participate in the organization because I am a government's or mass organization's representative at that organization
5.	I organize activities for this organization but do not have a say in planning stages of these activities
6.	I introduce new activities/initiatives, plan and implement them

APPENDIX 2: Questionnaire

Promoting the Voice of People with Disabilities to Reduce Stigma and Discrimination

INTRODUCTION

The Institute for Studies of Society, Economics and Environment (iSEE) is working on the study *"Promoting the Voice of People with Disabilities to Reduce Stigma and Discrimination"* to analyse stigma and discrimination that people with disabilities perceive and experience in different aspects of life.

If you are a disabled person, at least 18 years old, and living in Vietnam, we would like to invite you to participate in this survey.

Your participation in this survey is voluntary, anonymous and confidential. We only publish the final survey results and commit to not disclosing any personal information of the respondents to third parties.

You only need 30 to 35 minutes to complete this survey.

Before you share your feelings, we would like you to provide some basic information about yourself as follows:

1. If you agree to let us contact you to add the information (if necessary), you may leave your phone number or email or your Facebook nickname in the dialog box below. However, this is not mandatory. You can start answering the survey without filling out the box:

2. Please indicate your gender (choose ONE from the following options)

   a. Male

   b. Female

   c. Other (Please specify):

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3. What year were you born? (You just need to write the year of birth, for example 1987):

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4. What ethnic group are you?

   a. Kinh

   b. Other: (Write down your ethnic group. For example, write "Chinese" if you are Chinese):

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5. In the past year, where do you mainly live (from 6 months and above). Please provide the following information:

   a. Province:

   b. District:

   c. Ward/Commune:

PART 1: PERCEIVED STIGMA AND DISCRIMINATION

In this section we would like to explore your feelings in the ONE past year (from October 2016 to date) related to stigma and discrimination against people with disabilities.

6. In the following question, choose **ONE** option that is most suitable to your feelings.

	None	Mild	Moderate	Severe	Extreme
a. In the past year, how much embarrassment did you experience because of your disability?	☐	☐	☐	☐	☐
b. In the past year, how much discrimination or unfair treatment did you experience because of your disability?	☐	☐	☐	☐	☐

PART 2: PERCEIVED STIGMA: MENTAL HEALTH

In this part we would like you to share experiences related to mental health. Before going into the questions related to the experience, in this section, we would like you to self-assess your mental health.

7. Think about your mental health experience in ONE year. For each of the comments from a to e, choose **ONE** that best matches your experience from the time frequency column.

Note: *Most of the time* is from 7 to 11 months; *More than half the time* is about 6 to 7 months; *Less than half the time* is about 3 to 5 months; *From time to time* is from 1 to 2 months; *Never* is not anytime in the past year.

	Always	Most of the time	More than half the time	Less than half the time	From time to time	Never
a. I feel happy and excited	☐	☐	☐	☐	☐	☐
b. I feel calm and comfortable	☐	☐	☐	☐	☐	☐
c. I feel energetic and healthy	☐	☐	☐	☐	☐	☐
d. When I wake up in the morning, I feel refreshed and relaxed	☐	☐	☐	☐	☐	☐
e. My daily life is full of interesting things	☐	☐	☐	☐	☐	☐

8. Have you ever felt discriminatory attitude or behaviour against you from other people?
   a. Yes *(please go to question 9)*
   b. No *(please go to question 10)*

9. When you find someone who has discriminatory attitude or behaviour against you, what do you often feel? (Choose **ONE** or **MULTIPLE** options)
   a. Feel nothing
   b. Feel embarrassed by my disability
   c. Feel angry
   d. Feel sad
   e. Feel it is unfair
   f. Feel anxious
   g. Feel helpless
   h. Other feelings (please specify):

Now, let's talk about an important factor for mental health, which is love. First of all, please share about your marital status.

10. Tell us about your marital status by choosing **ONE** of the following options:

   a. Married
   b. Divorced
   c. Not married
   d. Living with your lover
   e. Other (please specify):

11. Have you ever thought that you should not love anyone because you are a person with disability?

   a. Yes
   b. No

12. Have you ever thought that you should not marry because you are a person with disability?

   a. Yes
   b. No

13. Have you ever thought that you should not have children because you are a person with disability?

   a. Yes
   b. No

PART 3: ACCESS TO HEALTHCARE SERVICES

Before going into your experience, we would like to learn more about health insurance.

