

# PSYCHOSOCIAL WELL-BEING AMONG VIETNAMESE ADOLESCENTS WITH VISUAL AND PHYSICAL DISABILITIES

**PhD Candidate:** Thu Phuong Dinh Thi

School of Psychology,

Faculty of Social and Behavioural Sciences,

Flinders University

**Supervisors:** Dr. Julie Robinson

Dr. Brian Matthews

Assoc. Prof. Gour Dasvarma

Date of award completion

23 March 2018

**DECLARATION**

I, Thu Phuong Dinh Thi, certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

## ACKNOWLEDGEMENTS

The work of this dissertation has been conducted at the Faculty of Social and Behavioural Sciences, School of Psychology, Flinders University, Australia. However, I would never have been able to finish my dissertation without the support and encouragement of my supervisors, my colleagues, my friends, and my family.

First of all, I would like to express my deep gratitude to my supervisor, Dr. Julie Robinson. Thank you very much for your patient guidance, encouragement and useful critiques of this research work. More important, I am greatly indebted for your spiritual support in many aspects of life. You have helped me to know not only work but also enjoy and appreciate the process of personal growth in both academic and individual life. I have treasured all those nice memories during the time working with you in my mind.

I would also like to express my sincere thanks to Dr. Brian Matthews, my second advisor for your revision and guidance of my work. Although you cannot officially supervise me in the role of a co-supervisor in the last year, your continuous support and guidance have been always appreciated. Thank you for allowing me to attend your helpful classes. I am very grateful to Assoc. Prof. Gour Dasvarma for your inspiring advice and valuable comments during the planning and development of my work. You also supported me with the new literature and pointed me to good ideas. And I should not forget to thank you for the small farewell party you organized. I was touched. Thank you!

I am especially grateful to service providers, parents, teachers, my colleagues in Vietnam and children with disabilities who were involved in the data collection for entrusting me with their hopes and dreams for the future of good support services in Vietnam. Thank you Hanh - my best friend in Australia for your supporting and understanding me even in the most difficult situations. It has been my luck to be a friend, a sister and a colleague with you.

Finally, thank you Mom, Bon, Xeng, Bi, Ly and anh Sao Khue. Thank you for being patient and being beside me during the up and down moments in the last four years. I understand and treasure more the value of family when I am far away from you to study. Now I am back and will be yours totally ☺. Although I will not have the chance to share this work with my father and my younger sister, you are my motivation and inspiration that help me overcome the toughest time. You are all in my heart. Thank you all again!!!

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## **ABBREVIATIONS**

EGRA	Early Grade Reading Assessment
CDA-Q	Cognitive Development Assessment-Quantity
DASS-21	Depression, Anxiety and Stress Scale 21
IEA	International Evaluation Association
LAMICs	Low- and middle-income countries
LOT-R	Revised Life Orientation Test
NGO	Non-government Organization
PANAS	The Positive and Negative Affect Scale
PPVT	Peabody Picture Vocabulary Test
PWD	People with disabilities
SDQ	Strengths and Difficulties Questionnaire
UN	United Nations
WHO	World Health Organization

## **ABSTRACT**

The psychological and social well-being of young people with disabilities has been addressed in many studies. However, little attention has been given to young people with disabilities in low- and middle-income countries (LAMICs). Disability is over-represented in such countries, especially in those with a legacy of war. This program of research is the first to study psychosocial well-being of the large number of young people with visual and physical disabilities in the variety of settings in which they are cared for in Vietnam. It consists of three studies. Study 1 used longitudinal case studies to describe the developmental context and developmental outcomes of twelve Vietnamese children with visual and physical disabilities who were followed from infancy to pre-adolescence. Results were interpreted with reference to a large sample of their non-disabled peers. The results showed that both children with visual and physical disabilities experienced extreme material deprivation, and that most participants had smaller vocabularies, poorer physical development and lower well-being than most of their non-disabled peers. This study provided the context for Study 2, a cross-sectional quantitative study of the level and predictors of psychosocial well-being among Vietnamese adolescents with visual and physical disabilities. Although adolescents with these disabilities experienced moderate levels of well-being in several positive domains, including satisfaction with life, flourishing and positive affect, they also experienced very high levels of symptoms of anxiety and depression. Optimism, social support and discrimination were independent predictors of a large number of positive and negative domains of well-being, and discriminated between clusters of adolescents who showed different patterns of well-being. In the final study, in-depth interviews with a subset of the participants in Study 2 captured their perceptions about the factors that influenced their well-being in their own words. They identified challenges to their well-being, the types of support they needed to overcome these challenges, and the qualitative characteristics of service providers that influenced their well-being. Based on these responses, a model was developed to guide the development and revision of support services. Despite its limitations, this program of research provides some of the data necessary to make the first steps towards evidence-based practice in the provision of support services for Vietnamese adolescents with a visual or physical disability.

**KEYWORDS:** Well-being, adolescents, visual disability, physical disability, Vietnam.

# CHAPTER 1 - OVERVIEW

## 1.1 Background

Disability affects more than “a billion of people” around the world which is about 15% of global population (World Health Organization, 2011a, p. 29). However, there have been evidence that the prevalence and types of disability in different age groups varies between high-income and low-and-middle-income countries (LAMICs).

It has been estimated that LAMICs have much more people with disability than high-income countries. Result from the World Health survey across 59 countries showed that the disability prevalence in high-income countries is around 11% while this number is much higher with up to 18% in low income countries (World Health Organization, 2011a). In other survey, data varies but the pattern is similar. For example, the Global Burden of Disease study indicated that the disability prevalence for high-income countries is 15.4%, while this number is 16% and 16.4% for LAMICs in South East Asia and European respectively. LAMICs in other regions such as African, Americas and Western Pacific rank around 14 - 15% (World Health Organization, 2011a, p.30). It has been noticed that LAMICs tend to report a lower disability prevalence rate as disability data are usually collected through “*censuses or use measures focused exclusively on a narrow choice of impairments*” while high-income countries often conduct surveys recording activity limitations and participation restriction which “*report higher disability prevalence*” (World Health Organization, 2011a, p.22). Therefore, it can be referred that in reality LAMICs may have much higher disability prevalence than number reported.

Although both high-income and LAMICs have highest disability prevalence in the older group because of increasing age people develop disability due to chronic diseases and sensory impairments (World Health Organization, 2004, 2011a), LAMICs have more number of young people with disability than high-income countries (The World Bank, 2006; United Nations, 2011). The UN estimates that over 80% (150 out of 180 million) of the worldwide population of people with a disability aged 10-24 years live in LAMICs (United Nations, 1990a). Recently, the Global Burden of Disease study reported similar results based on available data sources across 17 subregions of the world (World Health Organization, 2008). Accordingly, disability prevalence for children 0-14 years of age who has moderate or severe disability in high-income countries was 2.8%, while this number for LAMICs ranked from over 4% to 6.4% over six regions of the world (World Health Organization, 2011a).

Disability is concentrated in young people in LAMICs because of the consequence of combined reasons such as non-communicable diseases, traffic accidents, natural disaster and the legacy of war (United Nations, 2012a, 2012b). Due to the above reasons, physical and sensory disabilities, not intellectual, are the most common types among young people in LAMICs (Braithwaite, Carroll, Mont, & Peffley, May, 2008; Takamine, 2004; UNICEF, 2013; United Nations, 2012a). In the Asia-Pacific region, for example, 78% of people with disabilities have a physical or a sensory disability (United Nations, 2012b). This prevalence is even higher in some parts of Africa (World Health Organization, 2004). Disability data from Vietnam and Ethiopia are examples for this pattern (UNICEF, 2010; Wa'el International Business and Development Consultant, 2000).

Despite this, most disability research has been conducted in high-income countries and focused on intellectual disability (Maulik & Darmstadt, 2007). This has led to the current “woefully inadequate” level of knowledge about young people with disabilities in LAMICs (Maulik & Darmstadt, 2007, p. 51). As a result, theorists, service providers and policy makers lack the foundation for evidence-based practice for this population. Thus, this group has been identified as a major target for research (UNICEF, 1999).

A number of specific gaps in research have been identified. In particular, attempts to assess the well-being of people with disabilities in LAMICs are rare. Indeed, research on many domains of well-being is rare in any population in LAMICs. For example, it was estimated that only 6% of indexed research about mental health is carried out in those countries (Saxena, Paraje, Sharan, Karam, & Sadana, 2006). In addition, literature relating to young people with a disability has focused on the economic and social difficulties of families with children with disabilities (Brinchann, 1999; Read, 2000), or on the way specific aspects of children’s developmental context (e.g., inclusive schooling) shapes their experiences (Davis & Watson, 2001) rather than on their wellbeing. There is also a lack of research examining outcomes for young people with some types of disability. This includes children and adolescents with a visual or physical disability living in low- and middle-income countries. In addition, longitudinal data is lacking. This dissertation reports three empirical studies designed to help to bridge those gaps.

## 1.2 Research aims

The overall objective of the current programme of research was to gain insights into the life circumstances and positive and negative domains of well-being experienced by young people with a visual or physical disability in Vietnam, by examining these through the lenses provided by a variety of different research approaches: case studies, variable-focused statistical analyses of quantitative data, person-focused statistical analyses of quantitative data and content analysis of qualitative data. The rich description allowed by longitudinal case studies (Study 1) provided the foundation for subsequent studies by providing insights into the developmental context and developmental trajectories of children with visual and physical disabilities in the years leading up to adolescence. The multi-site cross-sectional study of Vietnamese adolescents with visual and physical disabilities (Study 2) allowed multiple positive and negative domains of their well-being to be described, and for the factors that contributed to these to be explored using both variable-focused and person-focused analyses. This was complemented by a qualitative study (Study 3) that gave voice to the lived experience of Vietnamese adolescents with visual or physical disabilities, by using their own words to document the daily challenges to their well-being, and their perceptions about the types of support that could improve their well-being, in their own words.

**Study 1.** The aim of this study was to examine the diversity in developmental contexts, developmental trajectories and levels of well-being among children with a visual or physical disability in Vietnam through the intensive case study of a small number of individuals drawn from different parts of the country. The use of a longitudinal design allowed this to be described across childhood from infancy to preadolescence. The findings from this study provided contextual information that aided the interpretation of the results of the subsequent two studies, which narrowed the focus to psychosocial well-being and extended the developmental period to adolescence.

**Study 2.** This study aimed to document the level psychosocial well-being among Vietnamese adolescents with visual and physical disabilities, and to examine the factors that influence this. The possible role of these predictors as moderators of the relationship between severity of disability and well-being outcomes was also explored. These aims were achieved through both variable-focused and person-focused analyses of quantitative data relating to both positive and negative domains of well-being that were collected at four research sites.

**Study 3.** This qualitative study used data from in-depth interviews with a sub-set of participants from Study 2 to capture adolescents' own perceptions about the challenges to

their well-being, the types of support needed to maintain or restore their well-being, and the service provider characteristics that influenced their wellbeing. This and other information was summarized into a model to guide the development of services for this population that are responsive to their priorities and preferences.

Taken together, the findings from the three studies provide a first step in addressing our “woefully inadequate” understanding of well-being among the vast number of young people with a visual or physical disability to live in LAMICs. In doing so, the program of research identifies areas for the development of theory and provides the first foundation for future evidence-based policies and practice to improve the well-being of young people with a visual or physical disability in Vietnam.

### **1.3 Thesis structure**

The thesis is organized into seven chapters (Figure 1.1).

**Chapter 1**, the current chapter, provides a brief overview of the topic addressed in the research program, its aims and the organization of the thesis.

**Chapter 2** provides the background to the research program by identifying gaps in current research concerning young people with visual and physical disabilities in LAMICs. It. In addition, this chapter identifies a suitable theoretical framework for the three studies, Bronfenbrenner and Morris’s bio-ecological framework (Bronfenbrenner & Morris, 2006). Overall, this chapter functions as a map of current research that points to the types of research needed to address gaps in our understanding and the relevance of the current research program.

**Chapter 3** outlines the reasoning behind the choice of research methods, and discusses the ways in which specific characteristics of Vietnamese culture and Vietnamese living conditions needed to be accommodated in the research.

**Chapter 4** reports Study 1, the longitudinal case studies that allowed a description of the developmental contexts, developmental trajectories and level of well-being among Vietnamese children with a visual or physical disability.

**Chapter 5** reports the main quantitative study, Study 2. This was a large-scale, multi-site quantitative study that investigated the level of the psychosocial well-being experienced by Vietnamese adolescents with visual and physical disabilities, and the factors that predicted this.

**Chapter 6** reports Study 3. This qualitative study “gave voice” to Vietnamese adolescents with a visual or physical disability by capturing their perceptions of their

challenges and support needs and summarized their responses into a culturally relevant model of support services.

**Chapter 7** summarizes the major findings of the three studies. In addition, it highlights the contribution of the program of research and implications of the findings in terms of theory, policy and practices. Finally, the chapter acknowledges the limitations of the research program, and makes recommendations for future research.

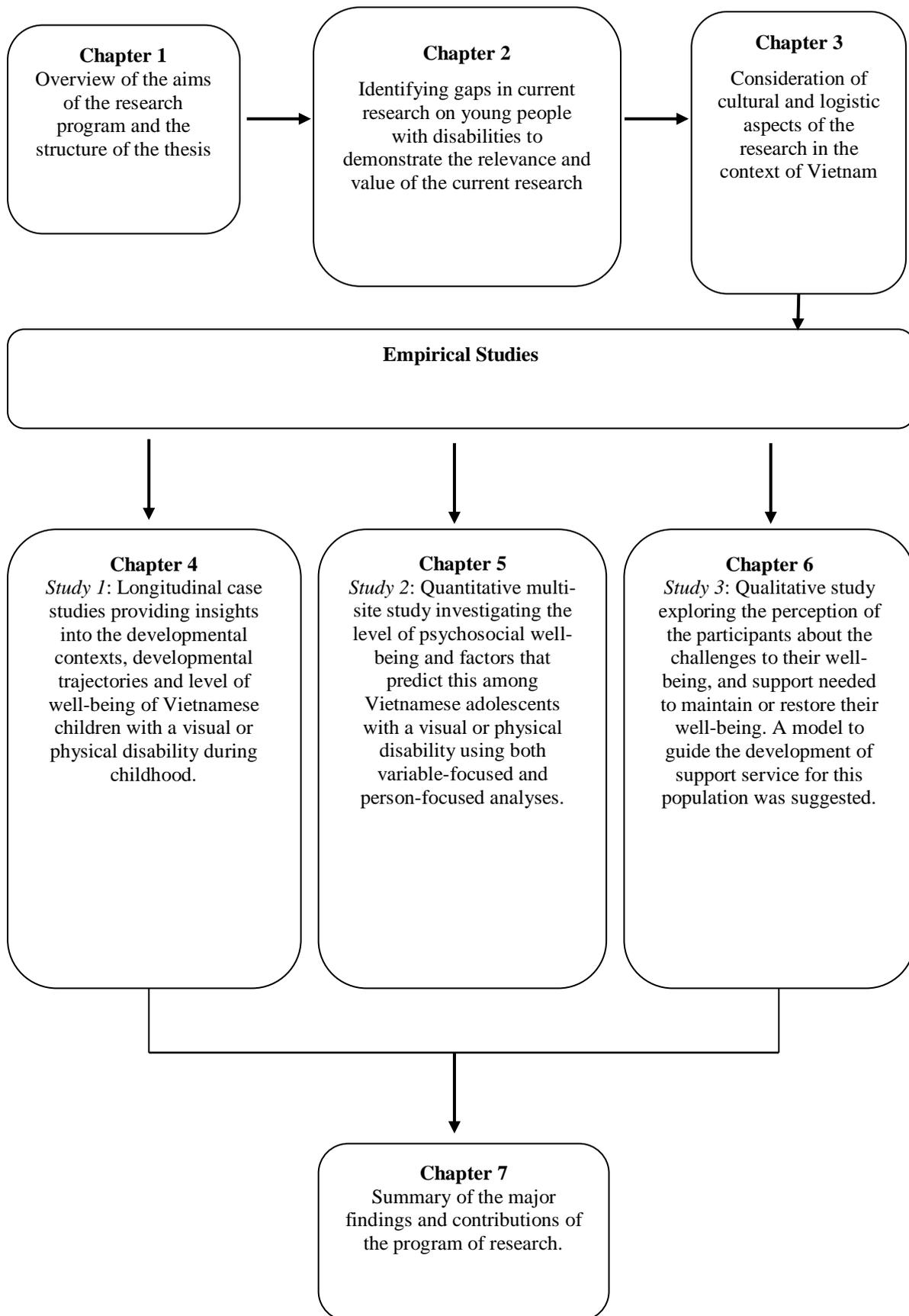


Figure 1.1: Organization of the thesis

## **CHAPTER 2 - THE PSYCHOSOCIAL WELL-BEING OF YOUNG PEOPLE WITH DISABILITIES**

This chapter presents a selective review of literature concerning (1) young people with disabilities in LAMICs; (2) the level of well-being experienced by these young people and predictors of this; (3) young people with disabilities in a particular middle-income country, Vietnam. The aim of this review is to outline our current understanding of these topics and to identify gaps in existing research. Then the theoretical framework that informed the current program of research is described.

### **2.1 Well-being of young people**

#### **2.1.1 Challenges to well-being among adolescents**

Adolescence is the “transition stage” between childhood and adulthood (Wyn & Dwyer, 1999). However, there is no consensus about the age boundaries for this period. For example, there is a marked discrepancy in the upper age boundary of adolescence as defined by researchers in the American Academy of Child and Adolescent Psychiatry (10 to 21 years of age) (American Academy of Child and Adolescent Psychiatry, 2008) and the World Health Organization (10 to 18 years of age) (UNICEF, 2010). Such differences are partly due to contextual differences in the pace of physical development, cultural customs and legal responsibilities that affect the timing of the transition from childhood to adulthood across locations.

In Vietnam, most of the social and legal privileges and responsibilities of adulthood, such as the right to vote in elections, obtain a drivers’ license, entering into a marriage, and serve in military, begin at 18 years of age. In addition, most existing empirical research reports by international NGOs define adolescence in Vietnam as the period from 10-18 years of age (UNICEF, 2010). For this reason, and because this research uses the WHO perspective on disability, it also adopts the WHO definition of adolescence.

Although there is no data for global prevalence of adolescents for the age period 10-19 according to the definition of WHO, United Nations does have statistics about adolescents and young people. In 2012, there are 1.6 billion persons aged 12-24 worldwide, of which 721 million were adolescents aged 12-17 and 850 million were youth aged 18-24 (United Nations, 2012c).

Children enter adolescence with a variety of personal and environmental resources. At the same time, they encounter many challenges that make this period a “hot spot” in terms of development. Rapid brain development and the onset of puberty are distinctive features of human adolescence that challenge the balance between physical and psychological processes (Spear, 2004). Psychosocial challenges include the mismatch between sexual and psychosocial maturity (Kleinert, 2007; Patton & Viner, 2007). This mismatch has been exacerbated by the reduction in the age of puberty that has resulted from improved nutrition and health care, coinciding with a delay in psychosocial maturity as a result of longer schooling and economic dependence (World Health Organization, 2005). In addition, the pressure of assuming increasing social responsibilities, undertaking high-stakes academic assessment, making important decisions about future education and relocation have contributed to stress among many adolescents. In summary, adolescence is a period typically characterized by a range of challenges related to biological, psychosocial and academic factors, and future orientation.

If these challenges are not successfully overcome, they can result in poor well-being for individuals during adolescence. This may be revealed through substance abuse, suicide, accidental and intentional injuries, and psychosocial problems during this period of life (Patton & Viner, 2007). Adolescence is a particularly vulnerable life period for the development of such problems. While the lifetime prevalence of mental health problems is about 25% (Wells, Bushnell, Hornblow, Joyce, & Oakley-Browne, 1989; World Health Organization, 2001), most of these (20%) emerge during adolescence (World Health Organization, 2013a).

Many adolescents with poor well-being suffer silently and alone. Even in high-income countries, only about 20% of children with a mental disorder receive mental health services (National Alliance for Mental Illness, 2012). This may be the result of poor provision of appropriate support services, adolescents’ low unawareness of their condition, lack of knowledge about where to seek help, and/or stigma of seeking help (Fisher, 2007).

Lack of attention to psychosocial problems that emerge during adolescence can have long-term consequences. Untreated mental health problems contribute to poor educational attainment, victimization, family dysfunction, crime and other antisocial behaviors (Kadel & Davies, 1986). It also increases the risk of a range of physical illnesses, such as diabetes (Kleinert, 2007; McDougall, 2011). All these further reduce well-being, quality of life and life satisfaction. Therefore, identifying and addressing psychosocial problems during

adolescence holds the possibility of reducing future challenges on young people, their families and society as a whole. The main study of the current program of research focuses on psychosocial well-being.

### **2.1.2 Challenges to well-being among adolescents in LAMICs**

A low- and middle-income country is defined as a country with a per capital annual income under U\$12,476 (The World Bank, 2016). One of the distinctive features of LAMICs is their young population. It is estimated that about 86% of the world's adolescents and young people live in LAMICs (United Nations, 2011).

This population faces additional challenges to their well-being. Not only do they face the challenges typical of this age but they also face threats specific to their living environments. In LAMICs, young people are more likely to experience insecure living conditions, early pregnancy, disease and the death of parents (The World Bank, 2006). In many of these countries, girl teenagers face additional challenges to their well-being as a result of gender inequalities and discrimination (Pearson, 1995; Yu & Sarri, 1997). These problems may be magnified when young people attempt to escape the stress of poverty and hopelessness by using unhelpful coping techniques such as illicit drug, tobacco, and alcohol abuse (The World Bank, 2006).

Exclusion from a wide range of developmental opportunities, such as education, is another challenge for many young people with a disability. Banks and Polack (2017) report that even when children with a disability attend school in LAMICs, their dropout rates are high. As a result of missing the developmental, social and economic opportunities afforded by schooling, many children with a disability face financial challenges as adults. Although the many paths between disability and poverty in adulthood are not well understood, the relationship is well-established. About 80 percent of the 97 epidemiological studies in a recent review found a positive relationship between disability and poverty (Banks & Polack (2017). Unemployment and underemployment are likely to contribute to this. For example, more than 70% of the 17 studies with relevant measures found the positive association between disability and unemployment (Banks & Polack (2017).

One reason why adolescents in LAMICs may use unhelpful coping techniques is that they have low access to support services. Well-being and mental health remain a low priority and receive very low economic investment and support from governments in most LAMICs. In the Asia-Pacific region, for example, mental health spending is no more than 2% of the

health budget, with 80-90% of this going to psychiatric hospitals (Maramis, Tuan , & Minas, 2011). Those support services that are available, are usually concentrated in urban centres and are often poor in quality and inaccessible or unaffordable for much of the population. In many LAMICs, national mental health policies do not exist, or if they do exist, are not well implemented (Maramis et al., 2011; Meshvara, 2002; World Health Organization, 2001, WHO, 2014).

## **2.2 Young people with disabilities in low- and middle- income countries**

This section will consider various perspectives on disability, then compare the most common types of disability in LAMICs and high-income countries.

### **2.2.1 Perspectives on disability**

#### **2.2.1.1 *Global prevalence of disability***

In 2011, the WHO/World Bank's World Disability Report reported data on the prevalence of disability based on two sources: the World Health Surveys in 2002-2004 and the 2004 Global Burden of Disease Study. Data from the World Health Surveys were for 59 countries. The survey included questions about the extent of functional impairment due to disability in six domains (vision, hearing, mobility, cognition, self-care, and communication). Based on stratified, multistage cluster sampling in these countries, the study calculated that the global prevalence of disability among adults over 18 years of age was prevalence 15.6 percent, and thus, disability was estimated to affect 650 million people worldwide (World Health Organisation, 2011b). Although the World Health Survey is the largest multinational survey of disability that has used a consistent set of questions and methods, it also has several limitations. First, only 59 countries participated, so the data are based on only 64 percent of the world population. Second, the data were based on self-report of conditions that are often stigmatized. Third, the severity of each disability was rated on a single 4-point scale. Fourth, these responses were awarded scores between 0 and 100, and the same cut-score was imposed across countries for identification of a person with a disability despite cultural differences in the ways in which rating scales are used. In addition, no data about the prevalence of disability among children was collected.

However, a very different approach to the assessment of disability produced a very similar estimate of the global prevalence of disability. The 2004 Global Burden of Disease

study estimated the global prevalence of about disability to be approximately 15.3 percent, and that the vast majority of these (about 978 million people) had a moderate or severe disability (World Health Organization, 2008, 2011a). The strengths of the Global Burden of Disease study are that it was more comprehensive in terms of both the number of countries (covering 17 sub-regions of the world) and the types of disabilities it included (based on more than 130 health conditions), and it covered the entire lifespan (World Health Organization, 2008, 2011a). However, in order to achieve this, the study relied on all available data sources. Thus, the method of identifying persons with a disability, types of disabilities included, sampling strategy, data collection methods etc. are not consistent across data sources or countries. Also, the amount and quality of data from low-income countries is consistently lower than that for high income-countries. In addition, in many cases in which high quality data were not available, cases of disability needed to be inferred from data concerning health conditions and impairments (World Health Organization, 2011a).

### **2.2.1.2 *Perspectives on approaches to disability***

Estimates of national and global prevalence of disability are influenced by the sampling and assessment techniques used in the research on which they were based. Typically, prevalence of disability is collected through three sources: censuses, surveys and administrative registers of persons with disabilities (United Nations, 2015). The first of these, administrative registers, record the number of people registered as eligible for disability services under the relevant legislation in that country. These data present several challenges: countries differ in the types of disabilities for which services are provided, the criteria (e.g., severity of functional impairment) required for eligibility for such services, and opportunities for people with a disability to be aware of available services and to access registration. Thus, aggregation of data across countries is hampered, and prevalence rates for specific countries usually exclude many people who meet the International Classification of Functioning, Disability and Health (ICF) criteria for being disabled.

In contrast, censuses and surveys use different approaches to collecting disability data. Some directly ask participants whether they have a disability. This approach has the shortcomings of offering only two categorical responses (“Yes” and “No”) and being vulnerable to social desirability bias in contexts in which shame and stigma are associated with “disability”. As a result, this method is likely to underestimate the true prevalence of disability. The second approach is to ask participants to respond to a list of specific

conditions associated with disability (e.g., blindness, movement disorder, autism). Such lists are not exhaustive, rely on opportunities for participants to receive a diagnosis, often include diagnostic terms (e.g., autism) that are not widely understood by members of the general population, ignore the possibility that persons with one of the listed diagnoses may have little functional impairment or participation restriction, and remain vulnerable to social desirability biases. This method has been reported to lead to cases of both over-reporting and under-reporting of the prevalence of disability (World Health Organization, 2015). It is particularly likely to lead to underestimation in contexts in which participants have limited health literacy. The World Health Organization has attributed the under-estimation of the prevalence of disability in many LAMICs to research based on “censuses or use measures focused exclusively on a narrow choice of impairments” (World Health Organization, 2011a, p.22). The third approach, “functioning based approach” identifies people with disabilities by asking them to report their level of difficulty in accomplishing basic activities such as walking, hearing, seeing etc. The advantages of this approach are that it results in lower levels of social desirability bias, and overcomes misunderstandings about the meaning of diagnostic terms. It is judged to be the most effective approach to identifying persons with disabilities in surveys and censuses and leads to a higher estimates of disability prevalence than any of the other approaches (United Nations, 2015b). It is clear that when considering reports about global and national prevalence rates for all disabilities and for specific disabilities, it is important to critically appraise the research methods that underlie the report.

### **2.2.2 Prevalence of disability among adolescents**

Estimates of the prevalence of disability among adolescents also differ due to two additional reasons. The first is that adolescents with disabilities are usually grouped together with children, young adults or adults (United Nations, 1990a). This makes any attempt to estimate their numbers as a distinct group difficult. Secondly, the screening tools used to assess disability vary widely. In some nations, only individuals with a severe level of disability are included, while in others, individuals with mild disabilities are also identified. In Uganda, for example, two separate surveys conducted in the same year, 2006, reported two totally different child disability prevalence rates: 7% and 20% (UNICEF, 2013). Similarly, in Australia, there was a large discrepancy between the prevalence of disability derived from four questions asked in the Survey of Disability in 2006 (4%) and from 17 questions asked in the Aging and Careers study in 2009 (19%) (UNICEF, 2013). Because of the important role it

plays in determining the outcomes of research, one of the first tasks of the researcher is to choose an appropriate way in which disability is defined.

### **2.2.3 Patterns and sources of disability in LAMICs**

#### **2.3.1.1 *Prevalence of disability in low- and middle-income countries***

The overall prevalence of disability, its prevalence across age groups, and the prevalence of specific types of disability appear to differ across countries. Many studies report differences between high-income countries and low-and-middle-income countries (LAMICs) in both the prevalence and pattern of disability. For example, the World Health Survey estimated that the prevalence of disability in low-income countries was almost twice that in high-income countries (18 and 11 percent, respectively) (World Health Organization, 2011a). However, not all studies find this pattern. For example, the Global Burden of Disease study reported similar prevalence rates for moderate and severe disability in low- and high-income countries: the mean disability prevalence for high-income countries was 15.4 percent, while that for LAMIC ranged from 14.0 percent to 16.4 percent (World Health Organization, 2011a). It is unclear whether this finding can be attributed to the poor quality of much of the data available for low-income countries.

#### **2.3.1.2 *Prevalence of disability across age and type of disability***

Both studies, the 2004 Global Burden of Disease Study and World Health Surveys in 2002-2004, found that the prevalence of disabilities is not distributed uniformly. The overall prevalence of disability, its prevalence across age groups, and the prevalence of specific types of disability appear to differ across countries. Many studies report differences between high-income countries and low-and-middle-income countries (LAMICs) in both the prevalence and pattern of disability. For example, the World Health Survey estimated that the prevalence of disability in low-income countries was almost twice that in high-income countries (18 and 11 percent, respectively) (World Health Organization, 2011a). However, not all studies find this pattern. For example, the Global Burden of Disease study reported similar prevalence rates for moderate and severe disability in low- and high-income countries: the mean disability prevalence for high-income countries was 15.4 percent, while that for LAMIC ranged from 14.0 percent to 16.4 percent (World Health Organization, 2011a). It is unclear whether this finding can be attributed to the poor quality of much of the data available for low-income countries.

In addition, disability is less prevalent among children than among adults. For example, the 2001 Global Burden of Disease Study estimated that only 5.1 percent of children aged 0-14 years had a moderate or severe disability while 19.4 percent of people over 15 years of age had a moderate or severe disability. However, the distribution of disability across age groups differs between high-income countries and LAMICs. Elderly people have the highest rates of disability in both contexts (World Health Organisation, 2004). However, LAMICs have a higher prevalence of disability among young people (The World Bank, 2006; United Nations, 2011). For example, the Global Burden of Disease Study reported that the prevalence of moderate or severe disability among children 0-14 years of age in LAMICs across six regions (4 to 6.4 percent) was two to three times higher than that in high-income countries (2.8 percent) (World Health Organization, 2011a). The global prevalence of disability among adolescents is unclear since none of the data available in the World Report on Disability specifically related to this age group. However, older data from the United Nations estimates that over 80 percent (150 out of 180 million) of the worldwide population of young people (aged 10-24 years) with a disability live in LAMICs (United Nations, 1990a).

The elevated prevalence of disability among young people in LAMICs is the combined result of greater exposure to risk factors: communicable (e.g., prenatal exposure to measles) and non-communicable diseases (e.g., trachoma), poor antenatal care or birth complications, exposure to toxins (e.g., prenatal exposure to pesticides), injuries (e.g., from traffic accidents or natural disasters) and the legacy of war (e.g., unexploded ordnance, chemical weapons) (United Nations, 2012a, 2012b). This epidemiology necessarily influences the types of disability seen in LAMICs. In particular, young people in LAMICs appear to have an elevated prevalence of physical and sensory disabilities (Braithwaite, Carroll, Mont, & Peffley, May, 2008; Takamine, 2004; UNICEF, 2013; United Nations, 2012a). There is currently no systematic data on which to base global comparisons between LAMICs and high-income countries of the prevalence of specific disabilities among young people. However, national prevalence data suggest that the prevalence of physical and sensory disabilities in LAMICs may be elevated across age groups. For example, in the Asia-Pacific region, which is dominated by LAMICs, 78 percent of people with a disability have a physical or a sensory disability (United Nations, 2012b). In addition, Table 2.1 illustrates the dominance of visual and physical in two LAMICs in different world regions: Vietnam and Ethiopia (UNICEF, 2010; Wa'el International Business and Development Consultant, 2000).

Table 2.1: Prevalence of specific types of disability in two low- and middle-income countries

Type of disability	Prevalence (%)	
	Vietnam	Ethiopia
Physical	29.4	32.1
Visual	13.8	32.3
Hearing	9.3	19.2
Intellectual	6.5	6.5
Mental health	16.8	NA
Other	17.1	9.9

Despite the large global population of young people with visual or physical disabilities, most disability research involving young people has been conducted in high-income countries and focused on intellectual disability (Maulik & Darmstadt, 2007). This has led to the current “woefully inadequate” level of knowledge about young people with disabilities in LAMICs (Maulik & Darmstadt, 2007, p. 51). As a result, theorists, service providers and policy makers in LAMICs lack the foundation for evidence-based practice for this population. Thus, this group has been identified as a major target for research (UNICEF, 1999). Young people in one LAMIC are the focus of the current thesis.

#### 2.2.4 Causes of disability in low and middle-income countries

The high prevalence of visual and physical disabilities among young people in LAMICs has its origins in a number of circumstances that occur more frequently in LAMICs than in most high-income countries. These include a very high challenges of diseases, traffic accidents, natural disasters and armed conflicts (United Nations, 2012a, 2012b). LAMICs bear high challenges in both communicable (e.g., measles, chicken pox) and non-communicable diseases (e.g., cancer) that can lead to visual and physical impairment. It is noteworthy that those countries bear nearly 80% of the non-communicable diseases worldwide (Deen, Vos, Huttly, & Tulloch, 1999; United Nations, 2012a). Due to financial hardship and health care shortages, diseases that rarely lead to disability in high-income countries often lead to disability in LAMICs (United Nations, 2012a).

In addition, road traffic accidents are very common in LAMICs, and cause millions of deaths and cases of physical disability (United Nations, 2012a). The consequences of road traffic accidents are often more severe in LAMICs than in high-income countries, because a large proportion of vehicles are motorbikes and bicycles which offer little protection to occupants. In addition the streets are often crowded and with little regulation of traffic flow. For example, in 2005 in Asia and the Pacific, the number of people injured on the roads was at least two million (United Nations, 2012a). Although the prevalence and severity of childhood injuries resulting from road traffic accidents in LAMICs is unknown, the large number of children who are transported in precarious positions on motorbikes, bicycles and other vehicles makes it likely that this number is large. Limited access to reconstructive surgery also makes it likely that a substantial number of child survivors of traffic accidents become physically disabled.

A third contributor to the high prevalence of disability among children in LAMICs is natural disaster. LAMICs have both a high risk of natural disasters and limited resources to cope with these. For example, LAMICs in the Asia-Pacific region are at 25 times higher risk of natural disaster than Europe or North America (United Nations, 2012a). Many survivors of disasters live with ongoing disabilities (Irshad, Mumtaz & Levay, 2012).

The fourth contributor to disability is a history of armed conflict. There were about 229 armed conflicts in 148 countries recorded between the end of World War II and 2003 (Bustreo, Genovese, Omobono, Axelsson, & Bannon, 2005). Notably, the majority of these conflicts, for example the Vietnam wars, have occurred in LAMICs (Krause, 2011; UNICEF, 1996, 2013). It is important to note that the consequences of conflicts continue long after they have ended. Many subsequent generations of children born in conflict-affected areas continue to be the victims of war (Tamashiro, 2010; Teerawichitchainan & Korinek, 2012; World Health Organization, 2013a). Play and family tasks make children more likely than adults to encounter landmines and other unexploded ordinance, and their curiosity makes them more likely to be seriously injured by these (Pearn, 2003; US Fund for UNICEF). It is estimated that landmines from past conflicts have injured or killed more than six million children in the last decade (Bustreo et al., 2005). For every child who is killed as a result of armed violence, 100 children are left with life-long disabilities (United Nations, 2012a). In addition, leftover toxic chemicals such as dioxin or Agent Orange have a negative impact on health (Johansson, 2001; Revich et al., 2001; Tuyet-Hanh, Vu-Anh, Ngoc-Bich, & Tenkate, 2010; Uemura et al., 2009). It is estimated that nearly two-thirds of children whose parents were exposed to Agent

Orange showed congenital malformations or developed a disability in the first years of their life (Johansson, 2001). Many chemicals used during wars remain for a long time and infuse into soil and water and thereby into the food chain. These chemicals disrupt both prenatal and postnatal development in ways that add to the number of children with disabilities in contaminated areas (Mai, Doan, Tarradellas, de Alencastro, & Grandjean, 2007; Johansson, 2001; Revich et al., 2001; Tuyet-Hanh et al., 2010). As a consequence, sensory and physical disability among children and adolescents is particularly high in LAMICs affected by conflict.

In addition, one of the key underlying contributors to disability is the lack of adequate primary health care in LAMICs. About 80 percent of people in those countries rely on local health care, which is very often under-resourced in both staff and materials (WHO, 2011). Obstacles to accessing the care that is available include distance, transport, and cost (WHO, 2011). The lack in both quantity and quality of health care leads to disability in many ways. One of these is that poor antenatal care leads to many conditions to remain undiagnosed and untreated, often with the result that the baby is born with a disability (e.g., visual disability from prenatal exposure to rubella, physical disabilities resulting from birth injuries) that could be avoidable remain untreated (e.g. malaria)". Another is that limited access to orthopedic care and antibiotics may result in relatively minor injuries or infections leading to lameness.

In this study, visual and physical disabilities are defined in terms of the specific capabilities in "sensory functions", and "pain and neuromusculoskeletal and movement-related" functions outlined in *the International Classification of Functioning, Disability and Health for Children and Youth* (ICF-CY) (World Health Organization, 2007a). In addition, severity of disability is defined using the WHO Disability Assessment Schedule 2.0, which takes "impairments, activity limitations, and participation restrictions" into account (World Health Organization, 2013c).

### **2.2.5 Disadvantage among young people with visual and physical disabilities**

Young people with visual and physical disabilities are amongst the most marginalized and poorest of the world's youth (Groce, 2004). Many barriers contribute to the disadvantages they experience. These include poor health due to preventable secondary diseases and other health conditions and reduced opportunities to start and maintain their schooling. As a result, young people with a disability in LAMICs are less economically

active than their peers (World Health Organization, 2011). For example, unemployment rates among this population often exceed 80% (Roggero, Tarricone, Nicoli, & Mangiaterra, 2005). Furthermore, due to the lack of supportive living environments for people with disabilities in LAMICs (such as wheelchair, ramp), and widespread negative attitudes toward people with disabilities, most adolescents with visual and physical disabilities in LAMICs are unable to participate in community activities (World Health Organization, 2011). In summary, young people with visual and physical disabilities are excluded from many mainstream educational, economic, social and cultural opportunities (Groce, 2004; World Health Organization, 2011). Despite these disadvantages, adolescents with visual and physical disabilities have the potential to develop typical cognitive and social skills. To realize this potential, it will be important to understand their living conditions, the challenges they face, and the support they need.

### **2.3 Gaps in research on young people with disabilities in low- and middle-income countries**

Although there are a large number of young people with disabilities in LAMICs, research on this population is neglected and “woefully inadequate” (Maulik & Darmstadt, 2007, p. 51). This section of the thesis points out the main gaps in our understanding about young people with disabilities in LAMICs.

Little is known about the context of development for young people with a disability in LAMICs. From 1990 to 2011, there were 24 primary studies and 13 reviews conducted in more than 50 low- and middle-income countries concerning the household socio-economic circumstances of people with disabilities (Simkiss, Blackburn, Mukoro, Read, & Spencer, 2011). However, very few of these concerned young people with disabilities in LAMICs. The few exceptions have focused on the effect of the social, cultural and living environment on lives of young people with disabilities, such as how special and mainstream schools influence their experiences (Davis & Watson, 2001) and how adolescents with disabilities perceive their impairment, services, and their social relationships (Watson et al., 2000). There has been limited research on the wider developmental context of young people with a disability living in LAMICs (Simkiss, Blackburn, Mukoro, Read, & Spencer, 2011). In addition, little is known about their development trajectories because longitudinal research is rare (Maulik & Darmstadt, 2007; Simkiss et al., 2011). A category of research that included longitudinal designs, case-controlled, and randomized controlled trials accounted for only 15% of the total disability research in LAMICs (Maulik & Darmstadt, 2007).

However, data on the household economic circumstances of adults with disabilities from more than 50 LAMICs suggest that their living conditions are constrained by poverty (Simkiss et al., 2011). Evidence suggests that poverty is both a cause and consequence of disability among adults in LAMICs. It is currently unclear whether these findings can be generalized to children and adolescents whose living conditions are mainly influenced by the economic circumstances of adult family members. This is an important gap in our knowledge because living conditions can facilitate or limit the participation of individuals with disabilities (Bickenbach, 2012; Bickenbach, Chatterji, Badley, & Üstün, 1999; Colver & Dickinson, 2010; McDougall, Wright, & Rosenbaum, 2010; Wasserman, 2001). It is important to understand life circumstances and developmental trajectories among this population in order to inform effective interventions and support.

Another gap in the research relates to types of disability. Hearing and intellectual disabilities are the most commonly studied types of disability in LAMICs (Maulik & Darmstadt, 2007; Simkiss et al., 2011) despite the fact that visual and physical disabilities have a much higher prevalence in those countries. Research on young people with visual and physical disabilities is very rare.

It is also noteworthy that very little research has sought to capture the lived experience of young people with a disability in LAMICs. In high-income countries, some studies have attempted to “capture the voice” of young people with a disability (Alderson, 1993; Beresford, 1997; Stalker & Connors, 2007; Watson et al., 2000). For example, participants have been given the opportunity to share their perception about their impairment, services, and their social relationships (Watson et al., 2000); and speak for themselves about their bodies, their friends, their parents and experts (Mulderij, 1996). However, such perceptions and feelings have not been explored from young people with disabilities in LAMICs (Maulik & Darmstadt, 2007; Simkiss et al., 2011).

Therefore, the reasons for choosing young people with visual and physical disabilities as the target sample included:

(1) Sensory and physical disabilities have higher prevalence in LAMICs than high-income countries.

(2) Despite this, research on young people with visual and physical are rare. Most disability research has been conducted in high-income countries and focused on intellectual

disability (Maulik & Darmstadt, 2007). From 1990 to 2011, there were 24 primary studies and 13 reviews conducted in more than 50 low-and middle-income countries concerning the household socio-economic circumstances of people with disabilities (Simkiss et al., 2011). Data specific to people with people with visual and physical disabilities was available in only 1 and 4 projects respectively. **None of these used a longitudinal design.**

Another review of Maulik and Darmstadt in 2007 including 80 articles with 41 from low-income countries also provided the similar result (Maulik & Darmstadt, 2007). Cross-sectional accounted for almost 60 percent). Longitudinal design shared 15 percent) with case-control, randomized and control trials. Hearing and intellectual were the most commonly studied with 26 percent) each. All these number showed a fact that physical and psychological development of those children with visual and physical disability is absolutely potential gap in the disability literature. Future research needs to take steps to fill the gap.

(3) The lack of research about people with disabilities has led to the current “woefully inadequate” level of knowledge about this population (Maulik & Darmstadt, 2007, p. 51). As a result, theorists, service providers and policy makers lack the foundation for evidence-based practice for young people with visual and physical disabilities. Therefore, this dissertation reports three empirical studies designed to help to bridge those gaps.

In summary, a significant characteristic in disability globally is the large number of young people with visual and physical disabilities in LAMICs. However, research has largely neglected this population. There have been few studies about their lived experience, developmental context, developmental trajectories or well-being. This is despite a consensus that young people with disabilities face additional challenges to their psychosocial well-being in LAMICs. The next section will present a selective literature review about the psychosocial well-being of young people with disabilities in LAMICs.

## **2.4 Well-being and psychosocial well-being of adolescents with disabilities**

### **2.4.1 Psychosocial well-being**

Well-being is a multi-dimensional construct. The United Nations considers well-being to be condition of health with all its dimensions: physical, cognitive, emotional, social, physical, and spiritual. It consists of the full range of “what is good for a person: participating

in a meaningful social role; feeling happy and hopeful; living according to good values, as locally defined; having positive social relations and a supportive environment; coping with challenges through the use of appropriate life skills; and having security, protection, and access to quality services” (United Nations, 2014, p. 96). Similar multi-dimensional definitions have been adopted in psychology (e.g., Diener & Lucas, 1999).

Psychosocial well-being” encompasses psychological, emotional and social components (Keyes, 2002). One key feature of the construct is an emphasis on the connection between psychological aspects (such as emotions, thoughts, behaviors) and social aspects (such as relationships, community standing) of well-being. The construct also integrates hedonic (e.g., positive affect) and eudemonic (e.g., satisfaction with life, self-actualization) domains of well-being (Herget et al., 2015; Li, Chung, Ho, Chiu, & Lopez, 2012; King & Napa, 1998; Tsang, Wong, & Lo, 2012). As a result, psycho-social well-being is viewed as a multidimensional phenomenon, in which each dimension is distinct but related to other dimensions (Keyes et al., 2002). Empirical research supports this view. For example, Compton and colleagues found moderate correlations between 18 indicators of conceptually distinct dimensions of well-being (Compton, Smith, Cornish, & Quallston, Smith, Cornish, & Qualls, 1996).

The current research focuses on psychosocial well-being, which encompasses the emotional and social dimensions of well-being. “The term psychosocial underscores the close connection between psychological aspects of our experience (e.g., our thoughts, emotions, and behavior) and our wider social experience (e.g., our relationships, traditions and culture)” (Inter-Agency Network for Education in Emergencies, 2010, p.1). The relationship between emotional and social well-being is bidirectional. For example, emotional problems may disrupt the ability to maintain social relationships and roles; disruption of social relationships, and the inability to fulfill valued social roles can cause significant emotional distress.

The literature on psychosocial well-being tends to divide into two broad traditions that focus on hedonic well-being (Diener, 1984) and eudemonic well-being (Keyes, 1998). The hedonic approach is reflected in research on the experience of positive emotional states and the satisfaction of desire (Diener, 1984) while the eudemonic approach is reflected in research on meaning of life, human potential and self-realization (Keyes, Shmotkin, & Ryff, 2002; Ryan & Deci, 2001). Cross-cultural comparisons confirm that these two approaches fit within the overarching construct of psychosocial well-being (Disabato, Goodman, Kashdan, Short & Jarden, 2016)

Research on the well-being of people with a disability has tended to focus either on positive or negative domains. That is, well-being is assessed either by the presence of positive functioning (e.g., life satisfaction, optimism, flourishing, prosocial behaviour) or by the absence of dysfunction (e.g., depression, anxiety, antisocial behaviour) (Keyes & Magyar-Moe, 2003; Liu, Shono & Kitamura, 2009). Well-being is probably best perceived as a multidimensional phenomenon in which dimensions are related but distinct (Keyes et al., 2002). The study by Compton et al. (1996) investigated the relationship between 18 indicators of well-being and found out that factors reflecting subjective well-being and psychological well-being were moderately correlated (Compton, Smith, Cornish, & Qualls, 1996). Another study investigated features of the good life by asking people to rate their opinion and found out that there were two related factors: one reflecting happiness and the other reflecting meaningfulness (King & Napa, 1998). These studies suggested that although hedonic well-being and eudemonic well-being are related but distinctive in many indicators. Therefore, the current research assesses both domains of well-being. This is consistent with the social perspective on disability adopted in this research (Noca & Wood, 2011). And this perspective also fits with the modern notion of multidimensional psychosocial well-being in which it is acknowledged that the same individuals may show evidence of well-being in some domains and dysfunction in other domains. Based on this notion, the present program of research aimed to investigate the well-being of adolescents with visual and physical disabilities on multiple dimensions in positive and negative domains of psychosocial well-being.

#### **2.4.2 Psychosocial well-being in the context of disability**

Adolescents with disabilities are viewed as being at increased risk of psychosocial problems because, in addition to the challenges typically faced by other adolescents, they have to cope with additional challenges caused by their disability. Evidence accumulated over several decades confirms that disability is often negatively associated with several domains of psychosocial well-being among participants in high-income countries (De Castro et al., 2010; Freedman, Stafford, Schwarz, Conrad, & Cornman, 2012; Meltzer et al., 2012). However, it is not clear whether this association applies to adolescents with visual and physical disabilities, or to adolescents in LAMICs (Abubakar et al., 2013; De Castro et al., 2010; Kellerman et al., 1980; Orr et al., 1984). In addition, little is known about factors that contribute to low psychosocial well-being among adolescents with disabilities. This section

provides a narrative review of research on psychosocial well-being among adolescents with visual and physical disabilities in order to identify gaps in our understanding.

Using several keywords (*adolescents, young people, aged 10-19, visual disability, physical disability, well-being, psychosocial well-being, depression, stress, anxiety, conduct problems, negative affect satisfaction with life, flourishing, prosocial behaviour, positive affect, optimism, social support, adaptive coping, discrimination, out-of-home care*), a search was conducted to locate related papers. Five databases were searched: Scopus, PubMed, ProQuest Central, OneFile, and the electronic and hard copy holdings of the Flinders University Library. These searches yielded a total of 366 articles. An examination of titles and abstracts allowed 198 of these articles to be eliminated (duplicates or not relevant). A close reading of the remaining 168 research articles was conducted to identify articles that provided data relevant to the definition of psychosocial well-being adopted in this study from adolescents with a visual or physical disability. Five inclusion criteria were applied:

- (a) Reported data for young people between 10 and 19 years of age;
- (b) Reported data for participants who were explicitly identified as having either a visual or physical disability, or both;
- (c) Investigated one or more domains of psychosocial well-being;
- (d) Examined the association between psychosocial well-being and other psychological or social factors;
- (e) Peer-reviewed publication.