14. Do you have health insurance?

a. Yes *(please go to question 16)*
b. No *(please go to question 15, then question 20)*

15. Why don't you have health insurance? (Choose **ONE** or **MULTIPLE** options)
   a. Don't know what health insurance is
   b. Don't know where to buy health insurance
   c. Cannot afford health insurance
   d. Health insurance has no benefit to me
   e. Other (please specify):

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After answering question 15, please go to question 20

16. Which type is your health insurance in the following:
   a. State health insurance
   b. Private health insurance

17. Who purchased health insurance for you?
   a. You or your family
   b. The government

18. In the last visit to health facility, do you use your health insurance?
   a. Yes *(please go to question 20)*
   b. No *(please go to question 19)*
   c. I have never been to a health check-up *(please go to question 20)*

19. Why don't you use health insurance? (Choose **ONE** or **MULTIPLE** options)
   a. I don't want to be identified as person with disability
   b. Health insurance doesn't cover for my illness

c. Health insurance only covers a small amount of my medical fee

d. Health insurance payment procedures are not favourable for people with disabilities

e. Health insurance doesn't cover for me because I am out of service area

f. Other reason (please specify):

The following questions are related to your sexual and reproductive health. "Sexual health" is a healthy state of the body, emotion, mind and social connection related to sex. "Reproductive health" refers to the physical, mental, and social integration well-being in all aspects of the reproductive system throughout life.

20. Have you ever been to a medical facility for a sexual health check-up or counselling?

a. Yes *(please go to question 22)*

b. No *(please go to question 21)*

21. For what reason have you never been to one? (Choose **ONE** or **MULTIPLE** options)

a. I don't have a need for medical check-up because my sexual health is totally normal

b. No one take me to

c. No one understands if I go

d. I don't want to be identified as a person with disability

e. Being a disabled person, I'm afraid to talk about sexual matter

f. Other reason (please specify):

22. Have you ever been to a medical facility for a reproductive health check-up or counselling?

    a. Yes *(please go to question 24)*

    b. No *(please go to question 23)*

23. For what reason have you never been to one? (Choose **ONE** or **MULTIPLE** options)

    a. I don't have a need for medical check-up because my reproductive health is totally normal

    b. No one take me to

    c. No one understands if I go

    d. I don't want to be identified as a person with disability

    e. Being a disabled person, I'm afraid to talk about reproductive matter

    f. Other reason (please specify):

PART 4: FACING FAMILY MEMBERS

24. Has your family ever said that you were the cause of your disability?

    a. Yes *(please go to question 25)*

    b. No *(please go to question 26)*

25. What do you think of that view of your family?

    a. Agree with it

    b. Disagree with it

26. Has your family ever told you that you were useless?

    a. Yes *(please go to question 27)*

    b. No *(please go to question 28)*

27. What do you think of that view of your family?

a. Agree with it

b. Disagree with it

PART 5: DISABILITY ASSESSMENT

Before sharing experiences related to disability level assessment, we would like you to answer questions related to your disability.

28. The questions given here help us better understand your disability. For each question, please choose **ONE** answer that best describes your situation.

	No difficulty	Some difficulties	A lot of difficulties	Cannot do
a. How much difficulty do you have in looking, even when wearing glasses?	☐	☐	☐	☐
b. How much difficulty do you have in hearing, even when using hearing aids?	☐	☐	☐	☐
c. How much difficulty do you have in walking or climbing up and down stairs?	☐	☐	☐	☐
d. How much difficulty do you have in remembering or concentrating on something?	☐	☐	☐	☐
e. How much difficulty do you have in taking care of yourself such as taking a bath or dressing?	☐	☐	☐	☐
f. Using common language, how much difficulty do you have in communicating with other people? (For example, to understand and to be understood by others)?	☐	☐	☐	☐

29. In your opinion, why are you disabled? (Choose **ONE** of the following options)

   a. Natural
   b. Accident
   c. Ill/sick
   d. Other (please specify):

30. How long have you had your disability? (Choose **ONE** of the following options)
   a. Less than 1 year
   b. From 1 to 5 years
   c. From 6 to 10 years
   d. From 11 to 15 years
   e. From 16 to 20 years
   f. Over 20 years

The following questions relate to the assessment of disability that you may have been through.

31. Have you been assessed the level of disability? (Choose **ONE** of the following options)
   a. Yes *(please go to question 33)*
   b. No *(please go to question 32, then 37)*

32. Why haven't you been assessed the level of disability? (Choose **ONE** or **MULTIPLE** options)
   a. This is the first time I have heard of disability assessment
   b. The staff at my commune or ward said that I wasn't eligible for disability benefits so I didn't go for the assessment
   c. I don't know the benefits of the assessment, so I didn't go for the assessment
   d. I don't know who I can meet to get the assessment
   e. I don't believe in the assessment results

f. I don't want to be identified as a person with disability

g. Other (please specify):

After answering question 32, please go to question 37

33. In what year did you have your disability assessed? Please enter the year in the box below:

34. At which government level did you have your disability assessed?

a. Commune level

b. Provincial level

35. When you went for disability level assessment, which of the following factors determined your disability level? (choose **ONE** or **MULTIPLE** options)

a. The severity of the disability

b. Whether the disability assessor was sympathetic to you or not

c. Whether the disability assessor was your acquaintance or not

d. Whether you have money to pay assessors or not, in addition to other required fees

e. Other (please specify):