Because the imposition of these criteria yielded very few articles, one search limit and one inclusion criterion were relaxed. First, articles based on samples that contained young people with visual and/or physical disabilities, but also included young people with other disabilities or chronic illnesses, were included. Second, directly relevant research articles with publication dates between 1990 and 2005 were included. In total, the search yielded 11 articles that satisfied the relaxed criteria. These were the basis for the intensive literature review. A summary of these studies is presented in 5.10

Table 2.1 Summary of studies that investigated the well-being of adolescents with disabilities

Author/Year/Country	Research design	Population & sample	Age group	Well-being measure	Related result	Factors influences well-being
Abubakar et al., 2013, Kenya	Cross-sectional survey	N = 296 (disability = 151, no-disability = 145).	Mean age 16.84, SD = 1.75	Two measures: The Brief Multidimensional Students' Life Satisfaction and The General Health Questionnaire.	Adolescents with disabilities had significantly lower scores in life satisfaction than their non-disabled peers.	Gender (Females had lower life satisfaction and poorer mental health).
Maatta, et al., 2013 Finland	Longitudinal cohort study	8038 children with chronic health condition or disability at 7 years of age and 6680 at 16 years of age. Participants with disabilities were included but were not a focus and their number was not reported.	At two age points: 7 and 16.	Adolescents' subjective well-being was measured by a single item life satisfaction and self-reported health.	Chronic conditions including disability did not lower their life satisfaction.	NA
Da Silva et al., 2011 Portugal	Cross-sectional survey	Research group: n = 325 participants with multiple sclerosis (including those with visual and	Age range: 16-71 years. Research group: mean age = 39.5 (SD = 10.8). Control group:	The Hospital Anxiety and Depression Scale	People with multiple sclerosis had a higher level of depression and anxiety than their healthy peers.	NA

		physical impairment but unknown number of them). Control group: n = 183 healthy participants.	mean age = 39.6 (SD = 10.8).			
Honey et al., 2011 Australia	Cross-sectional survey	Nationally representative sample n = 3392, in which disability sample n = 475.	Age 15-29 years	Mental health scale (depression, anxiety and positive mental health)	Young people with disabilities reported poorer mental health than their non-disabled peers.	Social support and financial hardship
De Castro et al., 2010 Brazil	Cross-sectional survey	165 Participants with physical disability. 8125 Participants without physical disability.	All age ranges. Physically disabled participants <19 years olds: n = 28 (19.3% of the disabled sample). The under-19 participants in the total sample: n = 3898 (34.9%).	Depression and anxiety. No standardized measures were mentioned.	Participants with physical disability reported more symptoms of depression and anxiety than their non-disabled peers.	NA
Gutman et al., 2010 United Kingdom	Longitudinal cohort study	Secondary data. 3481 had data at all three time points. 3197 had data at two of the	At three age points: 7.5, 10.5 and 13.8 years.	Four dimensions of psychosocial well-being: emotional, behavioural, social and subjective	Children with speech and language difficulties did not experience declines in well-being relative	NA

		three time points. 2431 had data at only onetime point. Participants with disabilities were included but were not a focus and number was not reported.		school well-being.	to their typical peers while children with special education needs are more likely to have poor and declining well-being than others through mid-childhood and adolescence.
Berntsson et al., 2007, Sweden	Qualitative study	N = 15 adolescents with long-term illness or disability.	Aged 12-19 years	“Feeling good” is used as synonym for “well-being” in an interview question. Example question: What is important for you to feel good in everyday?	Many adolescents with illness/disability experience well-being. Accepting attitude towards illness/disability, social support and a feeling of personal growth.
Jemta et al., 2005 Sweden	Quantitative cross-sectional.	141 children and adolescents with mobility impairment.	Children and adolescents aged 7 to 18 years, mean age = 12.3.	Well-being was measured by Snoopy scale.	The majority of physically disabled participants had a high level of well-being. Risk factors: not with both parents, acquired disability. No difference in well-being due to degree of disability, or gender. Impairment did not negatively affect well-being.
Kef et al., 2000 Netherland	Cross-sectional study	Research group: 316 adolescents	Adolescents from 14 to 24	Happiness: the Cantrill scale.	Visually disabled adolescents Risk factor: Dependence

		with visual disability. Compared group: N = 63 non-disabled adolescents (result from another study).	years.	Loneliness: 11-item Loneliness scale.	experienced a high level of happiness. There was no difference in level of happiness or loneliness between the adolescents with and without disability.	on others for mobility. No relationship was found between out-of-home care and well-being.
Wolman et al., 1994 United States	Cross-sectional survey	Mixed chronic illness and disability sample. Typical adolescents = 1650. Adolescents with disabilities/ chronic illness = 1683.	Adolescent students in grades 7-12	Minnesota Adolescent Health Survey (assessed physical, social, mental health issues and emotional well-being).	Adolescents with disability/chronic conditions had lower scores on emotional well-being. However, disability was not the strongest predictor of emotional well-being.	NA
Gortmaker et al., 1990 United States	Cross-sectional survey	National representative sample N = 11699 with chronic health condition including hearing, visual and physical disabilities.	4-17 years	The Behaviour Problem Index	Physical condition, including disability was a risk factor for behaviour problems, independent of socio-demographic variables.	NA

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Note. n = number of participants. NA = Not applicable.

From Table 2.2, it can be seen that the vast majority of studies on the psychosocial well-being of adolescents with a visual or physical disability use cross-sectional quantitative design and were conducted in high-income countries. In addition, studies that provide data specific to either visual or physical disability among adolescents are rare. However, the literature provides some insights into level of psychosocial well-being and predictors for this population, which are outlined in the discussion below.

#### **2.4.2.1 Level of well-being for adolescents with visual and physical disabilities**

The research in Table 2.2 reported inconsistent results about the level of well-being among adolescents with visual and physical disabilities. Many studies reported that adolescents with a disability, including a visual or a physical disability, showed lower psychosocial well-being than their non-disabled peers on a number of domains: global mental health (Honey et al., 2011), symptoms of anxiety and depression (De Castro et al., 2010), and life satisfaction (Abubakar et al., 2013). For example, Abubakar et al. (2013) found that adolescents a visual or physical disability have lower life satisfaction than their peers without a disability.

In contrast, other studies indicated that adolescents with visual or physical disability had a high level of well-being. For example, Kef et al. (2000) reported that adolescents with a visual disability had levels of happiness that did not differ from those of non-disabled adolescents. In addition, a longitudinal study by Määttä et al. (2013) showed that most Finnish adolescents with a disability or a chronic disease were satisfied with their lives and that physical condition (including disability) did not affect well-being their life satisfaction. The conflicting results from these studies raise the possibility that the well-being of young people with a disability is influenced by contextual factors, the domain of well-being that is assessed and type of disability. The main study in the current program of research, Study 2, is designed to investigate this possibility.

#### **2.4.2.2 Factors influencing well-being among young people with disabilities**

The research summarized in Table 2.2 also pointed out some factors that are associated with psychosocial well-being of adolescents with visual and physical disabilities. Factors that were positively associated with well-being included social support (Berntsson et al., 2007; Honey et al., 2011), an accepting attitude of illness/disability and a feeling of personal growth (Berntsson et al., 2007). Factors that were negatively associated with well-being were also identified, including greater age, out-of-home care (not living with both/any parents), being a first-generation immigrant, having an acquired disability, experience of pain (Jemtä et al.,

2005), financial hardship (Honey et al., 2011) and being a female (Abubakar et al., 2013). However, these relationships were not always consistent across studies. For example, Abubakar et al. (2013) found that Kenyan female adolescents with a visual or physical disability had lower life satisfaction and more mental health problems than their male peers. However, Jemta et al. (2005) found that gender was not related to global well-being among Swedish adolescents with a physical disability. Again, the currently available research suggests that findings may be influenced by contextual factors, the domain of well-being that is assessed, and type of disability.

In order to promote the well-being of people with disabilities, it is important to identify factors that relate to the way adolescents regard their psychosocial well-being and factors perceived as important for their well-being play a key role for a happy life of adolescents with disability in a specific context with a particular type of disability. The following section will provide a brief summary of five predictor factors that the current research chooses to investigate in the Vietnamese context.

### **2.4.3 Planning a systematic investigation of predictors of psychosocial well-being among adolescents with visual and physical disabilities**

There is extensive empirical research on predictors of well-being in adolescents without a disability. Much of this has been informed by resilience frameworks, positive psychology or applications of Lazarus and Folkman's theory of stress and coping (Lazarus & Folkman, 1987; Dumont & Provost, 1999; Frison & Eggermont, 2015). However, it is rare to see the applications of these empirical findings or theoretical frameworks in previous research on psychosocial well-being among adolescents with a disability. In order to provide a more systematic investigation of predictors of well-being in this population, Study 2 focused on three factors identified as being positively associated with well-being (optimism, social support, adaptive coping) and two factors identified as being negatively associated with well-being (discrimination and out-of-home care) in previous empirical research and theory. The selection of these five factors that influenced well-being in this study was based on the literature. As a result from the literature review, several factors that are positively and negatively associated with the well-being of young people with disabilities. Poverty has been negatively associated to positive domains of well-being among people with disabilities (e.g., Banks & Polacks, 2017). However, there is considerable debate about the most appropriate method of assessing poverty for individual participants even in high-income countries (e.g., absolute household income,

income relative to household size, income relative to national average or local cost of living). In LAMICs, where many people in rural areas continue to meet many of their basic needs without cash transactions, the difficulties are greater. These are compounded in the case of children and adolescents with a disability in LAMICs, because many have their basic needs supported by a charity or religious institution rather than out of their family's household income. As a result of these measurement difficulties, poverty was not included as a predictor of well-being in the current study.

Within the scope of this thesis, 5 factors were chosen based on the inconsistent findings about its influence and its meaning in terms of practical implication to improve well-being. It was predicted that these five factors might play an important role in well-being of people with disabilities in the Vietnamese context. Clarification about this choice was informed by empirical and/or theoretical considerations which is described below:

#### **2.4.3.1 Factors positively associated with well-being**

Previous research has identified both internal assets (e.g., optimism, adaptive coping strategies) and external resources (e.g., social support) that consistently show positive association with positive domains of well-being and/or negative association with negative domains of well-being.

**Optimism:** is a general tendency to anticipate positive outcomes in the future (Reker, 1997). A positive association between optimism and various domains of well-being has been well established in cross-sectional and longitudinal research in many other populations. For example, optimism is negatively related to two negative domains of well-being (depression and negative emotions) and positively related to two positive domains of well-being (self-esteem and life satisfaction) among adults in high-income countries (Wrosch & Scheier, 2003). Similarly, optimism is negatively associated to negative affect and positively associated with positive affect among adolescents in high-income countries (e.g., Ben-Zur, 2003). Moreover, similar associations have been found among adolescents in a country adjoining Vietnam. Optimism was positively associated with life satisfaction and negatively associated with psychosocial problems among adolescents in Hong Kong (Ho, Cheung & Cheung, 2010). The self-concordance model (Sheldon & Elliot, 2000) suggests that this association reflects a causal bidirectional relationship. The greater individuals' optimism, the more willing they are likely to be to engage in meaningful activities that are likely to support positive domains of well-being, which in turn is likely to sustain their optimism (Sheldon & Cooper, 2008). Because the self-concordance model can be applied across cultures, ages, and to people with a

disability, it is expected that optimism will be positively associated with positive domains of well-being and negatively associated with negative domains of well-being among Vietnamese adolescents with physical and visual disabilities.

**Adaptive coping.** “Coping” refers to the “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 108). Adolescents with disabilities use a variety of coping strategies to manage the complex challenges they face (Eiser, 1989; Williamson & Zeitlin, 1988). By definition, adaptive coping strategies are positively associated with positive domains of well-being. Such strategies include problem-focused and support-seeking strategies. In contrast, maladaptive coping strategies, by definition, are negatively related to positive domains of well-being. These include escape and avoidance strategies (Thompson et al., 2010). However, it is currently unclear how coping strategies are related to well-being among adolescents with disabilities, who face some challenges may not be overcome by problem-focused coping. Some previous research has shown no relationship between coping strategies and well-being in this population (Gallegos, Langley, & Villegas, 2012; Monsen, 1992). Several researchers have argued that adaptive coping strategies differ for adolescents with and without a disability (Janelle, 1992; Monsen, 1992). However, on balance, previous research suggests that problem-focused and support-seeking strategies are effective among adolescents in high-income countries and among persons with a disability in high-income countries. Although no data are available for Vietnamese adolescents with a disability, it is predicted that these coping strategies will be positively related to positive domains of well-being and negatively related to negative domains of well-being in this population. It is also feasible that adaptive coping strategies may diminish the adverse effect of severity of disability on well-being. This research, therefore, also examined whether coping strategies moderate the relationship between severity of disability and well-being.

**Social support.** Two aspects of social support have been a focus of research: received social support and perceived social support. This research focuses on perceived social support, which refers to individual’s opinion about how much support is available when needed (Wills & Shinar, 2000). Perceived social support is a predictor of well-being in a wide range of research using either a resilience framework (e.g., Dumont & Provost, 1999) or applying Lazarus and Folkman’s theory (e.g., Frison & Eggermont, 2015). Because there are large individual differences in perceived social support among adolescents with a disability due to

the many barriers in seeking social support that they face, it was judged to be a likely predictor of individual differences in their well-being. One result of these barriers is that many adolescents with a visual or physical disability may have fewer friends and smaller social networks (e.g., Kef et al., 2000) or less intimate friendships (e.g., Stevens et al., 1996) than their non-disabled peers. In addition, their relationships with the adults who often provide adolescents with social support are often ambivalent. The support they provide may be perceived to be (Skär, 2003). Thus, adolescents' perceptions of the social support they received were predicted to be associated with their wellbeing. Previous research, also suggests that social support may buffer the negative effects of disability on well-being (Honey, Emerson, & Llewellyn, 2011; Turner & Noh, 1988). Therefore, it was also predicted that perceived social support would moderate the relationship between disability severity and psychosocial well-being among Vietnamese adolescents with visual and physical disabilities.

#### **2.4.3.2 Factors negatively associated with psychosocial well-being**

Previous research has identified both internal vulnerabilities (e.g., insecure attachment, body dissatisfaction) (Franko & Striegel-Moore, 2002; Sund & Wichstrom, 2002) and external risk factors (e.g., discrimination, out-of-home care) that consistently show negative associations with positive domains of well-being and positive associations with negative domains of well-being. This discussion focuses on two external risk factors.

**Discrimination.** One of the greatest impediments to the psychosocial well-being of adolescents with disabilities is discrimination, partly due to the social exclusion it often leads to (e.g., Groce, 2004). Adolescents with disabilities may experience discrimination and social exclusion in every aspect of life (UNICEF, 2013), including leisure activities (Buttimer & Tierney, 2005), employment (Lindsay, 2011) and education (Pardeck, 1999). Although inclusive education may provide adolescents with a disability with expanded opportunities for learning and diverse social interactions, it also exposes them to the prejudices held by their classmates. As a result, greater social interaction may not result in friendship (Scheepstra, Nakken, & Pijl, 1999). It may instead result in increased social isolation. Thus, I predicted that perceived discrimination would be negatively associated with positive domains of psychosocial well-being and positively associated with negative domains of well-being. It is also feasible that discrimination magnifies the adverse effect of severity of disability on well-being. This research, therefore, also examined whether discrimination moderates the relationship between severity of disability and well-being.

**Out-of-family care.** In general, the closer adolescents feel to their family, the better their well-being. One practice that may disrupt the sense of connection to family among adolescents with a disability in LAMICs is the requirement that they live out-of-home in centralized institutions in order to access education, vocational training and/or employment. In other populations, out-of-home care is consistently found to show a negative association with well-being. For example, Dinisman, Montserrat, and Casas (2012) found that adolescents living with two parents had better subjective well-being in all life domains than their peers who were living “in care”. It is unclear whether these findings can be generalized to young people with a disability in LAMICs where out-of-home care also provides valued opportunities. Wolman et al. (1994) concluded that one of the main contributions to the lower emotional well-being of adolescents with a disability in high-income countries was a difference in connection to family. However, Kef et al. (2000) found no association between out-of-home care and psychosocial well-being among adolescents in a high-income country who had a visual disability. Despite the latter finding, I predicted that out-of-home care would be negatively related to positive domains of psychosocial well-being and positively correlated with negative domains of well-being.

In conclusion, five candidates for predictors of well-being were identified from previous research. This research largely focused on other populations. The predictors of wellbeing among adolescents with a disability living in LAMICs have rarely been explored. There have been no previous explorations in the Vietnamese context. The current research aims to bridge this gap by investigating whether the predictive power of the factors can be generalized to Vietnamese adolescents with visual and physical disabilities.

## **2.5 The context in Vietnam**

### **2.5.1 Disability in Vietnam**

Vietnam is a middle-income country located in South-East Asia that experienced three major wars in the 20<sup>th</sup> century. The per capita income was US\$2,100 in 2015 (The World Bank, 2017).

#### **2.5.1.1 Prevalence of disability in Vietnam**

Estimates of the prevalence of disability in Vietnam are highly variable. Some estimates are lower than the global average. For example, recent United Nations estimates suggest that only 7.8 percent) of the Vietnamese population aged 5 years or older has a disability (United

Nations, 2015). There are several reasons to believe that this is an under-estimate. First, this figure was based on government-reported data about living standards, in which disability questions were limited in both quantity and quality. There were few screening questions and response categories, and therefore many people with mild or moderate disabilities are unlikely to have been identified. Second, the sampling strategies did not produce a national representative sample. In contrast, reports based on data collected using a “functioning based approach” have reported disability prevalence rates as high, or higher, than the global average. The 2009 Census in Vietnam included questions that allowed judgments about disability that were consistent with the International Classification of Functioning, Disability and Health (ICF). It showed that persons with disabilities accounted for 15.3 percent) of the country’s population (National Coordinating Council on Disability, 2010). This was similar to the prevalence level of other studies that allow judgments consistent with the ICF framework. For example, the 2006 Vietnam Household Living Standards Survey reported a disability prevalence rate of 15.7 percent) (Mont & Nguyen, 2011). Data from this survey have been considered to be of particularly high quality because of the comprehensive sampling strategy (36,701 individuals aged 5 years and over from eight geographic regions), the inclusion of functional impairments in six domains (seeing, hearing, walking, self-care, communicating and concentrating), and the rating of level of functional impairment on a four-point scale rather than as a “Yes/No” response. Thus, the highest quality data suggests that the prevalence rate for disability in Vietnam is between 15 and 16 percent).

### **2.5.1.2 Prevalence of disability among Vietnamese children and adolescents**

It is more difficult to draw conclusions about the prevalence of disability among Vietnamese children and adolescents. UNICEF (2000) estimated that the prevalence of disability among children aged 0-17 years was 3.1 percent), which would suggest that there are of children, indicating that there are approximately 1 million children with a disability living in Vietnam. This estimate was based on a research design that primarily focused on the wellbeing of children who were identified as having a disability. Data were collected from two different samples. A community-based survey that identified, and gathered parent-reported data for, 1,148 children with disabilities who were living in households in 16 provinces/cities was supplemented with self-reported data from children in eight institutions providing disability services (UNICEF, 2000). The main strength of this study as the basis for estimates of the prevalence of disability is that a multi-stage stratified random sampling procedure was used in

the community-based survey. However, higher prevalence rates have been reported by studies with wider geographical sampling and which adopted a “functioning based approach”. In particular, the 2009 Census, estimated the child disability prevalence to be 4.3 percent) even though data were gathered only for children aged 5-17 years, and only for four domains of functioning (Mont & Nguyen, 2011). The prevalence of disability for Vietnamese children aged 0-18 when all six domains of functioning in the ICD are considered is therefore estimated to be above 4.3 percent). No data specific to Vietnamese adolescents are available.

### 2.5.1.3 Types of disabilities in Vietnam

There appears to be only two sources of population level data concerning the types of disability observed in Vietnam. The 2006 Vietnam Household Living Standards Survey reported that visual, mobility and cognitive disabilities had the highest prevalence among Vietnamese population five years of age or older: 11.4 percent) of this population reported difficulties seeing, 6.0 percent) reported difficulties with walking; and 4.7 percent) reported difficulties in remembering and concentrating (Mont & Nguyen, 2011). Other disabilities had prevalence rates under 4 percent). The only other source of data is statistics from the Ministry of Labor, Invalids and Social Affairs (MOLISA) (Le, Khuat and Nguyen, 2008, p.8). These data, based on persons registered as having a disability, show a different pattern (Figure 2.1). However, physical, cognitive and visual disabilities were again identified as having the highest prevalence.

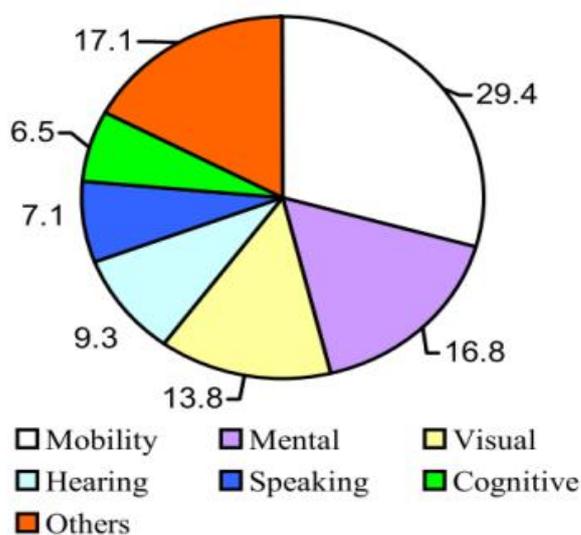


Figure 2.1: Types of disability in Vietnam (Le, Khuat and Nguyen, 2008, p.8)

### 2.5.1.4 Types of disabilities among children and adolescents in Vietnam

Similarly, two sources also provide data specific to disability among Vietnamese children and adolescents. However, their findings are less easy to reconcile. The 2006 Vietnam Household Living Standards Survey reported that visual, self-care, communication and cognitive disabilities had the highest prevalence among Vietnamese children aged five to eighteen years of age: parents reported that 1.9 percent) of this population had difficulties seeing, 1.2 percent) had difficulties with self-care; 1.1 percent) had communication difficulties and a similar percentage had difficulties with remembering and concentrating (Mont & Nguyen, 2011). All other disabilities, including physical disabilities, were reported to have a prevalence of under 0.7 percent) These results are in stark contrast to those reported by UNICEF (2010), which identified physical disabilities as having the highest prevalence in all age groups and vision impairments as being relatively rare (Figure 2.2).

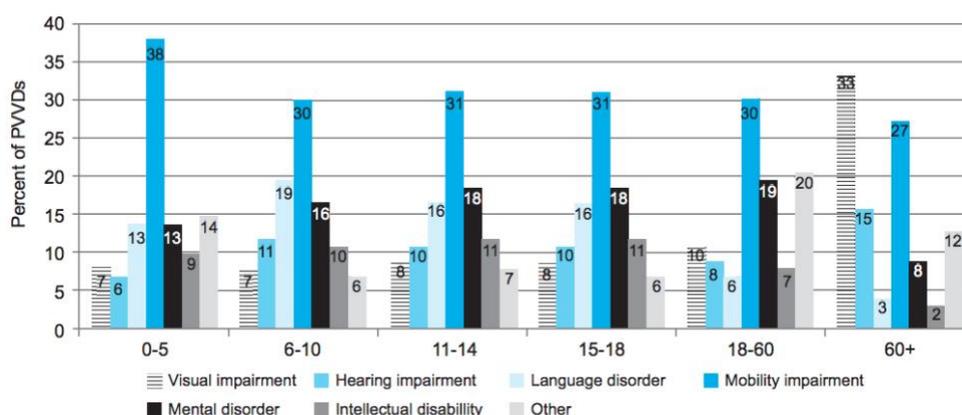


Figure 2.2: Percentage of Vietnamese persons with a disability in six age groups who reported specific types of disabilities

Since the two studies were conducted less than five years apart, were based on relatively large samples, and used a “functioning approach” to identifying individuals with a disability, the source of the discrepancy in their findings is currently unclear. Only one additional study provides a point of comparison. This study applied diagnostic criteria for a range of visual impairments in population-based sample of 28,800 children aged 0-15 years drawn from 16 provinces (Limburg, et al, 2011). Such clinical criteria are much more stringent as a means of identifying children with a visual impairment than the parent- or self-reports used in censuses and surveys. This study estimated that the prevalence of visual impairment among

Vietnamese children was only 0.0076 percent). Although they estimate that approximately 16,400 Vietnamese children were blind from all causes, these data are consistent with the relatively low contribution to the prevalence of disability prevalence among Vietnamese children reported by UNICEF (2010). However, the visual impairments detected in this study were often severe, significantly impairing children’s functioning and limiting their participation. It was also noted that a large percentage of children with refractive errors did not have access to spectacles that might correct these, and therefore continued to experience preventable functional impairments and participation limitations. This thesis will focus on the wellbeing of young people in Vietnam who have a physical or visual disability.

### 2.5.1.5 Causes of disability in Vietnam

Administrative data provided by the Vietnamese government is the only available source of information about causes of disability across the Vietnamese population. It shows that congenital birth defects and disease account for almost 70 percent) of disabilities in Vietnam (Figure 2.3). Because the statistics place congenital birth defects attributable to prenatal exposure to dioxin in a separate category (War/Dioxin) the total percentage of disability attributable to congenital birth defects is larger than that shown in the figure.

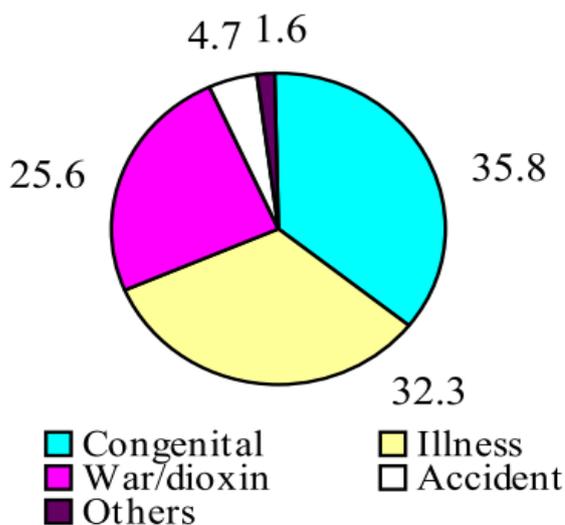


Figure 2.3: Sources of disability in Vietnam (Le, Khuat and Nguyen, 2008, p.8)

### **2.5.1.6 Causes of disability among children and adolescents in Vietnam**

Only one source provides information about the causes of disability among children in Vietnam. UNICEF (2010) reported that the vast majority of these disabilities were attributable to either congenital birth defects (55.0 percent of community-dwelling children identified as having a disability, and 64.6 percent of children with disabilities living in institutions) or disease (29.1 percent of community-dwelling children identified as having a disability, and 23.5 percent of children with disabilities living in institutions). Thus, the limited available information suggests that most Vietnamese children with a disability have had this since their birth.