36. During the disability assessment, did you experience any of the following? (choose **ONE** or **MULTIPLE** options)

a. I met with difficulty because the assessment office I trust was too far from where I live

b. I met with difficulty because the assessment office didn't provide enough information for me to complete the necessary procedures

c. The assessor had stigma against me

d. The assessor had discriminatory behaviours towards me

e. I wasn't explained about the assessment results

f. Assessment office had incorrect conclusion about my disability

g. Assessment office had incorrect conclusion about my disability level

h. I didn't have any of the experiences above

i. Other (please specify):

37. Are you entitled to the government sponsored disability benefits?

a. Yes

b. No

PART 6: EDUCATION AND EMPLOYMENT

In this section, we would like you to share your experiences related to education and employment opportunities. Before answering questions about these experiences, we would like to find out about your educational background.

38. What do you do now? (choose **ONE** of the following options)

a. Work

b. Study

c. Looking for a job

d. Stay at home, not working

39. Which is the highest education level you are studying or have completed? (choose **ONE** of the following options)

a. Haven't completed primary school/haven't attended any school

b. Primary school

c. Middle school

d. High school

e. College/Vocational training

f. Undergraduate or graduate level

In the next questions, we would like to learn about your experience regarding stigma and discrimination in your learning process.

40. Some people with disabilities do not go to school or do not complete their education as they wish for a variety of reasons. Please let us know if you have any experiences below. (Choose **ONE** or **MULTIPLE** options)

a. I don't go to school because there is no school for people with disabilities in my area

b. I don't go to school because the schools in my area do not admit students with disabilities

c. I don't go to school because I cannot afford the costs of studying

d. I don't go to school because I think there is no need for people with disability to study

e. I didn't complete the degree I wanted because I couldn't follow the study programme for people without disabilities

f.   I didn't complete the degree I wanted because I couldn't afford the costs of my studying

g. I didn't complete the degree I wanted because I was often teased at school

h. I didn't complete the originally planned degree because I thought people with disabilities didn't need to be highly educated

i. I don't have any of the above experiences

j. Other reason (please specify):

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[                                                              ]
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41. Have you been vocationally trained?

a. Yes *(please go to question 42)*

b. No *(please go to question 43)*

42. Which occupation did you have training on? Please specify in the box below:

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[                                                              ]
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43. When you were at school, did you attend specialized school or inclusive school or both? (choose **ONE** of the following options)

a. Specialized school

b. Inclusive school

c. Both specialized and inclusive schools

d. I have never been to school

44. At your school, do teachers have tools (such as books and study supplies) or teaching methods that are appropriate for your disability?

a. Yes

b. No

c. I have never been to school

45. Does your school strictly handle cases in which students with disability were teased?
   a. Yes
   b. No
   c. I have never been to school

46. Do you get support from school to integrate into your class and school environment?
   a. Yes
   b. No
   c. I have never been to school

After discussing about your experience in the learning process, in the next part, we would like you to share about your current job

47. Have you ever been to a job interview?
   a. Yes *(please go to question 48)*
   b. No *(please go to question 49)*

48. Have you ever been refused a job because of your disability?
   a. Yes
   b. No

49. Since you were in the state of disability, have you ever had a job?
   a. Yes *(please go to question 50)*
   b. No *please go to question 56)*

50. Do you have a job at the moment?
   a. Yes *(please go to question 51)*
   b. No *(please go to question 54)*

51. Are you currently self-employed or hired by an employer?

a. I am the owner of a business, service (I do not work for anyone)

b. I am an employee (for example, for a company, factory, sewing workshop etc.)

52. At the moment, how do you work?

a. Full time (all day)

b. Part time

c. Seasonal

d. Other (please specify):

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53. Is your current job related to the profession you've been trained for?

a. Yes

b. No

54. During the past year, what was your average monthly income (including salary, benefits from the state, relatives or benefactors)? For example: If your income is one million per month, please enter "1 000 000" into the box:

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55. Think about how much you are satisfied with your current job in **ONE** past year. With each different aspect of the job from a to i in the column, choose ONE answer that best describes your level of satisfaction or disappointment in the rows.

	Very satisfied	Satisfied	Neutral	Unsatisfied	Very unsatisfied
a. With your achievements at work	○	○	○	○	○
b. With using your initiatives at work	○	○	○	○	○
c. With your level of being active at work	○	○	○	○	○
d. With extra trainings on the job	○	○	○	○	○
a. With promotion opportunities on the job	○	○	○	○	○
b. With your salary	○	○	○	○	○
c. With the stability of the job	○	○	○	○	○
d. With this kind of work	○	○	○	○	○
e. With being involved in the decision making on the issues related to you such as salary, bonuses, training opportunities, etc.	○	○	○	○	○

PART 7: TAKING PART IN ORGANIZATIONS

In this part, we would like you to share your experience when joining in associations, groups and clubs.