### **2.5.2 Situation of Vietnamese people with disabilities: legislation and reality**

Vietnam has adopted many laws and policies to help protect the rights and well-being of people with disabilities. As one of the first countries to ratify the United Nations Convention on the Rights of the Child in 1990, Vietnam has committed itself to ensure the basic human rights of children, including children with disabilities. The result should be that children with disabilities have “effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child’s achieving the fullest possible social integration and individual development” (United Nations, 1990b). Signing the United Nations Convention on the Rights of Persons with Disabilities in 2007 was another major milestone in Vietnam’s commitment to guarantee educational, political, economic, cultural and social rights for people with disabilities, including children.

The commitment of the Vietnamese government to protect this population has been ratified by many national laws and decrees that protect the rights of young people with disabilities. Some examples of these laws include: 1989 Law on Protection of People’s Health, the 1991 Law on Universalization of Primary Education, the 1999 Penal Law, the 2000 Law on Marriage and Family, the 2004 Law on Protection, Care and Education of Children, the 2005 Education Law, the 2006 Law on Vocational Training, the 2006 Law on Information Technology, the 2006 Law on Sports and Physical Education, and the 2008 Law on In-land Transportation (Rosenthal, 2009). At least 20 different decrees and regulations in different disability-related areas have been passed in an attempt to protect the human rights and well-being of young people with a disability. Any form of discrimination against persons with

disabilities is strictly prohibited by Vietnamese law. From a policy perspective, the Vietnamese government's attempts are considered to be "impressive" (Rosenthal, 2009).

However, the implementation of these policies in reality is less impressive. In reality, many people with disabilities do not experience the rights and services "guaranteed" by law (Rosenthal, 2009). In particular, the current social protection program was reported to be inaccessible in a recent focus group conducted by Palmer and his colleagues (2015).

Vietnamese people with disabilities continue to encounter challenges in almost all aspects of their lives. Because of the lack of ramps and disability-friendly equipment, many services and much public infrastructure are inaccessible to them. These include public transportation, schools, hospitals, toilets, workplaces, cultural and other buildings (UNICEF & MOLISA, 2004). As a result, young people with a disability are often marginalized from many important activities such as education, sport, recreation, work, health care and other essential development activities (UNICEF & MOLISA, 2004). For example, the majority of children with a visual disability have very limited access to information because reading materials in Braille, large font, or closed-captions are rare (Rosenthal, 2009). This has long-term consequence for opportunities for participation in the community and paid employment.

It is noteworthy that the social exclusion of young people with a disability starts early. Only 66.5 % of children aged 6-10 years with disabilities attend primary school while this rate for other Vietnamese children is up to 97.0 % (UNICEF, 2010). Girls with a disability are particularly disadvantaged. More than 55 % of girls with a disability have never once attended school, whereas the figure for boys with a disability is 39.0 % ( UNICEF, 2010). Of those who do attend school, about 20%, continue to experience exclusion as they are usually placed in separate schools or classes because of lack of expertise and financial support for inclusive education (UNICEF & MOLISA, 2009). One in every three children with a disability drop out of school ( UNICEF, 2010). This has long-term consequences. The illiteracy rate for children with disabilities is 43% (UNICEF & MOLISA, 2004) and for adults is about 30%. This is six times higher than the rate for other adults (5%) (Tatarski, 2013). In addition, the unemployment rate in Vietnam for people with a disability is more than three times that for people without a disability (14 and 4.3 % respectively). One in every three households with one member with disability lives in poverty (International Labour Organization, 2013).

### 2.5.3 Support services for people with disabilities in Vietnam

According to the social perspective on disability, having an impairment is not necessarily a barrier to inclusion and participation. Restriction comes from environments, attitudes and organizations. As one aim of this program of research is to suggest a model of support services for Vietnamese adolescents with disabilities (Study 3), this section describes the current provision of support for this population in Vietnam. This knowledge is also necessary to interpret the findings of Study 1 and Study 2.

*Policy and legislation for social support for people with disabilities.* The abundant laws and decrees that the Vietnamese States Parties have signed and enacted, including the United Nations Convention on the Rights of Persons with Disabilities, showed a philosophical commitment to provide support to ensure children and other people with disabilities have a full and meaningful life. Some of these laws and decrees specifically concern the provision of support. Examples are the Ordinance on the Disabled, 1998, Decree No 55/ 1999/N§-CP of July 10, 1999 on Guidelines for the Implementation of the Ordinance on the Disabled, Circular No 13/ 2000/ L§TBXH of May 12, 2000 by the Ministry of Labour, War Invalids and Social Affairs on Guidelines for the Implementation of Decree No 55/1999/N§-CP. The consequence of these is that the State must provide care and assistance, free of charge wherever possible, for education, training, health care, rehabilitation, preparation for employment and recreation opportunities for people with disabilities to facilitate their development and achievement to the fullest possible extent (UNICEF & MOLISA, 2009). In particular, children and other people affected by the consequences of war, such as Agent Orange/Dioxin and landmines will receive special care from the State and society. The State has budget fund specifically for assisting persons with a disability to receive appropriate support (health checks, treatment, functional rehabilitation, education, job training and procurement). In addition, severely disabled persons who have difficulty earning a living shall be cared for and assisted at their place of residence or in social institutions. However, the value of the allowance that is provided is woefully inadequate (about 180.000-360.000 VND which equals U\$10-20 per month, depending on severity of disability).

At present, in Vietnam and many other LAMICs, out-of-home care is the only available option for many young people with a disability, especially those living in rural areas, who wish to pursue an education or obtain employment. In addition, in LAMICs without a tradition of foster care or out-of-family adoptions, out-of-home care is often the only option for children with disabilities who are abandoned by their families or are orphans. For example, UNICEF

and MOLISA (2004) estimated that more than half of the Vietnamese children with disabilities living in institutions were abandoned and more than one quarter were orphans.

***Organization of disability services in Vietnam.*** Support and rehabilitation clinics have been established to assist people with disabilities at all levels of society from village to province and city. The main activities are job creation, education encouragement and home exercise. These services have been established and managed by the Ministry of Health (Ministry of Health, 1999). The main form of support provided by this Ministry is community-based rehabilitation and support. Currently, only ten specialist rehabilitation clinics have been established nationwide. However, most district hospitals also have rehabilitation clinics. In addition, many international non-government organizations have set up their own rehabilitation services. As a result, this form of support is available in 46 out of 64 provinces and cities, in 215 districts and 2,420 communes (UNICEF & MOLISA, 2009). However, it is not sufficient. For example, only 4.62 % of people with disabilities receive rehabilitation treatment (UNICEF & MOLISA, 2010).

In addition, only 63% of people with disability in Vietnam access health services (UNICEF & MOLISA, 2009). This reflects their limited awareness of, and access to, appropriate health care. One third of families with a disabled member have never sought health treatment. People with disabilities living in rural areas have lower access to health care and rehabilitation clinics than those in urban and areas (Vietnam, 2000) (UNICEF & MOLISA, 2009).

Social assistance centres provide financial support for people with disabilities in difficult circumstances. Some of these are the 97,000 children and other people with disabilities who attend one of more than 300 welfare centres. These are entitled to a monthly allowance of 140.000-210.000VND (less than U\$10). The number of social assistance centres is being reduced in response to the call by the Prime Minister (Decision No. 65/2005/QĐ-TTg) to transfer children with severe disabilities from those centres to facilities within their communities, such as orphanages, patronage, adoption, social houses and private and NGO facilities such as social houses and the care houses of pagodas or churches, (UNICEF & MOLISA, 2009). The government also encourages families to care for their family members with a disability by providing allowances for their caregivers (Decree 67/2007/NĐ-CP of Prime Minister on the policies of subsidies for families and caregivers of orphans and abandoned children). However, many children and adolescents with a disability and their carers do not

receive any financial support. For example, up to 60% of children with disabilities do not receive any form of support from the government, including subsidized education, free access to health care, or a monthly allowance (UNICEF & MOLISA, 2004).

Another shortcoming of service provision is that in most social assistance houses, people with different types of disabilities who need different kinds of support are often assigned to receive the same services or classes. For instance, the same services may be provided to children with a visual disability and children with a physical disability. Efforts to tailor service provision to the individual's needs are rare due to the lack of guidance, materials, expertise and human resources (UNICEF & MOLISA, 2004). As a result, there is often a mismatch between the services needed for young people with disabilities to develop their full potential and the services that are delivered.

To sum up, although the Vietnamese government is aware of the need to support people with disabilities, these people still face many barriers due to a failure to fully implement relevant policies. Currently, the majority of people with disabilities, including children and adolescents, are struggling to access the support sources they need, which are limited in both quantity and quality (Mensch, Clark, & Anh, 2003; UNICEF, 2010). In addition, there is a lack of tailored support.

#### **2.5.4 Research concerning people with a disability in Vietnam**

Vietnam signed the UN Convention on the Rights of Persons with Disabilities on 22 October 2007. In part this has led to many efforts being made to investigate and address the issues of children and adolescents with disabilities in Vietnam over the last two decades ( Zhao, Wendy-Ann Rowe, Kamioka, & Hegarty, 2012; Duong & Vinh, 2007; Daniel Mont & Nguyen, 2011; Rosenthal, 2009). Most empirical studies have focused on parental stress, social support and the early intervention experiences of Vietnamese children (D'Antonio & Shin, 2009; Gammeltoft, 2008; Goldberg, Dill, Shin, & Nhan, 2009; Park, Glidden, & Shin, 2010; Shin & McDonough, 2008). In addition, most research has been conducted in urban settings.

Despite the fact that more research attention has recently been paid to people with disability in Vietnam, the literature concerning this population is still relatively undeveloped (Harpham & Tuan, 2006). In addition, existing research has several limitations. In particular, data are usually provided by family members, such as parents or other caregivers, rather than the children themselves (Gammeltoft, 2008; Thang Trinh & colleagues, 2011). Failure to gather data from individuals with a disability may increase the risk of misrepresenting their level of

well-being. For example, McKinley and his colleagues found that the number of mental health problems reported by Vietnamese Australian teenagers was higher in self-report than in parent-reports (McKelvey et al., 2002). In addition, more studies focus on children with disabilities than on adolescents, and only a few focus on their psychosocial well-being. Only two studies have directly examined psychosocial well-being among Vietnamese young people with a disability. These used different research designs, outcomes and age groups. First, Fuhr and Silva (2012) conducted a quantitative study of the relationship between mental health and disability caused by chronic illness in a large sample of 8-year-old Vietnamese children who were recruited from twenty different locations. Results indicated that Vietnamese children who experienced long-term physical health problems had twice the incidence of mental health difficulties compared with their peers without long-term health problems (Fuhr & Silva, 2012). In contrast, Ngo and his colleagues (Ngo et al., 2012) conducted a qualitative study involving a small number of Vietnamese adolescents (14-19 years old) most of whom had a physical disability. Data were collected by interviews with both children and their mothers. The findings highlighted the barriers that Vietnamese children and adolescents face, such as a lack of disability diagnosis, and inadequate healthcare services and government financial assistance. Several coping mechanisms and protective factors were also identified.

In summary, Vietnam exemplifies many characteristics of conflict-affected LAMICs. It has large number of adolescents with visual and physical disabilities. These young people are likely to experience many challenges to their psychosocial well-being. However, there has been little research about this population. In particular, no research concerning the psychosocial well-being among young people with visual and physical disabilities are available. The current program of research consists of three studies that address this gap by investigating the lived experience of this population in childhood, their well-being in adolescence and their perception about daily challenges, support use and an ideal support service.

## **2.6 Theoretical framework: Bronfenbrenner and Morris's bio-ecological theory**

The bio-ecological framework of Bronfenbrenner and Morris informed all three studies in the current program of research (Bronfenbrenner & Morris, 2006). This framework recognizes the role of biological factors (the biosystem), the active role individuals play in their own development (child system), and the diversity of proximal and distal environmental factors that influence development (Figure 2.5).

The child's environment is organized into four systems that are arranged in a nested hierarchy, like Russian dolls: microsystem, mesosystem, exosystem, and macrosystem: There are thus six main systems:

- a. The biosystem encompasses physical development, nutrition, health conditions, genetic information, sensitivity of senses and impairments.
- b. The child/individual system encompasses the person's unique psychological strengths and vulnerabilities in terms of temperament, aptitudes, activity level, cognitive skills, coping strategies and mental health problems.
- c. The microsystem encompasses proximal environmental influences on the child. It includes the objects (e.g., household possessions, quality of housing, playground equipment, toys and books), events (e.g., birthday party, funeral) and people (e.g., parents, teachers, neighbours) and other living things (e.g., pets, farm stock) with which the child interacts directly.
- d. The mesosystem captures bidirectional relationships between agents in the microsystem, and to extent to which the influences in a child's microsystem are consistent. For example, is there agreement between parents over the way to discipline the child? Do the school and the place of worship reinforce or undermine each other's world views?
- e. The exosystem encompasses institutions, people and events that do not directly interact with the child, but influence the child indirectly through their influence on the child's microsystem (e.g., extent to which parents' workplaces have family-friendly policies, parents' social support system)
- f. The macrosystem encompasses the values, laws, customs etc. of the culture (e.g., legislation governing Medicare), and the educational, economic and political systems used in the society (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 1998, 2006).

The seventh system is the chronosystem, which focuses on time and encompasses the timing of key events in the child's life (e.g., age at which child acquired a disability, or entered out-of-home care) and the family's personal history (e.g., outcome of previous attempts at discipline), developmental transitions made by the child, and the historical context.

Bronfenbrenner and Morris's framework was used to organize the reporting of information about children's living conditions and developmental trajectories in Study 1. It was

also used to organize the research model for Study 2 and to organize participants' responses into a model designed to guide the development of support services for young people with a visual or physical disability in Study 3. Details of the way of the framework was adapted in each study will be described in the relevant chapters.

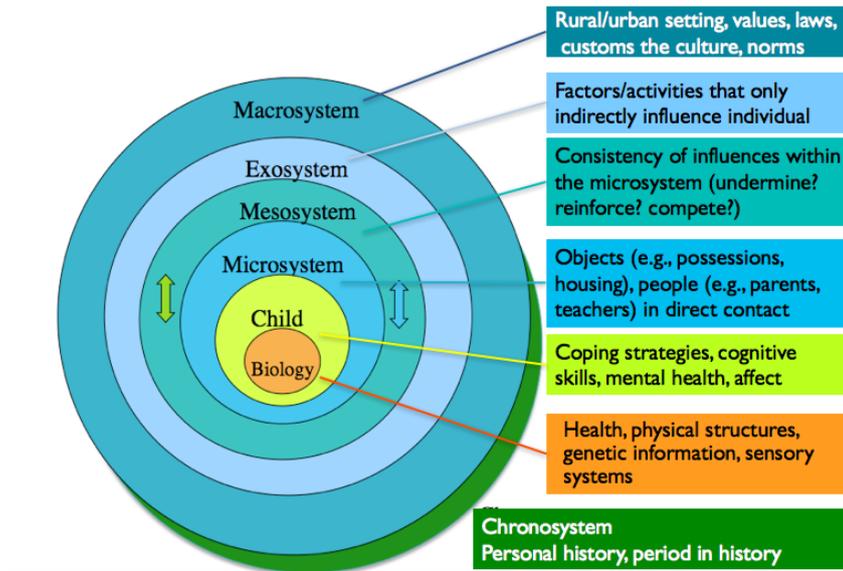


Figure 2.4: Schematic representation of Bronfenbrenner and Morris's bio-ecological framework for the study of child development

## **CHAPTER 3 – RATIONALE FOR RESEARCH METHODOLOGY AND CULTURAL ASPECTS FOR RESEARCH DESIGN**

In the previous chapter, I outlined the background, aims and theoretical framework that guide this program of research. This chapter presents how the research design was derived, and the cultural and scientific issues that guided the selection of the methods. In addition, the timeline for the research program is outlined.

### **3.1 Combination of quantitative and qualitative methods**

The current research seeks to understand psychosocial well-being and the factors that influence this. Thus, the researcher needs to choose between two broad approaches to researching human beings for each study: emic and etic approaches (Lett, 1990). An emic approach seeks to describe the “view from within”, and sometimes referred to as a “bottom-up” approach to understanding phenomena. In contrast, an etic approach is the “view from outside”, and is sometimes referred to as the “outsider’s” perspective or as a “top-down” approach.

In taking an emic approach, researchers seek to put aside information from other contexts in order to let the participants’ experience “speak”. This is to allow new themes, patterns, and concepts to emerge from the participants’ perspective. For example, a researcher may try to put aside information from previous studies about the factors that influence well-being in order to capture the participants’ insights about this issue in their own contexts. Advantages of this approach include the possibility of exploring the “particularity” of the context and individuals being studied, and uncovering unexpected findings.

In contrast, the etic approach uses as its starting point the theories, concepts and empirical findings of previous research, which was necessarily studied with different individuals and/or in a different context. For example, a researcher may use a previously validated scale that assesses the coping strategies used by another population. One of the strengths of the etic approach is that it allows for comparisons to be made across contexts and populations, and for the identification of concepts and findings that apply across settings, contexts and individuals.

Although the two approaches are defined in terms of perspectives rather than methods, the perspectives predispose researchers to selecting differing sets of methods. The emic perspective is predisposed towards the use of qualitative methods while the etic perspective

predisposes towards the use of quantitative methods (Morris, 2008). Although emic and etic approaches and quantitative and qualitative methods are distinct, they can be combined in a single study or in different studies in the same program of research (Tashakkori & Teddlie, 1998; Tashakkori, & Creswell, 2007). This is referred to as “mixed methods” research:

*“Mixed methods research is a research design (or methodology) in which the researcher collects, analyzes, and mixes (integrates or connects) both quantitative and qualitative data in a single study or a multiphase program of inquiry”* (Creswell & Clark, 2011, p. 119).

It is widely believed that the integration of quantitative and qualitative methods provides a more comprehensive analysis of a research problem than using either a quantitative or a qualitative method alone. It has been argued that a mixed methods approach draws upon the strengths of both methods (Johnson & Onwuegbuzie, 2004). Because of this, the mixed methods approach has been widely adopted in mental health and health services research (Palinkas, 2014; Palinkas, Horwitz, Chamberlain, Hurlburt, & Landsverk, 2011; Van den Bergh, 2015). The present program of research employed a mixed methods approach to capitalize on specific strengths of this approach (Pope & Mays, 2008) (Table 3.1)

Table 3.1: Ways in which the strengths of mixed method research design are used in the current program of research

Strength	Used
1. Findings from different methods are checked against each other.	Yes
2. Qualitative research facilitates quantitative research by generating hypotheses for testing or generating items for a questionnaire.	No
3. Quantitative research facilitates qualitative research by identifying people to participate in the qualitative enquiry.	Yes
4. Qualitative and quantitative research are conducted together to provide a bigger or richer picture.	Yes
5. Quantitative research accesses structural issues whereas qualitative research accesses processes.	Yes
6. Quantitative research emphasizes the researchers’ concerns whereas qualitative	Yes

research emphasizes the subjects' concerns.

- |  |     |
|--|-----|
| 7. Quantitative research helps to generalise qualitative findings.                         | Yes |
| 8. Qualitative research facilitates interpretation of findings from quantitative research. | Yes |

The present program of research adopted a mixed methods design not only because of its general advantages ( Table 3.1) but also because it is a particularly effective means of achieving the research objectives. The overall objectives are to examine the level of well-being among young people with visual and physical disabilities in the context of one LAMIC, Vietnam, and to identify some of the factors that may influence this well-being. Adopting an etic approach allows the research to benefit from empirical findings, theoretical framework and measurement instruments developed in previous research on the well-being of other populations of young people. However, there is very little previous research about the well-being of young people with these disabilities in Vietnam or other LAMICs. Reliance on research from high-income countries about young people with other disabilities or about young people facing other challenges would risk failing to identify phenomena and issues that are specific to the target population and context. This limitation can be minimized by supplementing studies that adopt an etic, quantitative approach with a study that adopts an emic qualitative approach and thereby allows young people with these disabilities the opportunity to describe their experience and perceptions in their own words.

The mixed methods approach allows quantitative and qualitative components to be mixed in a variety of ways. Based on the sequence of the components and the emphasis given to each, studies that use a mixed methods approach can be categorized as parallel, sequential or concurrent (Östlund, Kidd, Wengström, & Rowa-Dewar, 2011). Sequential mixed methods research, may allow data from earlier studies in a research program to inform the focus for later studies. One possibility is to conduct quantitative research to identify the core issues, mechanisms or outcomes that subsequently become the focus of in-depth qualitative research (Onwuegbuzie & Teddlie, 2010). The current research used a planned sequential mixed method approach. The findings from early studies were used to refine details in the design of subsequent studies. However, the broad goals and research approach of each of the three studies was planned before the research began.

### **3.1.1 A planned sequence of three studies**

The research program consisted of three studies, all of which were informed by Bronfenbrenner's bio-ecological framework (Bronfenbrenner & Morris, 2006). The first study was designed to provide a rich description of the life circumstances, trajectory of development and psychosocial well-being of Vietnamese children with a visual or a physical disability in the years leading to adolescence, before focusing on adolescents with disabilities in subsequent studies. Study 1 used an etic quantitative approach because this allowed data collection using previously validated measures and the interpretation of data for children with a disability by comparing these to those from a large reference sample of peers without a disability.

In study 2, the focus narrowed to psychosocial well-being and the age range increased to adolescence. These two studies were linked by Bronfenbrenner's proposition that "*the developmental outcomes of today shape the developmental outcomes of tomorrow*" (Bronfenbrenner, 1979, p.191). That is, Study 1 provided information about the prior developmental contexts and trajectories experienced by Vietnamese adolescents with a visual or physical disability. Although the participants in the two studies differed, Study 1 nevertheless provided important background information for understanding the results from Study 2.

Study 3 checked the accuracy and completeness with which Study 2 had identified the factors that predict well-being by capturing young people's perceptions of the factors that influence their well-being in their own words. It also expanded on Study 2 by deriving a model to guide the development of support services for young people with a visual or physical disability that represented their priorities and preferences. To achieve these goals, Study 3 adopted an emic qualitative approach, as this allows a detailed understanding of participants' perspectives to be captured (Curry, Nembhard, & Bradley, 2009). The sequence of research activities and the interrelationships between the three studies are illustrated in Figure 3.1.

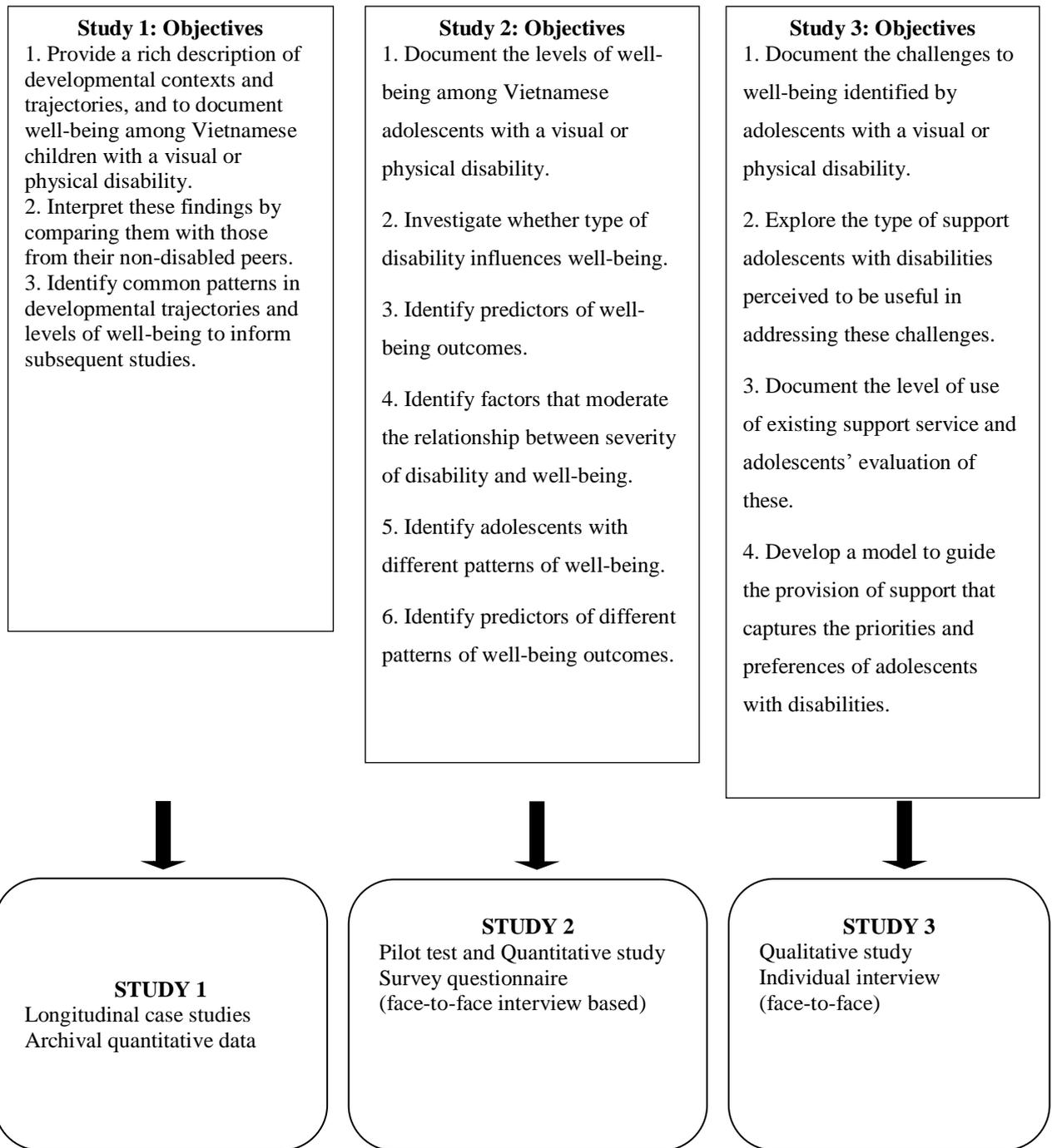


Figure 3.1: The sequence and objectives of three studies in the current program of research

### 3.1.2 Cultural issues

Even though culture remains a ‘woolly concept’ (Chapman, 1997, p.29) it is widely acknowledged to affect the developmental outcomes of individuals in many ways and to influence many aspects of the research process (Matsumoto & Juang, 2008). This section discusses some of the characteristics of Vietnamese culture that may influence the

implementation of the study and interpretation of research findings. Methodological and logistical challenges that arise in the context of Vietnam will also be addressed.