56. Are you currently a member of any group, club or association?

　　a. Yes (*please go to question 58*)

　　b. No (*please go to question 57*)

57. Why don't you participate in any association, group or club? (Choose **ONE** or **MULTIPLE** options)

a. Don't have time to participate for being busy at work or looking after children

b. Don't want to participate because don't want to communicate with others

c. Don't participate because don't know any association, group or club

d. Don't want to participate because the associations, groups or clubs don't have interesting activities

e. Unable to participate because cannot go to meeting places of the associations, groups or clubs

f.   Other (please specify):

58. Do you participate in the following associations or groups? (Choose **ONE** or **MULTIPLE** options)

a. Women's Union

b. Farmer's Union

c. Youth Union

d. Veterans Association

e. Association of the Elderly

f.   State-established association of disabled people

g. Organizations, associations, groups established by persons with disabilities

h. Performance group of people with disabilities

i.   Other (please specify):

59. Name the association, group or club that you engage in the most (please enter a specific name)

60. Who did establish the associations, groups or clubs that you engage in the most?
    a. The government
    b. People with disability
    c. Both the government and people with disabilities
    d. Do not know
    e. Other (please specify):

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61. Did you have to pay membership fee when joining the association, group or club that you engage in the most?
    a. Yes *(please go to question 62)*
    b. No*(please go to question 63)*

62. How much do pay for membership fee per month? (please enter a specific number):

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63. Why do you participate in the association, group or club that you engage in the most? (Choose **ONE** or **MULTIPLE** options)
    a. Meet and exchange with peers
    b. Share the difficulties or learn the experience in life or work
    c. Get to learn reading or writing sign language
    d. To study vocation
    e. Get employment opportunities
    f. Because it is the only association, group in my area
    g. Other (Please specify):

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64. When engaging in the association, group or club that you are most active in, how do you get involved? (choose **ONE** or **MULTIPLE** options that best reflect your level of participation)

a. I receive announcement on decisions approved by the organization

b. I am consulted on the organization's decisions but not allowed to decide to continue or cancel them

c. I participate in the activities of this organization because I get paid or received other benefits

d. I join because I am the representative of the government or union of civil society organizations

e. I involve in organizing activities but I do not have any opinion in planning these activities

f. I introduce new activities/initiatives, plan and implement these activities/initiatives

PART 8: PERCEIVED STIGMA: CHANGE

In this section, we would like you to share your thoughts on possible changes to improve the stigma and discrimination that you have been experiencing.

65. Do you think that stigma and discrimination against people with disabilities can be changed? Explain why you think that stigma and discrimination can or cannot be changed:

66. In your opinion, what need to be done to change stigma and discrimination against people with disabilities?

We sincerely thank you for your participation in this study!

APPENDIX 3: Guidance on qualitative interviews with people with mobility impairment, visual impairment, deafness and communication impairment

Conducting steps:

1. Ice-breaking – chatting

2. Introduction of the project (see the project information sheet) and the researcher (name, in corporation with iSEE to conduct this study), this section should also be used as ice-breaking to create a comfortable atmosphere for the interviews (part 1)

3. Research ethics: see the information leaflet on the subjects selected for the study (part 2)

4. In-depth interview: on 6 topics including job-employment, how to provide benefits, mental health, sexual/reproductive health, inferiority, violence, coping. These topics are grouped into sections with general information section that you would like to collect about the interviewees

   a. General information about the interviewees (Part 3)

   b. The participation of the interviewees in organizations, unions, associations (Part 4)

   c. Disability status and benefit determination (Part 5)

   d. Causes of disability and levels of stigma (Part 6) – use tool 1: naming stigma through pictures

   e. Employment state and job satisfaction (Part 7, 8, 9) – use the Income and Expenditure Matrix tool to encourage discussion on job and income

   f. Mental health (Part 10)

   g. Love, sex and reproductive health (Part 11)

   h. Inferiority (Part 12)

   i. Encountered violence (Part 13)

   j. Coping with stigma and discrimination (Part 14)

5. Closing:

Discuss about actions for the future (Part 15)

Interview contents:

1. Introduction of the project (see project information sheet) and the researcher (name, in corporation with iSEE to conduct this study), this section should also be used as ice-breaking to create a comfortable atmosphere for the interview

2. Research ethics: see the information leaflet on the subjects selected for the study

3. Learn about the interviewees (this part should also be done lightly and cheerfully to create an open atmosphere for the interview

Name?

Year of Birth?

Place of birth?

Ethnic group?

Current address?