### **3.1.2.1 *Traditional Vietnamese attitudes towards individuals with a disability***

Religion is a salient domain of culture in most contexts. Historically, Buddhism has been the dominant religion in Vietnam (McHale, 2004). It has distinctive beliefs about disability that have been incorporated into Vietnamese's traditional perspectives on disability. In Buddhism, disability is linked to theories of samsara, and cause and effect (D'Antonio & Shin, 2009). Illnesses and physical impairments are a result of individual fate (Cheng, 1990). Life is not a linear journey that ends in death. Instead, only the body perishes, the soul is reincarnated through many cycles. When people engage in evil, there are consequences for their descendants or for themselves in the next life (Hunt, 2002). Accordingly, a person with a disability is often viewed as someone who is being punished for sins that they committed in previous lives or that were committed by their ancestors. As a result, disability is associated with guilt and self-blame. In this context, research focusing on the well-being of Vietnamese young people with a disability is at odds with some of the traditional cultural beliefs in the context in which it is being conducted.

An understanding of traditional Vietnamese attitudes towards disability also informed the choice of predictor variables. Although people with a disability in Vietnam may receive sympathy from others, they can also be the target of discrimination and social exclusion. They may experience discrimination in almost all aspects of life, such as in daily activities, access to health care and other services, sporting and cultural activities, employment and marriage (Le, Khuat & Nguyen, 2008; Green, Davis, Karshmer, Marsh and Straight, 2005). In addition, it is common for a person with a disability to be addressed in a disparaging way by reference to their disability, for example person with a disability can be addressed as 'thằng mù' (blind person), 'thằng què' (limping person), 'đồ dở hơi' (crack-brained person). Social exclusion may also be an everyday event. One traditional superstition in Vietnam is that contact with, or seeing a person with a disability, may bring bad luck. Therefore, people may avoid individuals with a disability when they are walking on the street, and especially before an important departure. In 2008, a study by Le and her colleagues investigating the economic and social situation of people with disabilities in four provinces of Vietnam, indicated that people with disabilities were marginalized and excluded from their local community activities (Le et al.,

2008). In such a context, it was important to include experience of discrimination among the factors that may influence the well-being of Vietnamese young people with a disability.

In addition, these traditional attitudes may also affect the recruitment of participants. Traditionally, people with a disability were kept at home and out-of-sight to avoid public humiliation. It is possible that many young people with a disability continue to receive support only from members of their own families. Therefore, specific recruitment strategies were needed to identify and recruit such young people who could not be contacted through disability support services. Other families avoid public humiliation and the high workload of care that may be associated with raising a child with a disability by relinquishing the child's care to a Buddhist pagoda. Ironically, as a result, Buddhism also provides one of the main sites for support services for young people with a disability. In Vietnam, Buddhist temples are an important and distinctive site for the education and care of children with visual, physical and other disabilities. Because this type of site had not been studied in research in Western countries. Buddhist pagodas that provide support services to young people with a disability were a special target for recruitment in the current study. Christian churches also sponsor a number of important support services for young people with a disability in Vietnam. They too were targeted during recruitment.

However, modern perspectives on disability are overtaking traditional beliefs. The modern perspective on disabilities in Vietnam views many people with disabilities as victims of war and the weapons used in wars (Hunt, 2002). Many heroes of Vietnam's fight for independence became disabled during those conflicts. There is also widespread understanding of the ongoing consequences of the environment contamination resulting from past armed conflicts (e.g., Agent Orange and Dioxin) on disability. In addition, the Vietnamese government is actively attempting to change traditional attitudes by being proactive in passing legislation and signing international agreements that protect the rights of disabled people (Rosenthal, 2009).

### **3.1.2.2 *Collectivism and the role of the family***

Traditional Vietnamese culture is characterized by collectivism. In contrast to individualist cultures, collectivist cultures emphasizes an interdependent construal of self and the "*fundamental connectedness of human beings*" (Matsumoto & Juang, 2008, p.334). For example, people in collectivist societies tend to have self-identities that are inseparable from

their social relationships and their living context (Markus & Kitayama, 1991). In addition, they socialize to understand other peoples' minds, to sympathize, to act appropriately and to adjust themselves to fit into the communities to which they belong (Matsumoto & Juang, 2008).

Because they live in a collectivist culture, people with disabilities in Vietnam are likely to be strongly affected by their living context and the people around them (Craig, 1994) (Figure 3.2). It is therefore particularly important for researchers to understand the living contexts of individuals with disabilities when investigating their well-being and developmental trajectories. This is one of the reasons why the first study in the current research focused on providing a rich description of the developmental context of Vietnamese children with disabilities and why it was important to include a measure of the support provided by multiple sources among the predictors of well-being in Study 2.

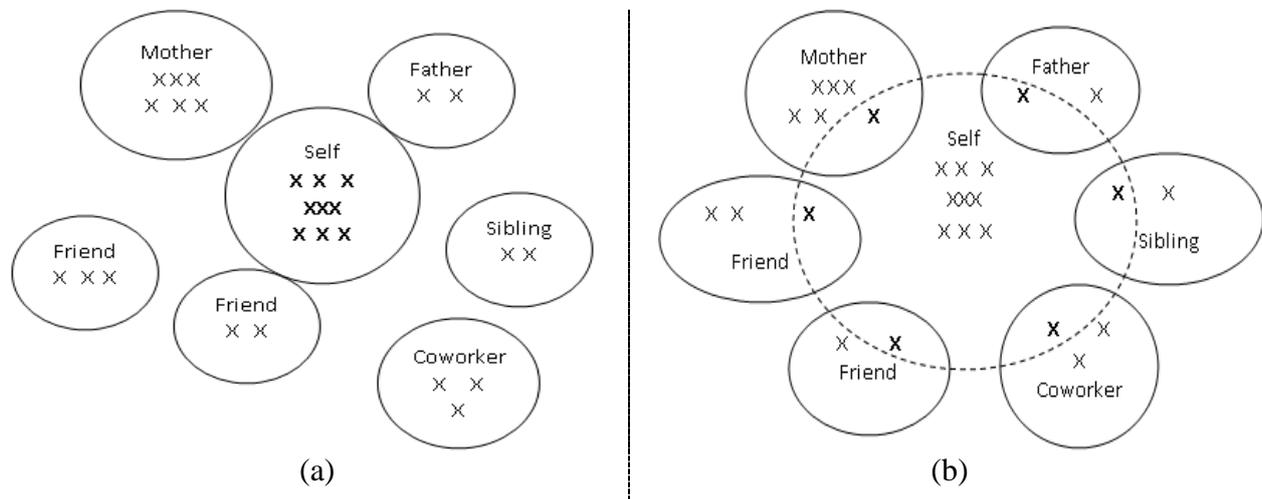


Figure 3.2: Independent (a) and Interdependent (b) construal of the self by people in individualist and collectivist cultures, respectively.

Although many foreign institutions influence Vietnamese culture, the family has remained one of its core institutions. In Vietnam, it continues to be common for many generations of a family to share a house and for socialization of children to promote values of harmony, support and duty to the family instead of the pursuit of individual desires. Parents are expected to take responsibility for the care of their children until their children get married. Siblings are also expected to support each other financially, emotionally and with practical caregiving. The family is considered to be the main service provider for people with disabilities, regardless of age or social status (Stone, 2005). This leads to two distinctive characteristics of the situation in Vietnam: (1) It is not an expectation that most people with

disabilities will live independently, unless they marry; (2) Many children with disabilities who receive residential support from external service have been abandoned by their families.

Because cultural norms do not support families relinquishing the care of children, when this is done, it is often done secretly. In this context, it is not possible for the child to maintain contact with other family members. Thus, young people with a disability who are in residential care often have no access to the social institution, the family, that provides the main social safety net in Vietnam. It was therefore important to include out-of-home care as a predictor of well-being in Study 2.

The collectivist cultural context also influenced the way constructs were measured. In collectivist cultures, there is a tendency to avoid reporting negative experiences caused by others because this is a threat to social harmony (Matsumoto & Juang, 2008). This tendency compounds the esteem maintenance mechanisms that often prevent people in both individualist and collectivist cultures from admitting that they are targets of teasing, social exclusion or discrimination (Tesser, 2000). One result of this mechanism is that research participants often under-report negative behaviour directed towards themselves but accurately report on negative behaviour towards others in their group (Wright, Taylor, Moghaddam, & Lalonde, 1990). To avoid this “personal-group discrepancy”, in Study 1, children were asked to report on physical punishment directed toward their classmate rather than the physical punishment that they personally received. Similarly, in Study 2, the wording of the measure of discrimination was modified to refer to other members of their group.

### **3.1.2.3 Culturally appropriate measures**

One of the obstacles to conducting research in LAMICs is that few measures have been validated in these countries. Very few of the measures used in the current research had been used in previous research in Vietnam. This had three consequences for the present research. First, it was necessary to test the acceptability and appropriateness of the measures in a pilot study. Second, it was important to interpret the data in comparison to a reference group of young people in Vietnam who did not have a disability whenever this was possible. Third, the meaning of data needed to be interpreted with caution. For example, the ability to interpret scores obtained on measures of well-being in comparison with published norms for the general population was limited due to a lack of cut-points for these measures in the Vietnamese context. Therefore, in Study 2, such interpretation was restricted to depression and anxiety scores, for which preliminary Vietnamese data were available. However, it should be noted that

cut-points for these measures in the Vietnamese population are still under review (Tran, & Fisher, 2013).

In summary, the distinctive characteristics of the Vietnamese cultural context needed to be accommodated in the research methods and processes, and need to be remembered when interpreting the findings of the research.

### **3.1.3 Ethics approval and timeline of research activities**

All three studies in this research program were conducted with approval from relevant research and ethics bodies. Study 1 used archival data from *the Young Lives* project which was granted ethics approval from the London School of Hygiene and Tropical Medicine Ethics Committee, the Social Science Division of Oxford University, Reading University UK and relevant ethics bodies in each of the countries involved in the study (Tuan et al., 2003). In Vietnam, ethical approval for the *Young Lives* project was also granted by the Vietnam Union of Science and Technology Associations (Tuan et al., 2003).

Ethics approval for Studies 2 and Study 3 was sought simultaneously from the Social and Behavioural Research Ethics Committee of Flinders University. The research activities were divided into two phases, each with a separate ethics application. The first application was for the first field trip to Vietnam, which had two aims: (1) to identify and recruit service providers for adolescents with visual and physical disabilities; (2) to conduct a pilot study using the measures that were planned for Study 2. The Committee granted full approval for the project on December 19<sup>th</sup>, 2013 (Project number 6356).

The second ethics application was for Studies 2 and 3, as these two studies involved the same sample of participants. Study 2 involved the collection data from a large sample of adolescents with visual and physical disabilities using a quantitative survey. Data collection took place in four provinces (Ho Chi Minh, Ben Tre, Thua Thien Hue and Da Nang). In Study 3, interviews with a subset of the participants in Study 2 captured the perceptions of adolescents with the two types of disabilities in their own words. I obtained the full ethics approval for these two studies on June 16<sup>th</sup> 2014 (project number 6486). A minor modification of the procedure became necessary after my arrival in Vietnam. This modification was accepted on August 22<sup>nd</sup> 2014. The ethics permission for conducting the study is valid until January 31st 2018.

The research needed no additional ethics approval from authorities from Vietnam. This was confirmed through email correspondence with the Vietnamese Embassy in Canberra,

Australia and confirmed again during the field trip to Vietnam in January 2014. Only written consent from formal service providers (or families in cases where there was no formal service provider), and from participants (or their guardians if they were under 18 years of age) were needed. The timelines for the ethics applications, data collection and data analyses process are provided in Table 3.2 and Figure 3.3 respectively.

Table 3.2: Timeline for ethics approval for Studies 2 and 3

<b>Project number</b>	<b>Month, Year</b>	<b>Milestone</b>
6356	November, 2013	Application submitted
	November, 2013	Conditional approval
	December, 2013	Meeting with the Chair of the Ethics Committee
	December, 2013	Full approval
6486	April, 2014	Application submitted
	May, 2014	Conditional approval
	June, 2014	Full approval
	August, 2014	Modification request
	August, 2014	Full approval

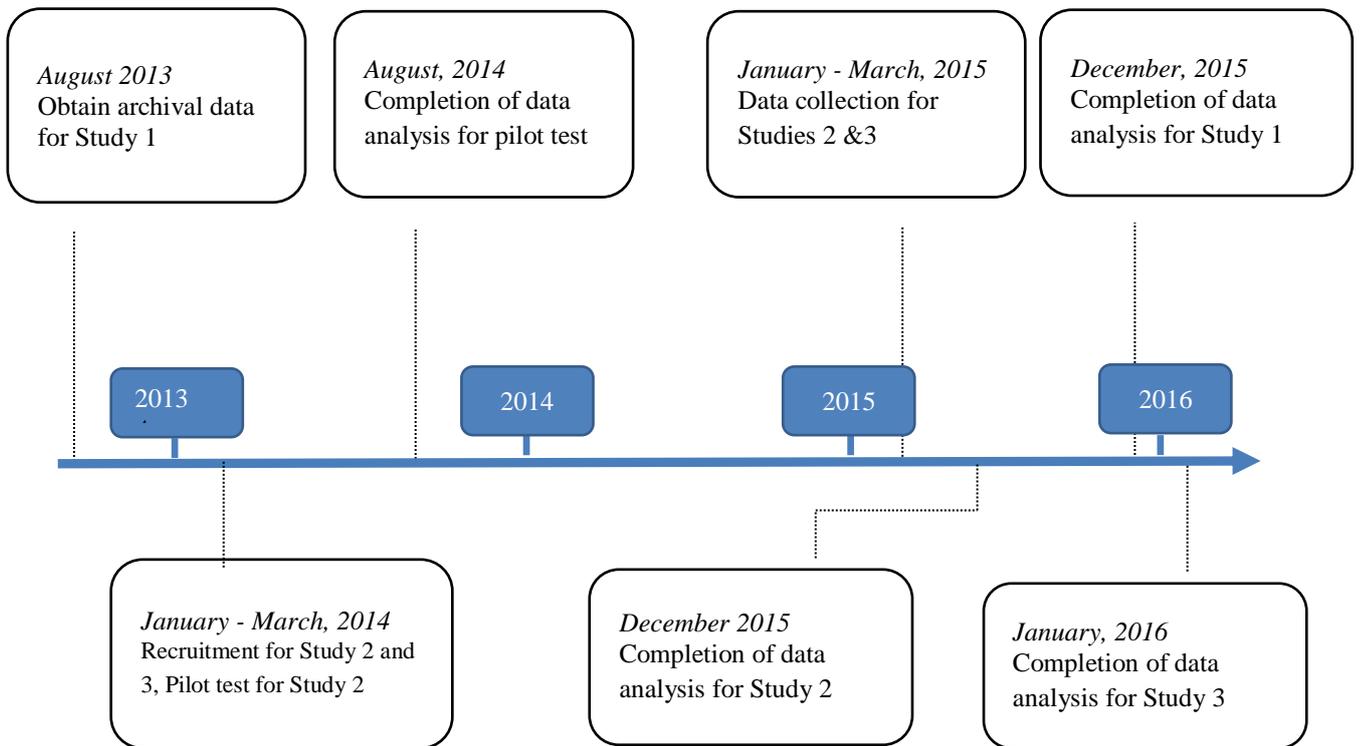


Figure 3.3: Timeline of data collection and analysis for the program of research

### 3.1.4 Summary

This chapter provided the reasoning behind the choice of a mixed methods research design, described the ways in which aspects of Vietnamese culture influenced the choice of variables and research procedures, and outlined the sequences of research activities.

# CHAPTER 4 - STUDY 1: LONGITUDINAL CASE STUDIES EXAMINING DEVELOPMENTAL CONTEXTS AND DEVELOPMENTAL OUTCOMES FOR VIETNAMESE CHILDREN WITH A VISUAL OR PHYSICAL DISABILITY

*"The developmental outcomes of today shape the developmental outcomes of tomorrow"*  
(Bronfenbrenner, 1979, p.191).

## 4.1 Abstract

The current program of research focused on the well-being of adolescents with visual and physical disabilities in Vietnam. However, Study 1 was conducted to provide insights into the developmental circumstances of this population when they were children. Specifically, a series of longitudinal case studies are presented to describe developmental contexts and trajectories among children with visual (n = 6) and physical disabilities (n = 5) in the years leading up to adolescence. Bronfenbrenner and Morris's bio-ecological framework was employed to organize this information. Data from a large sample of peers without a disability (n = 1753) was used to aid interpretation of the results. Both groups of children were assessed at 1 year, 5 years and 8 years of age as a part of the *Young Lives* study. Results indicated that although many children in both groups were raised in difficult circumstances, the majority of children with a disability showed particularly high levels of material deprivation and low levels of physical and cognitive development. The study portrayed both the uniqueness of each child's circumstances, and the common patterns observed across children. These served to inform Studies 2 and 3, which focused on adolescence.

## 4.2 Introduction

### 4.2.1 Model of disability

The way in which populations and phenomena are defined can greatly influence the outcomes of a field of research. In particular, different conceptions about disability can lead to very different conclusions about its prevalence, and the nature and extent to which particular interventions and support services are provided and judged to be effective. Because of the important role it plays in determining the outcomes of research, one of the first tasks of the researcher is to choose the most appropriate definition of disability.

Currently, the two most frequently reported approaches to defining disability reflect medical/biological and bio-psycho-social models. The medical model views disability as a "biological condition" (e.g., blindness, paraplegia) located in the individual. This perspective

therefore focuses attention on the affected individual and promotes interventions designed to eliminate or compensate for his/her biological condition (e.g., through use of medical technology, medicines, and rehabilitation) (World Health Organisation, 2012). One of the strengths of this perspective is that it provides a medical explanation for conditions that were often previously attributed to spiritual causes, and in doing so, has often reduced the stigma associated with disability. It also promoted research in technological innovations (e.g., in improved prostheses and electronic aids) that have significantly improved the quality of life for many people with a disability. The medical model also has a number of pragmatic advantages. It allows cases of disability to be calculated from medical records, or from participant's responses to checklists of diagnoses that typically result in disability, and this allows policy makers and service providers to anticipate demand for specific services (e.g., wheelchairs, hearing aids). However, this approach has significant limitations. No list of diagnoses will be comprehensive of all conditions that can result in disability, and most conditions can lead to disability of differing severity, depending on the aids available and the environmental context (e.g., refractive errors may lead to severe visual impairment in the absence of corrective lenses, but may lead to very little visual impairment when corrective lenses are available). Despite this, several major studies, such as the Global Burden of Disease study, continue to use a medical model of disability (e.g., GBD 2016 DALYs and HALE Collaborators, 2017).

Recognition of the shortcomings of the medical model prompted the development of a bio-psycho-social model of disability. This integrates the concept of a physical impairment (from the medical model) with an appreciation of the extent to which the environmental context contributes to the extent to which a specific impairment impairs functioning in everyday tasks and limits participation in social, educational and employment opportunities. The bio-psycho-social model perceives disability to be the outcome of the interaction between the person with an impairment and environments that contain higher or lower levels of physical, attitudinal, communication and social barriers. One consequence of this perspective is that disability cannot be assessed solely on the basis of the physical impairment. It can more directly be assessed through consideration of the extent to which a person experiences impaired functioning in everyday tasks (e.g., walking, seeing) and to which their participation in social, educational and employment opportunities is limited. One of the advantages of the bio-psycho-social model is that it promotes consideration of the ways in which changes to context can reduce the extent of disability even in contexts in which the physical impairment cannot be modified (World Health Organisation, 2001). In addition, the model promotes the recognition

that individuals with a physical impairment often have unimpaired functioning and participation in many domains. This recognition has been the basis for advocacy for equal rights that has improved the access to education, employment and leisure activities for many people with a disability.

Despite these advantages, the bio-psycho-social model of disability also has a number of limitations. In particular, it presents a number of pragmatic measurement challenges. First, regardless of whether an individual has a medically diagnosed condition, the extent of impairment in multiple domains of functioning and limitation in multiple domains of activity should be assessed. This greatly increases the time and cost for population-based surveys and censuses. Second, the accuracy with which disability is identified in surveys and censuses can be questioned because individuals and cultures differ in the ways in which they respond to rating scales. The consequence is that it is difficult to set a cut-off score for the identification of persons with a disability in studies that aim to determine disability prevalence. Third, the social model allows for different claims about the importance of environmental settings, and of domains of functioning (walking, seeing, concentrating etc.). The first of these may lead to the biased judgement that social setting is dominant over physical impairment in causing disability (Adam, 2007). In summary, many of the limitations of the bio-psycho-social perspective are most relevant to population-based surveys and censuses. The perspective has greater advantages than disadvantages in contexts in which clinical assessment of disability in individuals is possible.

Therefore, this thesis adopts the bio-psycho-social perspective on disability proposed by the World Health Organization:

*Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. (World Health Organisation, 2013a, p. 1)*

Importantly, this model distinguishes between ‘impairment’ and ‘disability’ (Figure 2.1). Impairment is used to refer to the physical attributes (or loss of attributes) of a person, for instance limbs, or senses. Disability results when society is unable to give sufficient accommodation to the needs of the individual with the impairment (Figure 2.1). This perspective opens the possibility that the well-being of adolescents with disabilities may improved through improving the support they receive s and by changing their living

environments in ways that allow greater social participation, even if it is not feasible to overcome their physical impairment. Therefore, this perspective is also most consistent with the overall aim of this thesis, which is to apply psychological knowledge to support the well-being of young people with disabilities without attempting to modify their physical impairment. Because the WHO definition of disability underlies the *International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY)* (World Health Organisation, 2007) and the World Health Organisation's *Disability Assessment Schedule 2.0* (World Health Organisation, 2013b), these were adopted in the main study in this thesis.

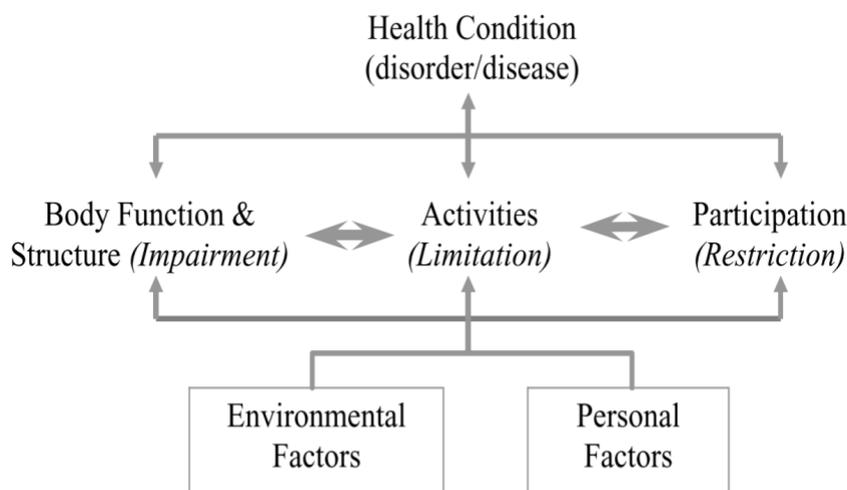


Figure 2.1: The World Health Organization model of disability (World Health Organisation, 2001)

#### 4.2.2 Gap in research in adolescents with visual and physical disabilities

As mentioned earlier, the prevalence and pattern of disability differs markedly between high-income countries and LAMICs. Although both high-income and LAMICs have highest disability prevalence in the older group because of increasing age people develop disability due to chronic diseases and sensory impairments (World Health Organization, 2004, 2011a), LAMICs have more number of young people with disability than high-income countries (The World Bank, 2006; United Nations, 2011). The UN estimates that over 80% (150 out of 180 million) of the worldwide population of people with a disability aged 10-24 years live in LAMICs (United Nations, 1990a). Recently, the Global Burden of Disease study reported similar results based on available data sources across 17 subregions of the world (World Health

Organization, 2008). Accordingly, disability prevalence for children 0-14 years of age who has moderate or severe disability in high-income countries was 2.8%, while this number for LAMICs ranked from over 4% to 6.4% over six regions of the world (World Health Organization, 2011a). Physical and visual are the most common disability types (Braithwaite, Carroll, Mont, & Peffley, May, 2008; Takamine, 2004; UNICEF, 2013; United Nations, 2012a). In the Asia-Pacific region, for example, 78% of people with disabilities have a physical or a sensory disability (United Nations, 2012b). This prevalence is even higher in some parts of Africa (World Health Organization, 2004).