4. Participation in organizations, unions, associations, groups (both online and offline, both state and non-state)

Prompts:

Do you participate in any organization or association? Which one do you like best? Name that organization? Level of participation (do you contribute your ideas or just listen)? Why?

Scale:

You receive announcement on decisions approved by the organization

You are consulted on the organization's decisions but not allowed to decide to continue or cancel them

You participate in the activities of this organization because you get paid or received other benefits

You join because you are the representative of the government or union of civil society organizations

You involve in organizing the activities but you do not have any opinion in planning these activities

You introduce new activities/initiatives, plan and implement these activities/initiatives

5. Disability status and benefit determination

General information:

Have you been assessed the level of disability (if yes, what type of disability were you recognized with)?

Scale:

On how to determine the level of benefits in the past year:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
My degree assessor did not have the necessary expertise					
I knew the level of benefit I received was determined by which factors					
When my benefits changed, I knew why					
When I received the allowance, it felt like they were doing me a favour					

Prompts:

Focus on understanding the aspects related to how this table uses the statements to ask what the respondents think

6. Causes of disability and levels of stigma – USE TOOL 1: NAMING STIGMA THROUGH PICTURES

General information:

Why are you disabled?

How long have you been disabled?

Prompts:

Have you ever felt:

Your family and/or surrounding people make you feel ashamed of your disability

Your family and/or surrounding people often say things that make you feel self-pity

Scale:

	None	Mild	Moderate	Severe	Extreme
In the past year, how much did you feel ashamed of your disability?					
In the past year, which is the level of discrimination or unfair treatment you experienced because of your disability?					

7. Employment state and job satisfaction asked together: USE INCOME AND EXPENDITURE MATRIX

General information

Current state of your employment? How long have you been going to work?

Are you doing anything for a living?

How much is your monthly income (including your benefits and salary)? (May use suggestions: how much do you earn from your job? How much is your allowance? What kind of expense and how much is it?)

Do you go to work regularly? Part time? How many months per year do you go to work? Why?

Does the job pay you enough to spend for yourself?

Who is the one keeping the money and deciding what to spend with your income?

The following sentences can be used as prompts

To initiate/open an idea for the interviewee to share their point of view, it is not necessary to use all of these sentences but to choose one or two sentences to guide the discussion before discussing the points raised in the scale:

Can you find a job that corresponds to what you studied and want to do?

Were you asked for your opinion about working conditions (seating, office space, walking hall)

At the same level and with the same job, I received lower salary than non-disabled colleagues

When given the opportunity, I can work as well as other colleagues without disabilities

At work, the boss encourages me to improve my skills

I am hired because I am a disabled person, not because of my capacity

I am entrusted by my boss and co-workers to tasks that require high capacity and responsibility

I am pressured at work

I am not commended and rewarded

When I am rewarded, my colleagues think it is because I am disabled, not because I am qualified

Scale

In each of the following sentences, pay close attention to the interviewees' thoughts related to these statements to explain why they are satisfied/not satisfied.

	Very satisfied	Satisfied	Neither satisfied or unsatisfied	Unsatisfied	Very unsatisfied
I am satisfied with my achievements at work					

I am satisfied with being able to use my initiatives at work					
I am satisfied with my level of being active at work					
I am satisfied with being appointed to trainings					
I am satisfied with having the o p p o r t u n i t y to develop my professional skills					
I am satisfied with my payment					
I am satisfied with my stable job					
I am satisfied with my job					
I am satisfied with being able to get involve in deciding the issues related to me					

8. If you are looking for a job: why haven't you found one?

9. If you are not healthy enough to go to work, move on to mental health section in part 10

10. Mental health

General information:

Were you granted the health insurance, or did you pay for it yourself?

Which level is your disability? Why were you not granted health insurance?

Prompts

The following sentences can be used to elicit discussion (do not have to use all these sentences), then the health scale to discuss further.

Do you not dare to tell others that you need mental health counselling (with feelings of disappointment, discouragement, depression, stress, pressure, wanting to die)?

Do you know where you can get mental health counselling?

Were you asked, encouraged, cared for when people know you have mental health problem?

Do you get angry when people don't treat you normally (don't think you should go out, eat out with friends, etc.)

Mental health scale

In the scale, ask more for where? Why?

	Always	Most of the time	More than half the time	Less than half the time	From time to time	Never
I feel happy and excited						
I feel calm and comfortable						
I feel energetic and healthy						
When I wake up in the morning, I feel refreshed and relaxed						
My daily life is full of interesting things						

11. Love, sex and reproductive health

General information:

Are you married? Do you have a boyfriend/girlfriend?