The high prevalence of sensory and physical disabilities among young people in LAMICs is the consequence of a combination of several distinctive circumstances. First, non-communicable diseases are a major cause of disability in LAMICs, which bear nearly 90% of the world's non-communicable diseases burden (United Nations, 2012a). Second, young people in LAMICs have an elevated risk of acquiring injuries caused by road traffic accidents and natural disasters (United Nations, 2012a). Third, in the last 50 years, many LAMICs have experienced at least one form of armed conflict. Even after these conflicts end, they often leave unexploded landmines and ordinance and environments contaminated with chemicals such as Agent Orange/Dioxin (Kett & Ommeren, 2009; Tamashiro, 2010; Tuyet-Hanh et al., 2010). The cumulative result is many millions of young people with sensory and physical disabilities can be found in LAMICs.

Despite the large number of young people with disabilities in LAMICs, research on this population has largely been neglected (Groce, 2004; UNICEF, 1999). They have been described as the disabled population about whom “*we know the least*” (Groce, 2004, p.13). This is because the majority of disability research has been conducted in high-income countries and has focused on hearing and intellectual disability (Maulik & Darmstadt, 2007). People with disabilities living in LAMICs have been identified as a major target for future research (UNICEF, 1999). Fujiura, Park, and Rutkowski-Kmitta (2005) stated:

*The imbalance between the sheer size of the developing world and what little is known about the lives and life circumstances of persons with disabilities living there should command our attention (Fujiura et al., 2005, p. 259).*

Two gaps in our knowledge about this population concern the conditions in which they live and their physical and psychological development during childhood. Previous studies on

disability have focused on the economic and social difficulties experienced by families with children with a disability (Brinchann, 1999; Read, 2000), or on these children's relationship with key adults in their lives (Davis & Watson, 2001). However, without an understanding of the living conditions and development of children with a disability in LAMICs, service providers, policymakers and other stakeholders lack sufficient foundation to make informed decisions to improve their life circumstances and well-being, and the advancement of theory is constrained (Mont & Cuong, 2011). The current study addressed this gap and provided background information for Studies 2 and 3, by investigating developmental contexts and developmental trajectories among children with visual and physical disabilities in a particular middle-income country with a legacy of war, Vietnam.

### **4.2.3 Vietnam and its disability situation**

Vietnam is a useful setting to explore the lived experiences of children with a physical and visual disability in LAMICs. It shares many common characteristics with other LAMICs. First, it has a large number of people with disabilities (National Coordinating Council on Disability, 2010; Takamine, 2004; The Department of United Nations Population Investigation in Vietnam, 2011). Although there is no recent data about the prevalence of confirmed disability cases in Vietnam, it is estimated that this proportion remains high (15.2% in 2004 (Takamine, 2004), 13.5% in 2006 (Mey, 2011) and 15.3% in 2007 (Ministry of Planning and Investment, 2007)). Second, the majority of people with a disability are young as 50 % are 6-12 years of age (The Department of United Nations Population Investigation in Vietnam, 2011). Third, the proportion of people who have an acquired disability is high: 90% of Vietnamese children with disabilities become disabled after five years of age (UNICEF, 2006). Fourth, wars during the 20th century have left Vietnam with a legacy of landmines, unexplored ordnances and environmental contamination, which continue to contribute to disability prevalence. Fifth, as in other LAMICs, the most common types of disabilities in Vietnam are visual and physical disabilities, which together account for over 50% of all disabilities (Figure 2.3). However, there is little research about the life of young people with visual and physical disabilities in Vietnam (UNICEF, 2010).

#### 4.2.4 Theoretical framework: Bronfenbrenner and Morris's bio-ecological framework

Bronfenbrenner and Morris's bio-ecological theory was deemed to provide the most suitable framework for investigating the developmental context and outcomes for Vietnamese children with disabilities. In contrast to other frameworks, which usually concentrate only on the hierarchy of factors influencing a child's development (e.g., Maslow, 1943), the distinctive characteristics of Bronfenbrenner and Morris's framework are "multiperson systems of interaction" and the bi-directional developmental effects of the interrelations between persons and their environments (Bronfenbrenner, 1979, p.21). The acknowledgement in this framework that these interactions vary across time makes it particularly appropriate for longitudinal research.

The bio-ecological framework provided a useful structure for organizing the variables included in this study (Bronfenbrenner & Morris, 2006).

- (1) The innermost system in the framework is the **Biosystem**. This study focused on four aspects of the child's biosystem (age, gender and type of impairment), and documented the developmental trajectory for one biosystem domain (physical growth).
- (2) At the heart of this framework is the child with his/her unique psychological strengths and weaknesses, skills, beliefs and attitudes. This study focused on the children's evaluation of their safety during out-of-home activities, and documented the developmental trajectory for two child system domains: cognitive skills and psychosocial well-being.
- (3) The **Microsystems** consists of settings, objects and agents with whom the child directly interacts (Figure 2.5). This study focused on the quality of the children's housing, the quality and quantity of household possessions and preschool and school attendance.
- (4) The **Exosystem** consists of "the interrelations among two or more settings in which the developing person actively participates" (Bronfenbrenner, 1979, p.25). These include the resources, beliefs, and attitudes of agents in the child's microsystem that influence the child indirectly by shaping events and the behaviour of agents in the child's microsystem. In this study, parents' trust in the local community was assessed.

- (5) The **Macrosystem** comprises cultural characteristics, cultural values, customs, laws and public policies, community infrastructure, and other community- or nation-wide conditions. The current study collected data on rural/urban location, language, religion, and ethnic group membership.

In summary, the developmental contexts of children with visual and physical disabilities were investigated by examining their microsystem from the perspective of the child's access to material capital (number of rooms in house, household crowding, wealth, electricity access, and toilet access) and social capital (education level of household head, pre-school attendance, school attendance). In addition, seven other characteristics of children's developmental contexts were examined using variables drawn from the biosystem (sex, age, impairment) and macrosystem (urban/rural location, language, religion and ethnic group membership). Developmental trajectories were assessed by examining changes over time in developmental outcomes in two domains. In the biosystem, physical development (stunting, wasting) was assessed, while in the child system, cognitive development (vocabulary, basic quantitative skills, basic mathematical skills) was assessed. The study also examined the children's psychosocial well-being (life satisfaction).

Several earlier studies of children with a disability have also employed Bronfenbrenner and Morris's model (Ben-David & Nel, 2013; Sontag, 1996). For example, Rous, Hallam, Harbin, McCormick, and Jung (2007) used Bronfenbrenner and Morris's model to describe how complex interactions between multiple factors influenced transitions among young children with disabilities. More recently, Ben-David and Nel (2013) applied Bronfenbrenner and Morris's model to guide their investigation of challenges facing children with physical disabilities in Kwa-Zulu Natal, in South Africa. In the current study, use of Bronfenbrenner and Morris's model allowed an exploration of "development and child outcomes as an interaction between the developing child, his/her environmental context, and the timing of the particular process being examined", which has been identified as a need in research (Rous et al., 2007, p. 138).

### **4.3 Research objectives**

The overall aim of this study was to describe developmental and living circumstances of Vietnamese children with a visual or physical disability. This was achieved through fulfilling three objectives:

1. To describe developmental contexts of Vietnamese children with a visual or physical disability;
2. To describe the trajectories of physical and cognitive development and the psychosocial wellbeing of these children across three time points (1, 5 and 8 years of age),
3. To identify diversity and commonalities in the developmental context and trajectories across children.

## **4.4 Methods**

### **4.4.1 Research design**

The study adopted a longitudinal quantitative case study approach. Data from children without disabilities were used as reference points when interpreting the findings for children with disabilities.

### **4.4.2 Participants and research sites**

#### **4.4.2.1 Origin of the data: The Young Lives study**

This study used archival data from the younger Vietnamese cohort in the *Young Lives* study<sup>1</sup>. This cohort included 2000 infants recruited from 20 sentinel sites across Vietnam. These children were followed from infancy through to mid-childhood. The sample for the current study consists of the eleven children with either a visual or physical disability who participated in the *Young Lives* study. *Young Lives* provides the only longitudinal research on children's development in LAMICs that is available to other researchers.

**Selecting sentinel sites.** The *Young Lives* team divided Vietnam into nine zones on the basis of their socio-economic development. Then they selected five of these zones using four criteria: (1) geographically inclusive. Samples were drawn from each of three geographic zones in Vietnam: the North, Centre, and South (2) inclusive of three different levels of economic development: urban, rural, and remote mountainous areas; (3) over-sampling of children from poor families; and (4) inclusive of some unique areas of the country, such as those affected by natural disaster and war (Tuan et al., September 2003). Thus, the study attempted to capture the

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<sup>1</sup> The data used in this study come from Young Lives, a 15-year study of the changing nature of childhood poverty in Ethiopia, India (Andhra Pradesh), Peru and Vietnam ([www.younglives.org.uk](http://www.younglives.org.uk)). Young Lives is funded by UK aid from the Department for International Development with co-funding by the Netherlands Ministry of Foreign Affairs, and Irish Aid.

diversity in the Vietnamese population but did not attempt to recruit a nationally representative sample.

Within the five selected zones, the *Young Lives* project used a process that combined random and purposive sampling. They selected one province from each of the five zones. Then, four sentinel sites were selected from each province. Based upon the size of population, each sentinel site consisted of 2-4 communes. In Vietnam, each province consists of many communes. A commune has a local government, primary school, commune health centre, post office and a market. Its average population is approximately 7000 persons (+/- 4000). In cases in which the selected commune had insufficient numbers of one-year-old children at the time of recruitment, a neighbouring commune with similar socio-economic conditions was also selected to reach the quota of index children. In total, there were 31 communes representing 20 sentinel sites (Tuan et al., 2003). In the next step, all children living in the sentinel sites who were born in January 2000 to the date of survey in the year 200 were identified in a survey (April to June 2002). A random sample of 100 children aged 6-17.9 months in each of 20 sentinel sites was invited to participate. The non-response rate was less than two percent (36 out of 3000 of families declined the invitation). Replacement sampling was used whenever an invitation was declined in order to reach the quota of index children (Tuan et al., 2003). The result of this process was the selection 2000 participants in Round 1 (when participants were infants) from Lao Cai (North-East region), Hung Yen (Red River Delta), Da Nang (City affected by past conflicts), Phu Yen (South Central Coast), and Ben Tre (Mekong River Delta) (Figure 4.1).

As mentioned earlier, the sampling strategy ensured that the *Young Lives* sample was not nationally representative of children in Vietnam. However, a comparison between indicators collected by the *Young Lives* study and those from the nationally representative Vietnam Household Living Standards Survey (VHLSS) suggested that the *Young Lives* sample remained broadly representative of the Vietnamese population (Glewwe, Chen, Katare, 2012).

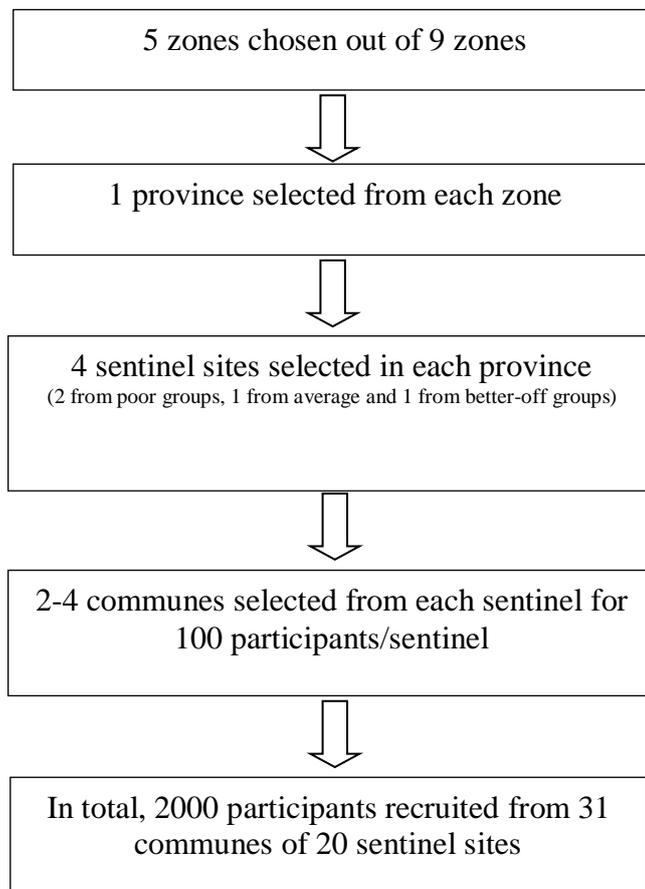


Figure 4.1: Derivation of the sample recruitment for the *Young Lives* study

#### 4.4.2.2 **Sample in the current study**

Two samples were drawn from the 1970 children for whom data were available in Round 2 (when the children were around 5 years of age): a sample of children with a physical or a visual disability ( $n = 11$ ) and a reference sample of children without a disability or long-term health problems ( $n = 1753$ ). Data for these children were available at three time points: during infancy (hereafter referred to as 1 year of age), and at 5 and 8 years of age.

Children with a disability were identified by parent-report when the children were 4-5 years of age. In accord with the WHO definition, the questions that identified disability asked about the child's functioning rather than about specific medical conditions, and ensured that transitory impaired functioning was not reported. Parents who answered "Yes" to the question, "Does the child have long-term problems?" were asked follow-up questions to clarify whether

this problem impaired one of the six key domains of functioning identified by WHO (walking: “Can child walk?; self-care: “...move arms and legs?; vision: “...see?”; hearing: ‘...hear?’; communication: “...speak/understand others?; concentration and remembering: “...learn to do things?”). The use of questions that required a “Yes/No” categorical response is likely to have excluded children with mild or moderate disabilities. Children whose parents indicated that they could not see formed the “visual disability” group. Children whose parents indicated that they could not walk, or that they could not move one or more arms or legs, formed the “physical disability” group. It should be noted that many of the underlying physical conditions that led to long-term impaired functioning among children in the *Young Lives Study* are unlikely to have had this result in a high-income country. For example, even 20 years after the children in the *Young Lives Study* were born, many children in Vietnam with myopia (near-sightedness) and other refractive errors do not have access to corrective lenses during their childhood (Limburg et al, 2012). It is therefore possible that some children with uncorrected severe refractive errors were correctly judged by their parents as being unable to see and were therefore included in the visually disabled group in this study. This outcome is consistent with the WHO conception of disability, which focuses on impaired functioning rather than the nature of the underlying medical condition.

The reference sample of children without a disability was created by excluding all participants with other types of disability and long-term health problems. This resulted in a reference sample of 1753 children without disability.

As the *Young Lives* study focused on poverty, the majority of the sample lived in rural areas. This was also reflected in the sample of children with disabilities. Nine out of the eleven children with a disability were located in rural or remote areas. Two children belonged to a minority ethnic group (H’Mong) while the rest were Kinh (Table 4.1). Despite the long history of Buddhism in Vietnam, the majority of parents reported that they had no religion (8/11), which was in line with the current communist political philosophy. The average age of the children at each of the three time points is shown in Table 4.2.

One noteworthy characteristic of the sample of children with a disability is that all eleven children had an adventitious (i.e., postnatally acquired) disability. That is, because of disease or injury, they acquired their disability between infancy and 5 years of age<sup>2</sup>. Such a

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<sup>2</sup> It can be concluded that all of the children in this study had acquired their disability postnatally because none of the parents who identified that their child had a physical or visual disability when the children were 8-9 years of age indicated that their child had a “long term problem” when their child was approximately 12 months of age. Because the screening questions identified only those children who

pattern is not typical in high-income countries but it is consistent with previous reports showing that globally approximately 90% of children with disabilities in LAMICs become disabled after birth (UNICEF, 2006). However, it is unusual that none of the children had a congenital disability resulting from exposure to Agent Orange, despite Da Nang being a site for recruitment. There appear to be two likely explanations for the absence of congenital disabilities in the current sample: (1) children born with congenital disabilities might not have been invited to participate in the study or parents of those children declined the invitation to participate; and (2) Children with congenital disabilities had a very high mortality rate between their recruitment in infancy and 5 years of age, when the sample for the current study was selected. Data collected during infancy suggests that the former reason is most likely. No participants in the *Young Lives* study acquired a disability between 5 and 8 years of age.

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had severe visual or physical disabilities, it is highly unlikely that parents were unaware that their child had a disability at 12 months of age if it had been present from birth.

Table 4.1: Demographic characteristics of the sample with disability and the reference sample without a disability

Sample	Location (%)	Language (%)	Ethnicity (%)	Religion (%)
Disabled (n = 11)	Rural 81.8	Vietnamese 81.8	Kinh 81.8	No religion 81.8
		H'Mong 18.2	H'Mong 18.2	Cao Dai 18.2
Non-disabled (n = 1753)	Rural 80.6	Vietnamese 86.4	Kinh 84.9	No religion 72.7
		H'Mong 5.8	H'Mong 5.9	Buddhist 18.2
		Dao 1.7	Dao 1.9	Ancestorworship 9.1
		Tay 1.5	Tay 1.8	Christian, Cao dai and others 2.2
		Nung 0.9	Nung 1.5	
	Other 2.7	E'de 0.1		

Note. n = Numbers of participants.

Table 4.2: Ages at three data collection points for the sample with a visual or physical disability and the reference sample without a disability

Data point and sample	Child age (years)	
	M	(SD)
Infancy		
Disabled	1.00	(0.25)
Non-disabled	0.97	(0.27)
5 years		
Disabled	5.20	(0.43)
Non-disabled	5.30	(0.32)
8 years		
Disabled	8.18	(0.29)
Non-disabled	8.09	(0.31)

Note. M = Mean; SD = Standard deviation

### 4.4.3 Measures and procedure

Not all the variables relevant to developmental context and developmental trajectories could be investigated at all three ages. The data collection plan used in the *Young Lives* study is outlined in Table 4.3.

Table 4.3: Data collection plan for variables investigated in Study 1

Variable	Three waves of data collection		
	1 year (2002)	5 years (2006)	8 years (2009)
Developmental context			
Biosystem			
Gender	X		
Age	X	X	X
Type of impairment	X	X	X
Microsystem			
Material capital			
Wealth Index score	X	X	X
Number of rooms		X	
Household size		X	
Electricity access		X	
Toilet access		X	
Social capital			
Education level of household head		X	
Preschool attendance		X	
School attendance			X

Exsosome				
	Parents' perceptions of safety	X	X	X
Macrosystem				
	Urban/rural location	X		
	Ethnicity		X	
	Language		X	
Child outcomes				
Biosystem				
	Faltering of physical growth			
	Stunting	X	X	X
	Wasting	X	X	
Child system				
	Language skills			
	Vocabulary (PPVT-III)		X	X
	Reading (EGRA)			X
	Numeracy skills			
	Basic numeracy skills (CDA-Q)		X	
	Basic mathematical skills (IEA)			X
	Psychosocial well-being			
	Current life satisfaction		X	X
	Expected future life satisfaction		X	

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Note. PPVT III = Peabody Picture Vocabulary Test - Third edition, EGRA = Early Grade Reading Assessment, CDA-Q = Cognitive development Assessment-Quantity, IEA = Test developed by International Evaluation Association.

**Developmental context.** The quality of two domains of children's developmental context was assessed: material capital and social capital. Material capital was assessed using five variables: wealth index, number of rooms in the house, household size (e.g., number of people living in the house), access to electricity and access to a toilet.

The wealth index is a composite measure that allows direct comparisons of wealth over time regardless of economic inflation. It is a simple average of three equally weighted elements: housing quality, consumer durables and access to services. Each of these individual indexes is made up of a subset of items. Specifically, housing quality was the simple average of the number of rooms per person and scores for the quality of the wall, roof and floor materials. The consumer durables score was the scaled sum of household possessions such as a radio, refrigerator, bicycle, motorcycle, car, mobile telephone, landline telephone, fans and a television. Quality of access to services was the simple average of scores for access to drinking water, electricity, toilet and fuel (e.g., if the household is able to use gas, electricity, kerosene or paraffin for cooking). Data about the number of rooms, household size, electricity access and toilet access were obtained by parent reports on single-item measures, except the wealth index. The wealth index is scored on the index range between 0 and 1, in which a higher wealth index indicates a higher socio-economic status. It can be classified into four groups: poorest ( $< 0.25$ ), very poor (0.25-0.49), less poor (0.5-0.74), and better off ( $\geq 0.75$ ) (Tuan et al., 2003).

Measures of social capital focused on perceptions of the level of child safety in out-of-home contexts, adults' level of education and preschool or school attendance. Parents reported the highest level of education they had completed. They also reported whether their child attended pre-school (5 years) and school (8 years); and if so, they also provided information about how long it took for the child to travel to school, what mode of transport they used, who they travelled with, and how well they performed in class. At 8 years of age, the children also provided self-reports about two aspects of out-of-home safety: frequency of physical punishment delivered by teachers and their perception of the level of safety in their community.

**Developmental outcomes.** Three domains of developmental outcomes were assessed: physical development, cognitive development and well-being. Height-for-age and weight-for-height were used to assess faltering in **physical development**. Very low height-for-age, known as stunting, reflects long-term malnutrition or exposure to chronic illness (World Health Organization, 2007b). In contrast, very low weight-for-height, known as wasting, usually indicates recent malnutrition or acute illness. Data were in the form of z-scores calculated with

reference to the WHO universal child growth standards (World Health Organization, 1995). These scores were calculated using the formula below:

$$Z\text{-score (or SD-score)} = (\text{observed value} - \text{median value of the reference population}) / \text{standard deviation value of reference population (World Health Organization, 1997, p.49)}$$

The advantage of using the z-score was that results for height-for-age and weight-for-height were comparable across age groups and genders.

The current study interpreted z-scores in two ways. First, the prevalence of stunting and wasting was calculated using the cut-off score ( $z < -2$ ) established by the WHO Global Database on Child Growth and Malnutrition. This cut-score led to 2.3% of the WHO international reference population being classified as malnourished on each measure (World Health Organization, 1997). Therefore, this study used 2.3% as one point of comparison when judging whether prevalence of stunting or wasting in the current study was elevated. Second, the prevalence of stunting and wasting among children with a disability was interpreted with reference to the prevalence in the sample of Vietnamese peers without disabilities or chronic illnesses.

**Cognitive development** was assessed using age-appropriate measures that captured vocabulary, language and numeracy skills.

**Vocabulary.** A Vietnamese language adaptation of the English *Peabody Picture Vocabulary Test-III* (PPVT-III) was administered to children at 5 and 8 years to assess the size of their receptive vocabulary (Cueto & Leon, 2012; Cueto, Leon, Guerrero, & Muñoz, 2009; Dunn & Dunn, 1997). The PPVT-III comprises 17 sets containing 12 words each. The level of difficulty increases from the initial set to the 17<sup>th</sup> set. Testing began with a “‘basal’ set which was determined by the child’s age. Each item in a set consists of four line drawings. The child’s task is to indicate which of the drawings depicts the word spoken by the administrator. If the child correctly answers 11 or 12 items in the basal set, the administrator proceeds to the next, more difficult, sets until the child is not able to correctly answer at least five out of 12 items in the set. The psychometric characteristics of the Vietnamese adaptation of the PPVT-III were examined by *Young Lives* researchers. Results indicated a high level of test re-test reliability and validity (Cueto & Leon, 2012). The score is the sum of correct items recorded across all sets. The current study used the corrected PPVT-III score. After excluding missing cases and improperly administered cases, PPVT-III scores were available for 1747 children.

**Reading.** At 8 years of age, language skills were also examined using a Vietnamese adaptation of Early Grade Reading Assessment (EGRA) (Glewwe, 1991). This test was developed by the United States Agency for International Development. It focuses on early reading and listening skills. The *Young Lives* project used three of the available sub-tests: (1) familiar word identification (the number of words read without mistakes in one minute); (2) reading comprehension (the number of words read without mistakes in one minute and the number of correct responses on a reading comprehension test); and (3) listening comprehension (the number of correct answers to questions based on a text that was read to the child). The corrected scores for these four sub-tests were subjected to an exploratory factor analysis to produce a global score for EGRA. Psychometric characteristics of the EGRA scores were tested by the *Young Lives* team. Scores were corrected for items with poor reliability and validity (Cueto & Leon, 2012).

**Basic numeracy skills.** At 5 years, numeracy skills were assessed by the quantity sub-tests of the Cognitive Development Assessment (CDA-Q), which was developed by the International Evaluation Association (Lund et al, 2012). The CDA-Q test consists of 15 items. However, one of the 15 questions (question 6) was excluded because it had little relationship with the average score on the test. In each item, the child was asked to pick an image from a selection of three or four choices that best reflected the concept provided by the examiner. Quantitative notions (e.g., a few, most, nothing, equal, a pair, etc.) were assessed with statements such as “Point to the plate that has a few cupcakes”. The raw score is the sum of correct answers, (possible range: 0-14). The *Young Lives* team collected valid data for 1906 children at 8 years of age.

**Mathematical skills.** At 8 years, a mathematics achievement test was administered. It contained 29 items relating to counting, number discrimination, knowledge of numbers, and basic operations with numbers. Specifically, nine items related to number identification and 20 items related to addition, subtraction, multiplication and division. To avoid bias resulting from poor reading skills, this test was conducted as a verbal interview in the child’s preferred language. Items with low reliability and validity were corrected to produce new data with strong psychometric characteristics (Cueto & Leon, 2012). The resulting test had high internal consistency (co-efficient  $\geq 0.80$ ) (Cueto & Leon, 2012).

**Well-being.** Two domains of children’s life satisfaction were assessed: current life satisfaction and expected future life satisfaction. Both single-item questions asked children to rank their life satisfaction on a nine-point scale in response to the following prompt: “Suppose

there are nine steps in this ladder, in which the top step of the ladder (score of 9) represents the best possible life and the bottom step (score of 1) represents the worst possible life”. Current life satisfaction was assessed by the question “*Where on the ladder do you feel you personally stand at the present time?*” A parallel question assessed the respondents’ predictions of what their satisfaction with life would be in four years time: “*Where on the ladder do you feel you personally will stand at the end of the next four years?*”

#### **4.4.4 Research design**

To describe the life circumstances and developmental trajectories of children with disabilities in the years preceding adolescence, this study employed an observational longitudinal design that covered the years between infancy and middle childhood. Data from 11 children with a visual or physical disability were interpreted with reference to parallel data from a large sample of peers without a disability ( $n = 1753$ ). It is important to know that the non-disabled group played a reference role, not comparison due to the large disparity in number. Variable-focused analyses and person-focused analyses were used to capture the uniqueness of each case as well as patterns observed across the sample.

### **4.5 Results**

The results are discussed here in three sections: screening data, variable-focused analyses and person-focused analyses.

#### **4.5.1 Screening and cleaning the data set**

Screening of the data identified no scores falling outside the possible range. Missing continuous data at an individual level had been replaced by variable medians at the community level by the *Young Lives* team. In total, less than 5% of data were missing. By far the highest percentage of missing data (2.6%) concerned father’s highest level of schooling (Behrman et al., 2013). Such a low percentage of missing data is believed to be unlikely to bias the outcomes of the analyses (Tabachnick and Fidell, 2007).

#### **4.5.2 Variable-focused analyses**

The variable-focused analyses were selected to capture the:

(1) developmental context of children with a visual or physical disability using descriptive statistics about the cultural context (urban/rural location, ethnicity, language, religion), and the child’s access to material capital (number of rooms in a house, household

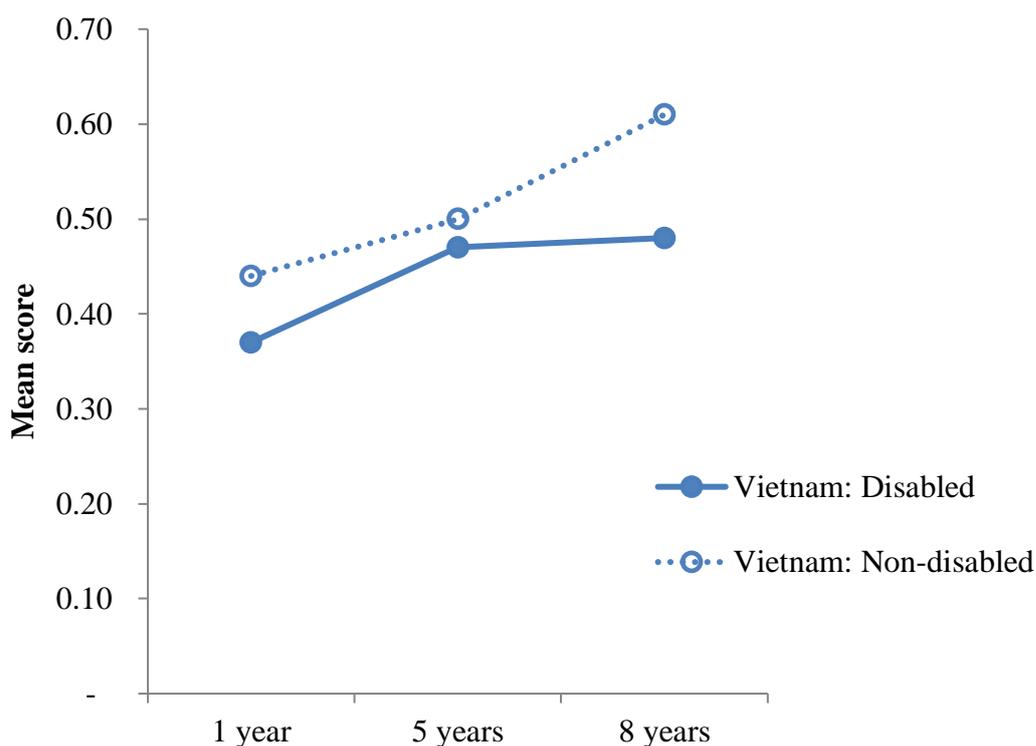
size, wealth index, electricity access, toilet access) and social capital (parents' education, education of household's heads, parents' educational aspiration for their child, pre-school attendance, school attendance);

(2) their developmental outcomes using descriptive statistics about physical development (stunting, wasting), cognitive development (language, mathematics skills) and well-being.

#### **4.5.2.1 Developmental context of the Vietnamese children with disabilities**

**Cultural context.** The majority (over 80%) of children with and without a disability lived in a rural area. Most participants were from families in the dominant Kinh ethnic group, were from families that followed no religion and spoke Vietnamese as their first language (Table 4.1). However, two out of 11 children came from the H'Mong minority ethnic group.

**Material capital.** Although there were notable exceptions, most Vietnamese families experienced extreme material deprivation. This was true for families with children with a disability and also for families without children with a disability. The mean wealth index for each of the three rounds of data collection (child ages 1, 5 and 8 years) in both groups ranged from 0.37 to 0.61 indicating that most families were extremely poor or very poor at all time points (Graph 4.1).



Graph 4.1: Mean wealth index scores at three time points for families with and without a child with a disability

The findings for the wealth index were confirmed by the more specific measures of the children’s living conditions. Houses containing only single room were the most common type among both families with an infant who later developed a disability (6 out of 11 - 54.5%) and families with an infant who did not develop a disability (41.5%). At 5 years of age, over 70% of families in both groups still lived in one- or two-room houses. The majority of these houses were used by four or more people: families with four or more members accounted for 81.8% to 100% of families with a disabled child, and 78.6% to 82.9% of families without a disability when children were at 1 and 5 years old respectively.

In addition, most of the families of children with a disability did not have access to a toilet. Moreover, some of those who did have access to a toilet used a very simple “long drop” toilet over a fish pond. Families without access to a toilet used open places such as a forest or field. In contrast, most families of a child with a disability had access to electricity (

Table 4.4).

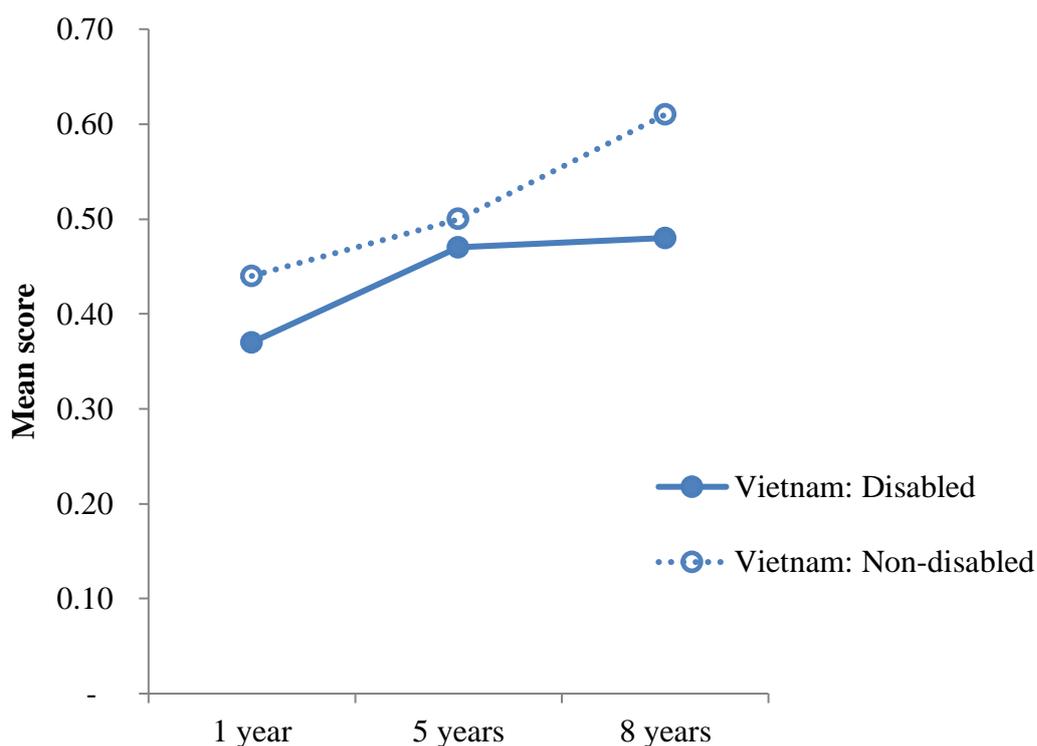
Table 4.4: Toilet and electricity access among two groups of Vietnamese children

Child age	No household toilet	No electricity access
	%	%
<b>Infancy</b>		
Children who later acquired a disability	72.7	18.2
Children who did not acquire a disability	36.3	15.7
<b>5 years</b>		
Children with a disability	63.6	18.2
Children without a disability	54.3	5.3

**Social capital.** Parents' education, their own access to schooling, and personal safety are all important domains of social capital for children.

*Parents' education.* About one third of the parents of children with a disability had not completed primary school (Table 4.5) The level of education of the head of household for these children was also low (heads of household are often grandparents).

*Parents' educational aspirations for their child.* Despite having a low level of education, parents had high aspirations for the education of their child with a disability. Seven out of 11 (63.3%) parents hoped their child would be able to complete university. This percentage was 76% for parents whose child did not have a disability. All parents of a child with a disability hoped that their child would complete high school.



Graph 4.2: Mean score of wealth index at three time points for the two groups

Table 4.5: The percentage of parents and household heads who had not completed primary school

Sample	Household head (%)	Father (%)	Mother (%)
Children with a disability, n = 11	63.6 (n = 7)	33.3 (n = 3)	30 (n = 3)
Children without a disability, n = 1753	29.1	20.9	24.4

Note. n = number of participants.

*Pre-school and school attendance.* The vast majority of parents acted on their high educational aspirations by ensuring that their children attended pre-school from 3 years of age and that they attended school at 5 years of age (Table 4.6). The most crucial reasons for this early education involvement were (1) the parents' awareness of the importance of their child mixing with other

children of the same age (40% for children with a disability and 33.0% for children without a disability) and (2) to help their child prepare for school (50% for children with a disability and 31.5% for children without a disability). Other less prevalent reasons for sending their child to pre-school and school included: to keep the child “out of the way” at home, there was no one available to look after the child at home, the child’s sibling went there, the child received nutritious food there, or to provide safe care when parents worked outside the home for money.

Table 4.6: Schooling of the children at 5 years of age

Sample	Attended pre-school from 3 years (%)	Currently attending school (%)	School performance is good (%)	Took >15 minutes to go to school (%)	Transportation mode %	Feel “in danger” when travelling to school (%)	Travelling without adults (%)
Children with a disability (n = 11)	90.9	100	90	54.5	Walk: 54.5 Bicycle: 27.3	36.4	36.4
Children without a disability (n = 1753)	90.5	97.9	71.7	42.4	Walk: 41.3 Bicycle: 32.4	32.8	29.2

Note. n = number of participants

The high percentage of the children with disabilities attending school is notable because more than half of the children with visual and physical disabilities needed to complete a lengthy walk to school every day, and one third made this journey without the assistance of adults (Table 4.6). Despite these challenges, most children with a disability were perceived by their parents to be doing well at school. At 5 years of age, 90% of these children (nine out of ten) also reported that their school performance was “good” or “excellent”.

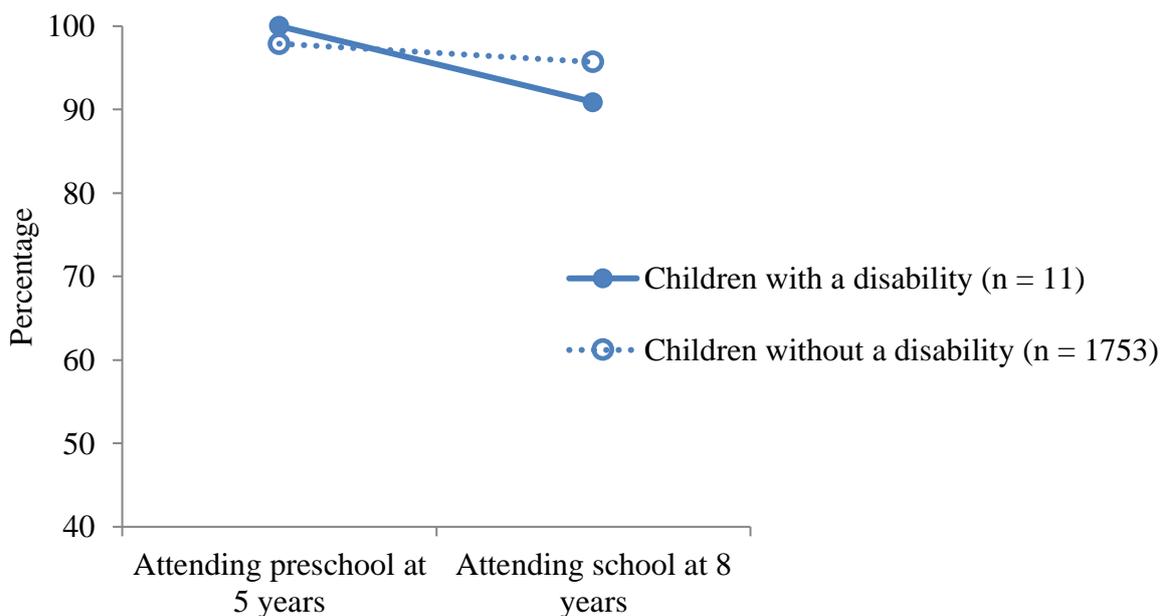
*Schooling of children at 8 years of age.* School attendance among children with and without disabilities remained high when they were 8 years old (Graph 4.2). Over 90% (10 out of 11) of the children with visual and physical disabilities attended school. In addition, despite the fact that the majority of children with a disability walked to school alone and felt in danger on the way, 90% of them had not been absent for over one week in the previous year. However, children’s rating of their school performance at 8 years of age was more modest than that at 5 years of age. Almost half of the children with a disability reported that they had worse

performance than their peers, while the remainder reported that their performance was about the same as their peers (Table 4.7).

Table 4.7: Schooling of children at 8 years of age

Sample	Currently attending school	No school absence more than one week in previous year	Performance compared to classmates
Children with a disability (n = 11)	90.9	90	Worse: 44.4 The same: 55.6 Better: 0
Children without a disability (n = 1753)	98.4	95.7	Worse: 19.4 The same: 56.7 Better: 23.8

Note. n = number of participants.



Graph 4.3: Pre-school and school attendance for Vietnamese children at two time points

*Out-of-home safety.* There were a variety of measures of children’s safety in out-of-home contexts. The frequency with which students were exposed to the risk of physical punishment was partly revealed via their responses to the question “In the last week, did you see a teacher used physical punishment on other students?” Most children with a disability reported that their teachers used physical punishment. In some cases it was used very frequently. About one third of children reported that they observed their teachers using physical

punishment “most or all of the time” (Table 4.9). Because the wording of the question was designed to avoid the personal-group discrepancy in reporting adverse events, it remains unclear whether or not children with a disability were spared from this threat to their safety.

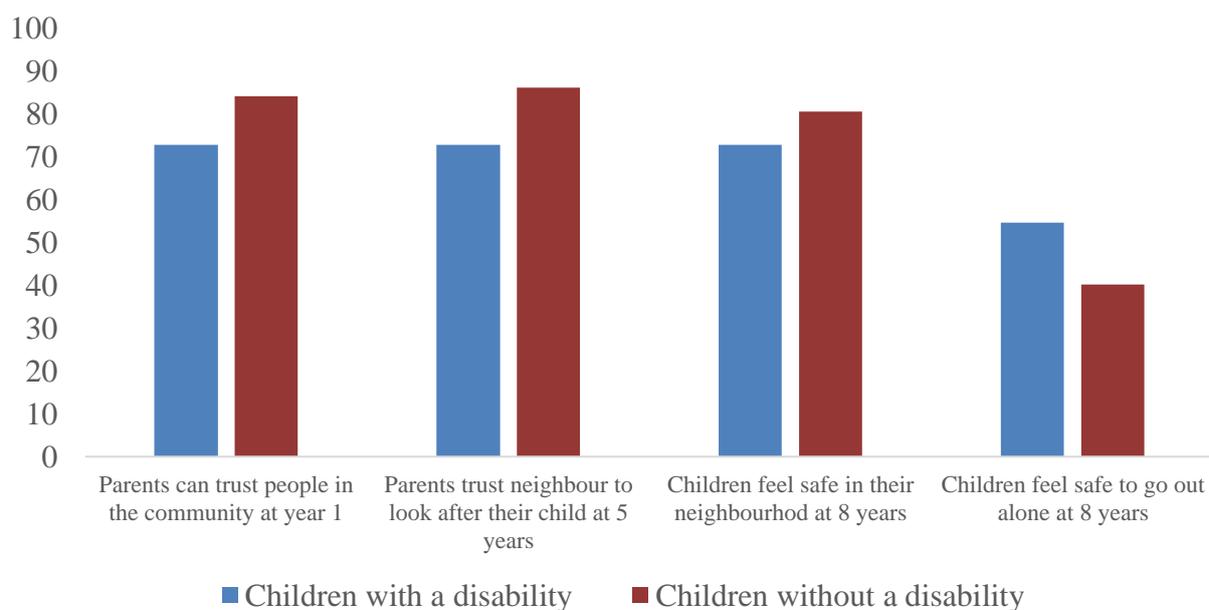
In addition, at 8 years of age, many children with a disability (36.4%) reported that they felt in danger on the way to school because the journey was often long and usually completed without adult supervision.

Table 4.8: Frequency with which teachers were reported to use physical punishment on students at 8 years

Frequency of physical punishment	Children with a disability (%) (n = 11)	Children without a disability (%) (n = 1753)
Never	44.4 (n = 4)	42.3
Once or twice	22.3 (n = 2)	29.8
Most/all of the time	33.3 (n = 3)	27.9
Refused to answer or missing	18.2 (n = 2)	0.1

Note. n = number of participants.

In addition, a minority of parents and children expressed concern about the level of child safety in their community (Graph 4.4). More than one in five parents and children reported that they did not feel safe on each of the four relevant items.



Graph 4.4: Percentage of respondents who reported feeling safe on diverse measures of community safety

**Summary.** Most of the young Vietnamese children with a visual or physical disability in Study 1 had developmental contexts characterized by extreme material deprivation. Two domains, crowded housing and poor access to sanitation, were likely to have implications for their health. In addition, the significant adults in these children's lives often had low levels of education. Most of the children with a visual or physical disability in this study showed evidence of growth faltering in the form of stunting and/or wasting at least one age. Despite this, they had high aspirations for their children's education, which were associated with high levels of pre-school and school attendance. A large minority of parents and children also perceived that there were threats to the child's safety in one or more out-of-home contexts. Such developmental contexts present many challenges and few resources for positive development among these young children.

#### **4.5.2.2 Developmental outcomes for Vietnamese children with disabilities**

##### **Physical development**

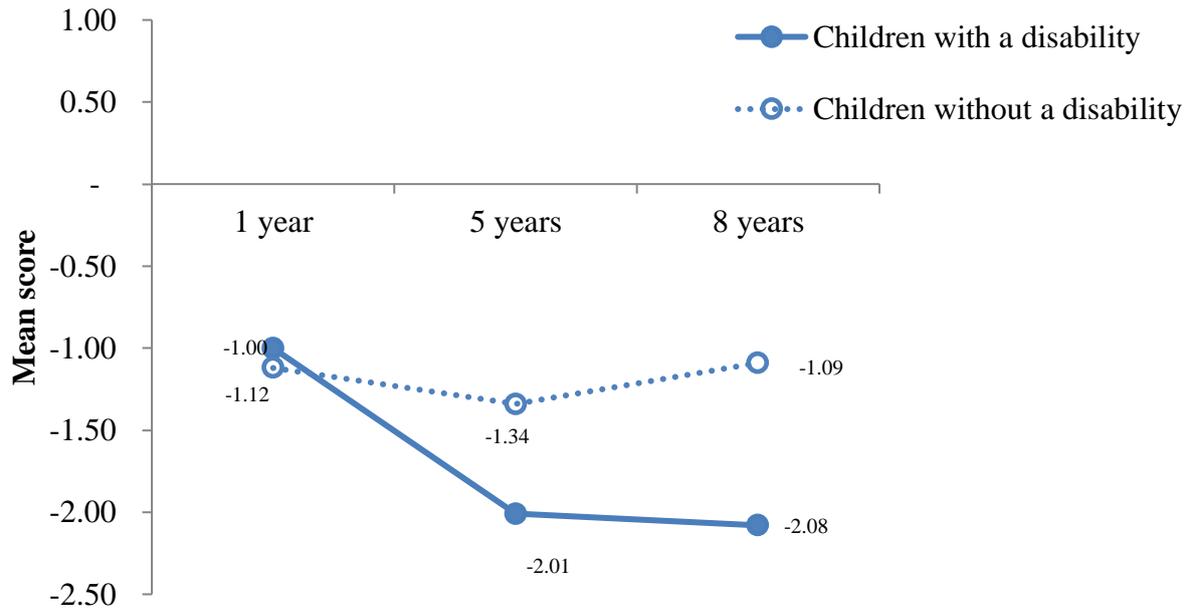
Height-for-age and weight-for-height were used to identify growth faltering. When interpreting findings during infancy, and change over time, it should be noted that all the children acquired their disability between the data collection point during infancy and the data collection point at 5 years of age. All eleven children with disabilities acquired their disability postnatal during early childhood.

At every age, children with a visual or physical disability had a mean z-score for height-for-age that was low relative to the *WHO Universal Child Growth Standards* (World Health Organization, 2007b). This was also true for the reference sample of children without a disability (Table 4.9 and Graph 4.5). At all three ages, 63% of the children with a disability met the criterion for stunting (z-score < -2). This finding suggested that the majority of children with a disability in this study experienced long-term malnutrition or chronic illness. In addition, while some children without disabilities who were stunted during infancy recovered by 8 years of age, no children with a disability did so.

Table 4.9: Mean z-score for height-for-age among the Vietnamese children with and without disabilities at three points in time

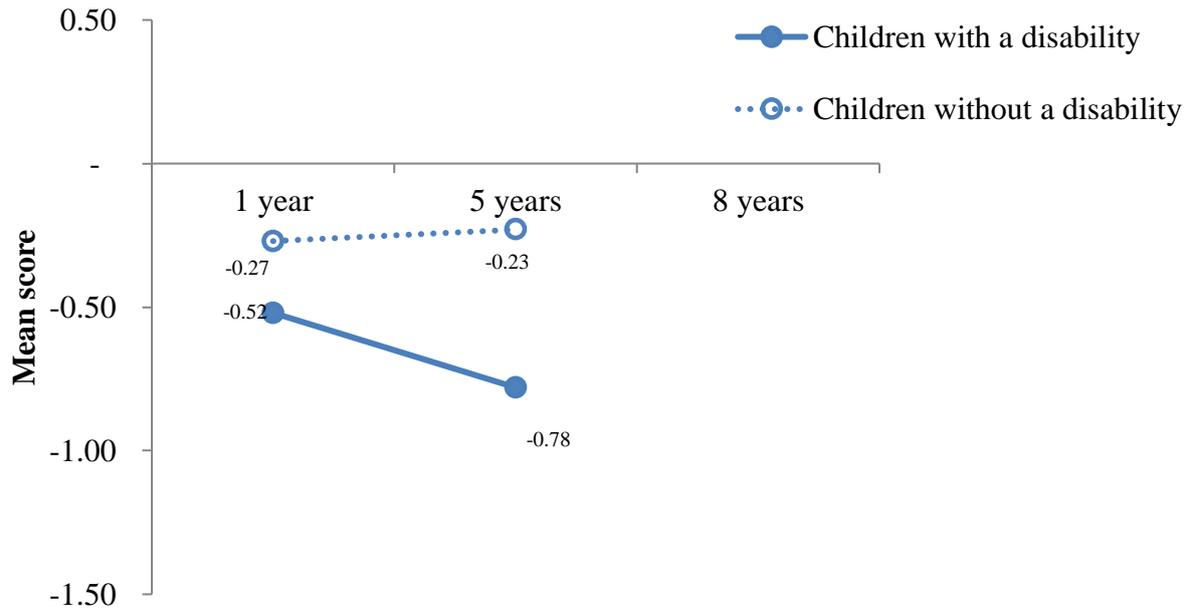
Sample	1 Year		5 Years		8 Years	
	M	SD	M	SD	M	SD
Children with disabilities (n = 11)	-1.00	3.86	-2.01	1.10	-2.08	1.76
Children without disabilities (n = 1753)	-1.12	1.28	-1.34	1.11	-1.09	1.07

Note. n = Number of participants. M = Mean score. SD = Standard deviation.



Graph 4.5: Mean z-scores for height-for-age for Vietnamese children with and without disabilities

Data for weight-for-height were available only during infancy and at 5 years. The mean z-scores for weight-for-height among children with a disability was within the normal range at both ages (Graph 4.5). Only one child with a disability showed evidence of wasting during infancy (i.e., before the disability was acquired) but four children met the criterion for wasting at 5 years of age (after their disabilities had been acquired).