Rating scale/Prompts:

Use the statements below as a basis to get the interviewees' comments and to discuss with them.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
I am afraid of being laughed at so I do not dare to love					
I don't dare to confess my feelings for fear of burdening the person I love					
The reactions of surrounding people make me not dare to say that I want to get married and have children					
My family don't want me to love a person with disability					
I have been educated/counselled on love, sex and reproductive and sexual health					
When in need of reproductive and sexual health counselling and examination, I know where to find counselling and examination services					
I am afraid of being laughed at if I go to centres or hospitals for reproductive and sexual health counselling and examination					
If I go to medical centre, I will be warmly helped by doctors, nurses and hospital staff					

12. On self-created inferiority:

Prompts:

Have you ever felt that you are the cause of unhappy things happening to you and your family? That you are useless?

Ask why?

How to deal with stigma and discrimination

Prompts:

Facing with stigmatizing, discriminatory or unfair words or actions, how do you respond? Leave without saying anything? Pretend not to hear/see and continue to do what you need to do?

13. Change in the future

To make changes, what do we need to do to make those changes? Discuss

APPENDIX 4: Guidance on qualitative interviews with people with cognitive difficulties

Conducting steps

1. Ice-breaking – chatting

2. Introduction of the project (see the project information sheet) and the researcher (name, in corporation with iSEE to conduct this study), this section should also be used as ice-breaking to create a comfortable atmosphere for the interviews.

3. Research ethics: Explain clearly the purpose of the study, how the collected information will be handled, the voluntary nature of the study participation, and that the participants may withdraw from the study anytime. Pay close attention when working with people with learning disability, when communicating with people outside their everyday world may be a rare occasion in which they have social relations with the outside world. Researchers should therefore consider this from the perspective of the interviewee.

Be especially careful to check if the interviewees understand and agree to participate in the study. See additional remarks when communicating with the target population in section 5 to ensure interviewees understand their participation in the study. Numbers indicate that the consent of the interviewee may be considered through high level of engagement via eye contact, body language, appropriate explanations (through comments in the contents of the conversation) and answers by gestures (like nodding). Indicators show that the interviewees do not seem to agree when they are less attentive or have vague responses. In this case, the researchers should check the answers with relatives or caregivers of people with disabilities.

For people with communication impairment (or those with severe learning disability), seeking consent of participation is still

needed to be done. In this case, it is important to identify the closest person who understand the interviewee for "Proxy consent", meaning that the respondents' consent is checked and confirmed by a relative or a person who understands the interviewee. Proxy consent is often not considered the best solution but is still considered an necessary alternative to seeking consent.

4. Subjects:

The World Health Organization (WHO) defines learning disability as a state of intellectual development being interrupted or incomplete. People with learning disability find it more difficult than others to learn, understand and communicate. Learning disability is a diagnosis rather than a disease and not a mental or physical illness. WHO classifies learning disability into three levels: mild, moderate and severe. The severity is often expressed through IQ, behavioural capacity, and the need for special support. According to WHO, the disability classification that this study applies for learning disabilities includes cognitive disabilities or intellectual disabilities.

In order to avoid overlapping categories involving terms such as intellectual disability, cognitive disability and learning disability, the selection of subjects should avoid the use of the categories described above. Instead, the categorizing by functional cognitive disability can be used to select/search for the interviewees. Using this kind of selection, people with difficulties in problem-solving, attention, memory, math comprehension, reading, linguistic and verbal comprehension should be sought for interviews. With the time and budget of the project and the above reasons, as iSEE had planned to interview 10 people in this disability group, researchers should choose to interview at least one person from the mentioned categories in accordance with functional cognitive disability, balance the number of male, female, ethnic, urban and rural respondents (if applicable).

Note: Depending on the severity of the learning disability, relative/caregiver of person with disability is needed to be invited. However, with the questions that need people with disabilities to express their feelings, the final answer to a specific question should be cross-checked with the person with cognitive disability before entering it as the answer to the question. The role of family members in interviews with people with cognitive/intellectual disabilities is to help convey what people with disabilities want to express/speak. Avoid asking family members to speak for/speak on behalf of the interviewed people.

It would be easier and the results of the interviews would be compatible with the other subjects in this study if the respondents were people with mild learning disabilities who would be able to answer most of the questions themselves. It is also important to avoid criticism (for example, power relations, rights issues) related to carrying out research with persons with severe learning disabilities through intermediaries.

5. Interview contents: The contents should be supported by supplementary tools to facilitate the exchange of information. Information on these tools has been prepared in previous interviews. *It is needed to specify in the transcription the person who answered mainly/long for each question.*

5.1. Find out about the interviewees (this should be done lightly and cheerfully to create an open atmosphere for the interview) (**This part can be exchanged with family members if they are involved**)

> Name? Year of Birth? Place of birth? Ethnic group?
>
> Where do you live? Whom are you staying with? How long have you been living there?
>
> Can you share about your disability? (How is it diagnosed and treated?) *This section is important for later analysis to determine the severity of the disability*.

5.2. Sharing on feelings related to stigma and discrimination
– **In this part, comments/judgments of people with disability should be listened to**.

- Is there anytime at present or recently that you felt embarrassed (because of your disability) while traveling, communicating or working? (Look at the following pictures (IDSS, 2012), have you ever encountered such cases?)

Why do you feel ashamed? Can you tell me in detail?

If you don't feel ashamed anytime, can you explain why?

- Is there any time now or recently that you felt you were treated unfairly (because of your disability)? (Use the above pictures again to encourage discussion and suggest situations that may be encountered)

Why do you think you were treated unfairly? Can you tell me in detail?

If you didn't feel that you were treated unfairly anytime, can you explain why?

Give suggestions for two questions above for the interviewee to understand and answer more easily:

Do you think you are discriminated against, for example, in your studying process because of the difficulties you encountered in cognition/learning?

Sometimes do you find the person who talks to you (a relative or an acquaintance) not positive or not encouraging towards you since they assume that you cannot do something because of your learning disability?

You don't feel upset or anything bad about yourself related to your disability.

5.3. Experiences on stigma and discrimination

- Mental health and healthcare services - *Must listen to comments/judgments by people with disability for this part, ask the relatives if it is needed but try to verify with people with disability for the final opinion.*

- Mental health:

How do you feel about your present life? Point to a face:
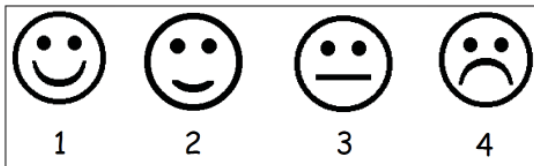
1: Very happy 2: Relatively happy 3: Sometimes happy, sometimes unhappy 4: Unhappy most of the time

Can you explain about your choice?

- What do you do to have a better mental life? – *Have to listen to comments/judgments by people with disability for this part:*

  ▪ Do you have friend to go out with or talk to? Can you tell me about your friend?

 Yes?   No?

- Can you talk to your family members? Can you talk about them?

☺ Yes?   ☹ No?

- Do you talk to a psychologist/psychiatrist? Why or why not?

☺ Yes?   ☹ No?

- Love, family - *Have to listen to comments/judgments by people with disability for this part:*

  - Have you got married/a lover? Can you talk about your family or lover?

  - Do you want to have a family of your own? Have you ever been badmouthed or criticized on your disability when talking about the subject of love and family? Please give details and explain why;

  - Do you have children? Do you take care, teach your children and go to parent meeting, etc. by yourself or do you have someone help you?

- Access to healthcare services related to reproductive and sexual health: - *Have to listen to comments/judgments by people with disability for this part, ask the relatives if it is needed but try to verify with people with disability for the final opinion:*

  - Do you have health insurance? Was it granted by the state or purchased by you?

  - Do you use health insurance when going for medical check-up and treatment? Why not?

  - Have you ever been introduced to reproductive and sexual health? Where? What were the contents introduced?

  - Have you ever consulted or examined reproductive

and sexual health? Where? Who took you there?

- Can you share your feelings when you go for an examination or counselling? (Such as you received good or awful welcome and examination/counselling?).

• When you went to medical facilities, for disability diagnose and treatment for example, what did you feel about the doctors, nurses or staff there in the way they treated you?

Suggestions for this question: Point to a face below to describe your feelings about the hospital. For example, when you meet a nurse/doctor, you are very happy to be treated well (1) or not happy at all (4) or neither sad nor happy (3) or happy a little (2). Can you explain why you choose a face 1, 2, 3 or 4? **(This section may be consulted by a relative or caregiver of the interviewee)**
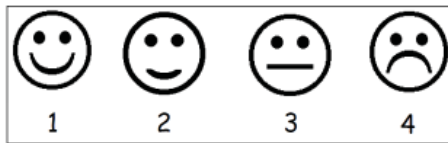
• Violence: physical and mental (compare between childhood, youth, now – if possible) - *Have to listen to comments/judgments by people with disability for this part*

(Ask these questions if the interviewees can answer)

- Being scolded, criticized, compared with others, and blamed for your disability?
- Got beaten, confined because of your disability?

(If the interviewees cannot answer the above questions, ask the following)

- Do you feel safe where you are living? (What makes you feel safe/unsafe where you live?)

- Disability level assessment (**It is able to discuss this part with the family members if they are involved**)
  - You can share the cause of your disability if possible
  - Have you ever been assessed the level of your disability (to be granted disability card and determined level of benefits)?
  - Please talk about you going/not going to disability assessment
    - Administrative procedures
    - Appropriate support from government for people with disabilities to complete the documents
  - Level of disability (severe, mild) determined for benefits:
    - Acquaintance (network, relations, social status of your family in the community)
    - Bribery during the assessment process (with families who have financial condition or are familiar with social interaction)
    - Do you receive monthly benefits from the state?
- Education and employment opportunities (**This part can be discussed with both the relatives and interviewees with disabilities)**
  - Education level?
  - Have you ever attended school? Why didn't you go to school or why didn't you study higher?
  - Have you been vocationally trained?
  - What are you currently doing?
    - Is your current job related to the profession you have studied? Why not?
    - Do you like your current job? Why?
    - Do you have income? Is your income enough for your living? Is it stable?
    - Are you taken advantaged of/exploited (long working shift, low payment, employers increasing

or reducing wages on their own) because you are person with disability?

▪ Have you ever been refused a job or got low-paid because of your disability? Please share your story

▪ Do you like your current job? (What do you like/ dislike there?)

☺ Yes?   ☹ No?

- Participation in associations, groups, clubs **(This part can be discussed with both the relatives and interviewees with disabilities)**

• Do you currently participate in any groups, clubs or associations?

▪ Why or why not?

• Are there any groups, associations of people with disabilities?

▪ On the internet like Facebook or a group of friends?

▪ This group, association was found by whom?

▪ How does the group or association work?

▪ What do you get when participating in this group, association or club?

• Which activities do you engage in this group/club?

6. Changes in the future **(This part can be discussed with both the relatives and interviewees with disabilities)**

- Do you think stigma and discrimination will change (reduce)? Discuss

- To make changes, what do you have to do and what support do you need to reduce stigma and discrimination? Discuss

APPENDIX 5: Tools that can be used to encourage discussion/ exchange in in-depth interviews

Tool 1: Naming stigmas through pictures (this tool can be used in both focus group discussion and in-depth and private interview) (Source: IDSS, 2012)

NAMING STIGMAS THROUGH PICTURES

This exercise is used to encourage participants to discuss about stigma against people with disabilities.

OBJECTIVES

This exercise helps participants to:

- Identify stigma and discrimination against the people with disability.

- Identify different forms of stigma and discrimination in different contexts.

- Start discussion on impact of stigma on the lives of people with disability and their families.

TIME

45 - 60 minutes

PREPARARIONS

- Select 8 - 10 pictures amongst the scenario pictures (see the Appendix on pictures).

- Stick the pictures on the wall or on the board.

- Flipcharts (A0 or ½ A0).

How to deploy this tool:

1) Cut these pictures out and stick them on the wall/an A0 paper or show the pictures for the interviewee to choose a certain one;

2) Ask the interviewee/group: What is the story in this picture?

3) What do you think about this story?

4) Do you think this situation also happens in real life? Have you been in that situation? Please share;

5) Based on the sharing of the interviewees, ask appropriate questions (from number 6) in the information sheet on steps and contents used in in-depth interview.

Tool 2: Talking mats with open questions in questionnaires used for qualitative research (see more at http://www. talkingmats.com/)

- helpful for groups with deafness, learning disability or people afraid of speaking in front of strangers in private interviews;

- and helpful for group interviews - with multiple types of disabilities - except in the case with blind people (in that case, the facilitators should use descriptive words for these people to participate in group discussions).

How to use the tool:

1) Select one topic card/write the topic you want to discuss on a piece of paper and place it in front of the participants;

2) Use images placing around the topic card as the answers for the respondent (if the images are not enough, encourage respondents to draw more);

3) Capture the answers and discuss around the images chosen by the respondents.

Tool 3: Historical diagram/comparison

- Used to support/specify a comparison of an event/a feeling before and after a specific time of your choice. It is often used to understand the impact on the interviewee. For example, if you want to discuss stigma in a year, you can remember a particular stigma in the past year and from that point on, you can discuss backwards or downstream of time to make it easier for the interviewer to sort things out regarding the events occurred in relation to the topic and the interviewer could ask more about the impact of the event on the interviewee.

- On an A4, draw a time vector and place it in front of the interviewer so that both can see. For the blind, it is possible to use this tool, but it needs to be described more in words.

Before event 1   Event 1: June   After event 1
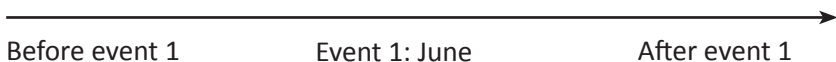
Tool 4: Income and Expenditure Matrix, see more at learning. vam.wfp.org/.../2.4.B_Handout_EN_Income_&_Expenditure_ Matrix.doc

- Identify and specify the relative importance of different incomes and expenditures;

- Using this tool also helps the researcher understand the level of uncertainty in the income of each group;

- In the expenditure matrix, we can see whether all or most or only a small part of the income is spent on basic needs such as food, water, clothing, housing, healthcare and education;

- We can also ask whether the interviewee has any money left at the end of the month to save or invest in something that will increase their chances of improving income or for entertainment;

- When using this tool, we also need to ask who decide what to spend and who keep the money.