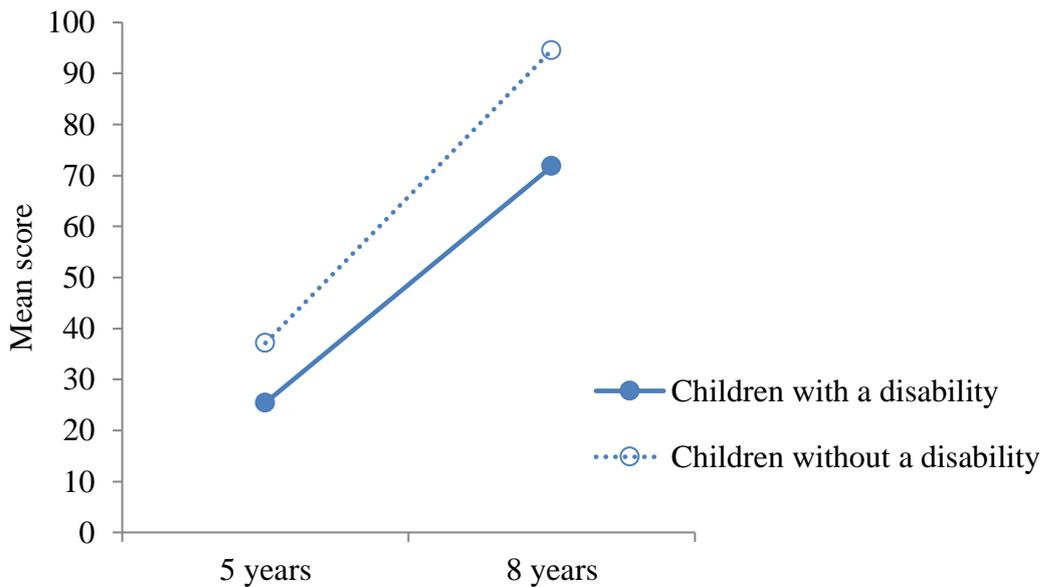
Graph 4.6: Mean score of weigh-for-height z-score (wasting) among Vietnamese children with and without a disability

In summary, most of the children with a visual or physical disability in this study showed evidence of growth faltering in the form of stunting and/or wasting at at least one age.

### ***Cognitive development***

Data for several domains of language development and two domains of numeracy were available at 8 years of age. For one domain of language, receptive oral vocabulary, data were also available at 5 years of age.

*Receptive oral vocabulary.* As expected, the size of the Vietnamese language vocabulary of children with a visual or physical disability increased significantly between 5 and 8 years of age (Graph 4.7). However, at both time points, the children with a disability had small vocabularies.



Graph 4.7: Mean scores on Peabody Picture Vocabulary Test-III for Vietnamese children with and without a disability

**Reading.** The global scores for the EGRA were available for only eight out of eleven children with a disability. They seem to have had a reasonable level of reading.

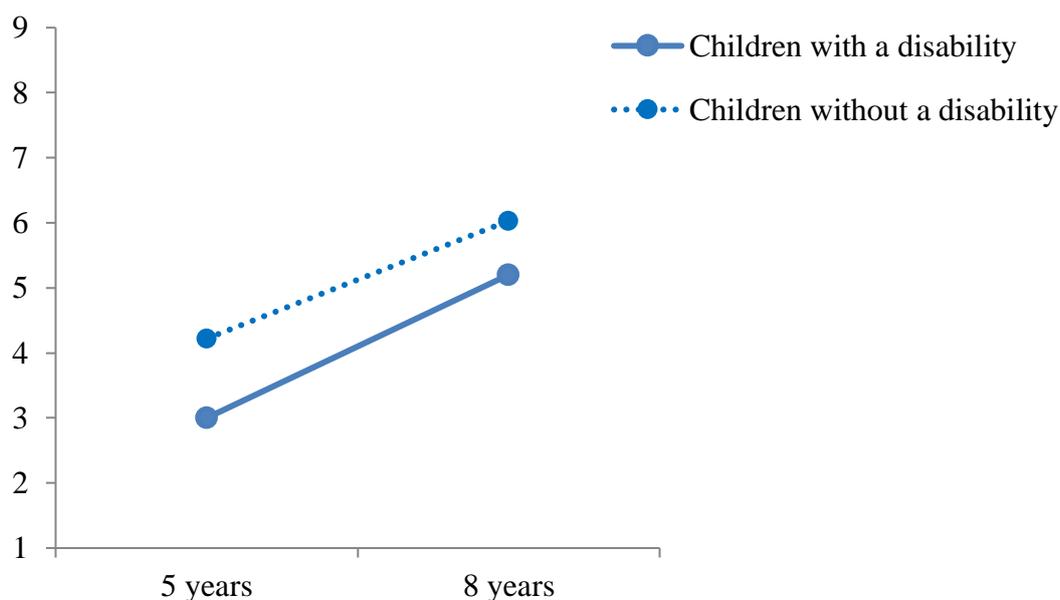
**Understanding of concepts concerning quantity.** Understanding of quantity among children with a disability was examined by inspecting raw scores from the *Cognitive Development Assessment-Quantity (CDA-Q)* and interpreting these with reference to scores from 1753 non-disabled peers. At 8 years of age, many children with a visual or physical disability shared a good level of understanding of concepts relating to quantity. The mean score from the reference disabled group shows that they also achieved this level (Children without a disability:  $M = 9.78$ ,  $SD = 2.50$ ).

**Basic mathematical skills.** Many children with a disability correctly answered about half of the mathematical problems that assessed skills in counting, number discrimination, knowledge of numbers, and basic operations. Children without a disability achieved average scores ( $M = 17.59$ ,  $SD = 5.48$ ).

**Summary of findings for cognitive development.** At 8 years of age, children with a visual or physical disability performed at a level comparable to their peers without a disability on all domains except receptive oral vocabulary. The size of the receptive oral vocabulary of children with a disability was somewhat smaller than that of children without a disability at both 5 and 8 years of age.

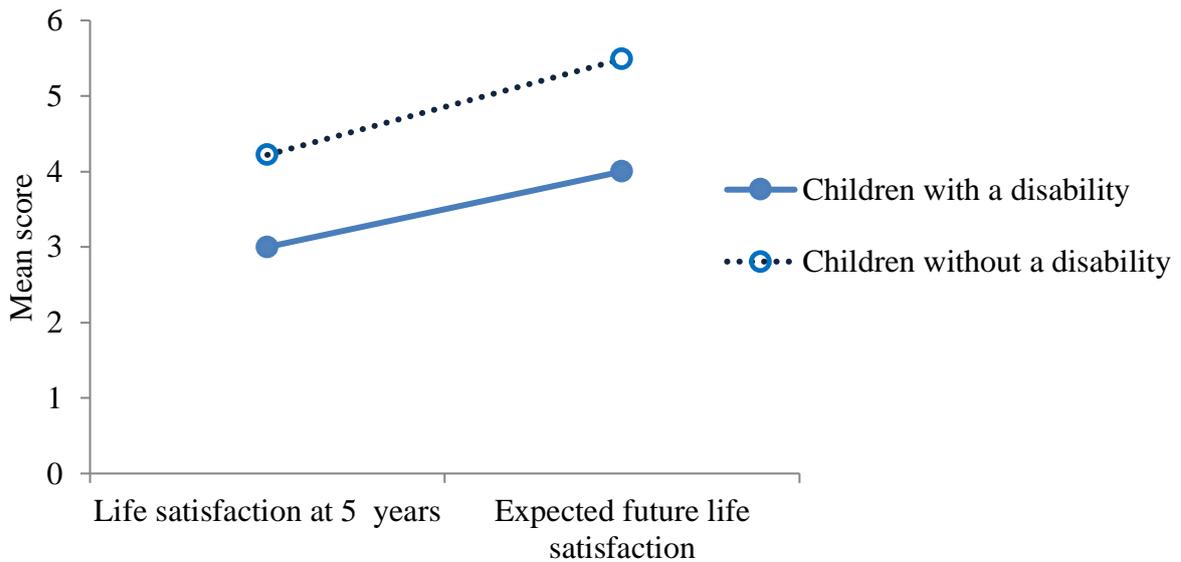
### ***Psychosocial well-being***

At 5 years of age, children rated their current and expected future life satisfaction. At 8 years, only one domain was rated: their current life satisfaction. The results showed that at 5 years, children in both groups rated their current life satisfaction below the midpoint on the 9-point scale (i.e., < 5) (Graph 4.8). At 8 years of age, this remained true only for the children with a disability.



Graph 4.8: Mean rating of current life satisfaction by Vietnamese children with and without a disability

At 8 years of age, children’s expectation about their life satisfaction remained under the midpoint on the 9-point scale (Graph 4.8). There was no evidence that current life satisfaction for children with a disability increased between 5 and 8 years of age. Responding to the question, “Where do you think you will be on the ladder in four years time?” many children with a disability expected that their life satisfaction would remain below the midpoint on the scale (Graph 4.9).



Graph 4.9: Mean ratings for life satisfaction and expected future life satisfaction of children with and without a disability at 5 years of age

In summary, children with a disability had current life satisfaction, and expected future life satisfaction, that were objectively low.

**Summary of variable-focused analyses.** Overall, although many children in both groups were raised in difficult circumstances, children with a disability showed particularly high levels of material deprivation, especially in terms of housing quality and access to basic amenities. In addition, the prevalence of growth faltering appeared to be high among children with a disability. They showed low levels of current and expected future life satisfaction. In contrast, children with a disability showed good cognitive performance in many aspects, except oral receptive vocabulary.

#### 4.5.3 Person-focused analyses

Each of the eleven Vietnamese children with a disability had a unique story in terms of their living context and developmental trajectory (Table 4.10). However, it was possible to identify a number of patterns in the data. The names used in the case studies have been changed to preserve confidentiality.

Table 4.10. Summary of developmental context and outcomes of eleven children with disabilities

Participant	Developmental context			Developmental outcome		
	Cultural	Material	Developmental	1 year	5 years	8 years
ID: Mot Girl with visual disability	Ethnicity: Kinh Language: Vietnamese Religion: Nil Location: Urban	No of rooms: 1 Household size: 7 Electricity: No Toilet: No Wealth index-Y1: 0.35 Wealth index-Y5: NA	Premature or low birth weight: No In school at 5: Yes In school at 8: Yes Education of household: Completed primary Community trust: Yes	Stunting (zhfa): Yes Wasting (zwhf): -1.80 - No	Stunting (zhfa): Yes Wasting (zwhf): -1.64 - No PPVT (vocabulary): 35 CDA (cognition): 12 SWL: 4	Stunting (zhfa): -2.25 - Yes PPVT(vocabulary): 67 EGRA(reading): 306 Maths: 13 SWL: 7
ID: Hai Girl with visual disability	Ethnicity: Kinh Language: Vietnamese Religion: Nil Location: Rural	No of rooms: 3 Household size: 3 Electricity: Yes Toilet: Yes Wealth index-Y1: 0.59 Wealth index-Y5: NA	Premature or low birth weight: No In school at 5: Yes In school at 8: Yes Education of household: Completed primary Community trust: Yes	Stunting (zhfa): Yes - 4.23 Wasting (zwhf): -0.57 - No	Stunting (zhfa): No Wasting (zwhf): -0.38 - No PPVT(vocabulary): 16 CDA(cognition): 6 SWL: 4	Stunting (zhfa): -1.04 - No PPVT(vocabulary): 57 EGRA(reading): 299 Maths: 21 SWL: 5
ID: Ba Girl with visual disability	Ethnicity: Kinh Language: Vietnamese Religion: Nil Location: Rural	No of rooms: 3 Household size: 5 Electricity: Yes Toilet: No Wealth index-Y1: 0.53 Wealth index-Y5: NA	Premature or low birth weight: No In school at 5: NA In school at 8: No Education of household: Completed primary	Stunting (zhfa): -3.90 - Yes Wasting (zwhf): -1.80 - No	Stunting (zhfa): Yes Wasting (zwhf): -2.09 - Yes PPVT(vocabulary): NA CDA (cognition): NA SWL: 1	Stunting (zhfa): -2.58 - Yes PPVT(vocabulary): NA EGRA(reading): NA Maths: NA SWL: NA

ID: Lan Girl with visual disability	Ethnicity: Kinh Language: Vietnamese Religion: Nil Location: Rural	No of rooms: 1 Household size: 4 Electricity: Yes Toilet: No Wealth index-Y1: 0.25 Wealth index-Y5: NA	Community trust: Yes Premature or low birth weight: No In school at 5: Yes In school at 8: Yes Education of household: completed primary Community trust: Yes	Stunting (zhfa): -2.54 - Yes Wasting (zwhf): -1.67 - No	Stunting (zhfa): -3.29 - Yes Wasting (zwhf): -1.96-No PPVT (vocabulary): 19 CDA (cognition): 12 SWL: 1	Stunting (zhfa): -1.47 - Yes PPVT(vocabulary): 65 EGRA(reading): 286 Maths: 15 SWL: 4
ID: Tam Girl with visual disability	Ethnicity: Kinh Language: Vietnamese Religion: Cao dai Location: Rural	No of rooms: 3 Household size: 10 Electricity: Yes Toilet: other Wealth index-Y1: 0.45 Wealth index-Y5: 0.31	Premature or low birth weight: No In school at 5: No In school at 8: Yes Education of household: Completed primary Community trust: Yes	Stunting (zhfa): -2.07 - Yes Wasting (zwhf): 0.21 - No	Stunting (zhfa): -2.03 - Yes Wasting (zwhf): -1.72-No PPVT (vocabulary): 32 CDA (cognition): 10 SWL: 3	Stunting (zhfa): -2.16 - Yes PPVT(vocabulary): 49 EGRA(reading): NA Maths: 4 SWL: 2
ID: Che Girl with visual disability	Ethnicity: H'Mong Language: Vietnamese Religion: Nil Location: Rural	No of room: 1 Household size: 7 Electricity: No Toilet: No Wealth index-Y1: 0.04 Wealth index-Y5: 0.17	Premature or low birth weight: No In school at 5: Yes In school at 8: Yes Education of household: No Community trust: Yes	Stunting (zhfa): -6.29 - Yes Wasting (zwhf): -1.64 - No	Stunting (zhfa): -2.70 - Yes Wasting (zwhf): -3.39-No PPVT (vocabulary): 11 CDA (cognition): 7 SWL: 3	Stunting (zhfa): -2.88 - Yes PPVT(vocabulary): 41 EGRA(reading): 259 Maths: 5 SWL: 4
ID: Bay Boy with physical	Ethnicity: Kinh Language:	No of room: 1 Household size: 7	Premature or low birth weight: No	Stunting (zhfa): -6.16 - Yes	Stunting (zhfa): -2.21 - Yes	Stunting (zhfa): -2.00 - Yes

disability	Vietnamese Religion: Nil Location: Rural	Electricity: Yes Toilet: No Wealth index-Y1: 0.29 Wealth index-Y5: 0.44	In school at 5: No In school at 8: Yes Education of household: No Community trust: Yes	Wasting (zwhf): -2.86-Yes PPVT (vocabulary): 25 CDA (cognition): 12 SWL: 3	PPVT <sub>(vocabulary)</sub> : 57 EGRA <sub>(reading)</sub> : 292 Maths: 16 SWL: 8	
ID: Tom Boy with physical disability	Ethnicity: Kinh Language: Vietnamese Religion: Cao dai Location: Rural	No of rooms: 2 Household size: 6 Electricity: Yes Toilet: Yes - flush Wealth index-Y1: 0.69 Wealth index-Y5: 79	Premature or low birth weight: No In school at 5: Yes In school at 8: Yes Education of household: No Community trust: Yes	Stunting (zhfa): -0.34 - No Wasting (zwhf): -1.70 - No	Stunting (zhfa): -1.52 - No Wasting (zwhf): -1.86-No PPVT (vocabulary): 22 CDA (cognition): 11 SWL: 5	Stunting (zhfa): -1.12 - No PPVT <sub>(vocabulary)</sub> : 57 EGRA <sub>(reading)</sub> : 249 Maths: 12 SWL: 9
ID: Chin Boy with physical disability	Ethnicity: Kinh Language: Vietnamese Religion: Nil Location: Rural	No of room: 1 Household size: 4 Electricity: Yes Toilet: No Wealth index-Y1: 0.42 Wealth index-Y5: 68	Premature or low birth weight: No In school at 5: Yes In school at 8: Yes Education of household: No Community trust: Yes	Stunting (zhfa): 0.05 - No Wasting (zwhf): -0.50 - No	Stunting (zhfa): -0.67 - No Wasting (zwhf): -1.43-No PPVT (vocabulary): NA CDA (cognition): 8 SWL: 4	Stunting (zhfa): 0.22 - No PPVT <sub>(vocabulary)</sub> : 78 EGRA <sub>(reading)</sub> : NA Maths: 19 SWL: 8
ID: Muoi Boy with physical disability	Ethnicity: Kinh Language: Vietnamese Religion: Nil Location: Urban	No of room: 1 Household size: 11 Electricity: Yes Toilet: No Wealth index-Y1: 0.52 Wealth index-Y5:	Premature or low birth weight: No In school at 5: Yes In school at 8: Yes Education of household: No Community trust: Yes	Stunting (zhfa): 7.50 - wrong data Wasting (zwhf): -2.23 - Yes	Stunting (zhfa): -0.29 - No Wasting (zwhf): -0.83-No PPVT (vocabulary): 52 CDA (cognition): 12 SWL: 1	Stunting (zhfa): 0.23 - No PPVT <sub>(vocabulary)</sub> : 89 EGRA <sub>(reading)</sub> : 304 Maths: 23 SWL: 3

ID: Alang	Ethnicity:	64	Premature or low	Stunting (zhfa):	Stunting (zhfa):	Stunting (zhfa):
Boy with physical	<i>H'Mong</i>	No of room: 2	birth weight: No	-2.37 - Yes	-2.84 - Yes	-2.97 - Yes
disability	Language:	Household size: 4	In school at 5: Yes		Wasting (zwhf):	PPVT <sub>(vocabulary)</sub> : 43
	Vietnamese	Electricity: No	In school at 8: Yes	Wasting (zwhf):	-1.03-No	EGRA <sub>(reading)</sub> : 282
	Religion: Nil	Toilet: No	Education of	-0.53 - No	PPVT <sub>(vocabulary)</sub> :	Maths: 9
	Location: Rural	WI-Y1: 0.01	household: No		17	SWL: 2
		Wealth index-Y5:	Community trust:		CDA <sub>(cognition)</sub> : 6	
		NA	Yes		SWL: 2	

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Note. Y1 = 1 year of age, Y5 = 5 years of age, PPVT = *Peabody Picture Vocabulary Test-III*, CDA = *Cognitive Development Assessment*, EGRA = *Early Grade Reading Assessment*, SWL = Subjective Well-being. NA = No answer.

#### **4.5.3.1 Diversity in development of the children with disabilities**

In order to capture diversity in living conditions and developmental outcomes, several case studies will be presented.

Differences in the life circumstances and outcomes of children of the same age, gender and impairment can be demonstrated by comparing the lives of two girls with visual disabilities. Participant Mot was a girl with a visual disability. Her family of three people shared a two-room house in a city. The fact that they did not have a toilet in a city was unusual and it was possible that they used a shared toilet with neighbours. Even though living in an urban setting is commonly associated with improved living conditions, Mot grew up with very limited resources: the family's wealth index was only 0.35. Her developmental trajectory was characterized by stunting or severe stunting at all three time points. However, she attended school and received scores on many measures that were comparable to, or above, the mean for children with, and even for children without, a disability. The measure for oral receptive vocabulary and reading will be used as examples (PPVT at 5 years: Mot's score = 35, mean for children with a disability = 25.44, mean for children without a disability = 37.14; EGRA at 8 years: Mot's score = 306, mean for children with a disability = 209, mean for children without a disability = 300). By 8 years of age, her current life satisfaction was objectively high as well as being higher than that of her peers with a disability (Life satisfaction at 5 years: Mot's score = 4, mean for children with a disability = 3; Life satisfaction at 8 years: Mot's score = 7, mean for children with a disability = 5.22).

A useful point of comparison with Mot is Hai who is also a girl with a visual disability. Despite living in a rural area, her family was "better-off" (wealth index = 0.59). Her house had three rooms for three people with access to both electricity and toilet. She did not experience any growth faltering at any time point. Unlike Mot, at the time she made a transition to school at 5 years of age, Hai had a very limited vocabulary (PPVT at 5 years: Hai's score = 16, mean for children with a disability = 25.4, mean for children without a disability = 37.1). However, after three years at school, she had acquired many reading skills. (EGRA score: Hai's score = 299, mean for children with a disability = 209, mean for children without a disability = 300). Hai rated her life satisfaction near the middle scale at both 5 and 8 years of age. Overall, this comparison suggested that even though the two girls had the same type of disability and similar levels of reading skills at 8 years of age, they had experienced very different living contexts and physical development.

Even larger discrepancies were seen between other children with a disability. Case studies for Ba and Bay illustrate this. Ba was a girl with a visual disability. She lived in a rural area in a three-room house shared by five people. It is noteworthy that she had access to a relatively high level of material capital (wealth index = 0.53). However, Ba did not attend school at 8 years of age. No information about her cognitive development was recorded, but it is clear that her physical development was poor. She was stunted at 5 years of age and severely stunted at 8 years of age. Her well-being was also extremely low. At 5 years of age, she gave her current level of life satisfaction the lowest possible rating (a score of 1) at 5 years of age.

In contrast, Bay was a boy with a physical disability. His access to material capital was much poorer than Ba (wealth index = 0.29). His family of 11 people shared a one-room house without a toilet in a rural area. He was stunted at both 5 and 8 years. However, he was attending school at 8 years. His cognitive development was at a moderate level (for vocabulary) and at better level (for mathematics) compared to other peers with disabilities, and he had very high level of psychosocial well-being. At 8 years of age he gave his current satisfaction with life the second highest possible rating (8 out of 9). Thus, the discrepancy in material resources and life satisfaction for these children were both large but in opposite directions.

#### **4.5.3.2 Common patterns across the participants**

Although diversity in developmental context and trajectories among 11 participants existed, it was possible to identify a number of cases that shared similar patterns. Two variables, material deprivation and schooling, showed similar associations with developmental outcomes across many children with visual and physical disabilities.

##### ***Material deprivation***

Two case studies will be used to illustrate the association between extreme material deprivation and adverse developmental outcomes. Che (a girl with a visual disability) and Alang (a boy with a physical disability) both belonged to the ethnic minority group (H'Mong) and lived in a very remote area. The families of Che and Alang were extremely poor: their wealth index during infancy was only 0.04 and 0.01 respectively. These scores are extremely low and indicate that the families had almost no material resources. At 5 years, their material circumstances remained extremely poor. (Che: wealth index = 0.02; Alang: wealth index = 0.17), especially for Che. Her family's wealth index was nearly the same and nearly zero (0.02) in the wealth index scale, indicating that they were literally "broke". Alang's family's circumstances were a little better when he was 5 years old but they remained extremely poor

(WI= 0.17). Che lived in a one-room house that she shared with seven other family members. Alang shared his two-room house with four people. Neither of their houses had either electricity or a toilet. This situation was likely to have health implications. Household crowding may increase the risk of children acquiring infectious diseases. The absence of access to any kind of toilet might also increase the likelihood of food and waterborne disease in both children. In addition, the combination of a visual or physical disability and the absence of a toilet increased the daily challenges of care in these children's families.

In such a development context, it is not surprising that both children shared poor physical development. At all time points (1, 5 and 8 years of age), both Che and Alang were stunted. At 5 years of age, Che was also wasted. In addition, their cognitive development was also poor (Table 4.11). Despite attending pre-school and school, Che's vocabulary at 5 and 8 years of age was only about half of the mean scores for other children with a disability. Her vocabulary score at 5 years of age and her mathematics score at 8 years of age were both less than one-third of the mean score for her peers without a disability. Her scores for language comprehension and understanding of quantitative concepts were also numerically lower than those of her peers with a disability. Similarly, although Alang's family sent him to both preschool and school, he showed impaired cognitive development. At both 5 and 8 years of age, his vocabulary scores were only half of the mean scores for other children with a disability. His scores for language comprehension, understanding of quantitative concepts and mathematics were all also numerically lower than the means for other children with a disability. Both children rated their current life satisfaction as being below the midpoint on the scale at both 5 and 8 years old (Table 4.11).

Table 4.11: Summary of comparative data for two children with a disability being raised in contexts characterized by extreme material deprivation

	WI at infancy	WI at 5 years	PPVT at 5 years	PPVT at 8 years	CDA_Q at 5 years	Maths at 8 years	EGRA at 8 years	SWL at 5 years	SWL at 8
Che	0.04	0.17	11	41	7	5	258.9	3	4
Alang	0.01	0.02	17	43	6	9	281.7	2	2
Disabled	0.38	0.48	25.44	71.78	9.60	14.25	290.31	3	5.20
Non-disabled	0.41	0.50	37.14	94.59	9.78	17.59	300.23	4.22	6.03

Note. WI = wealth index, PPVT = *Peabody Picture Vocabulary Test-III*, CDA\_Q = Quantitative subtest of the *Cognitive Development Assessment*, EGRA= *Early Grade Reading Assessment*. SWL = Satisfaction with life.

In summary, Che and Alang were two children living in extreme poverty who acquired a disability between infancy and five years of age. They began school with disrupted physical and cognitive development, which did not recover in the subsequent three years.

### **School attendance**

Another two case studies will be used to illustrate the divergence in developmental trajectories commonly seen between children who did and did not attend school. Lan and Tam were two girls with a visual disability with moderate severity level who were raised in similar circumstances. They lived in rural locations in houses with electricity but without a toilet. They were both stunted at 1 and 5 years of age). One difference between the girls was that Tam had access to more material capital than Lan (Table 4.12). Tam lived in a house with three rooms. Her family's wealth index scores were 0.45 and 0.49 (at 1 and 5 years, respectively), which were close to the mean for children with and without a disability. In contrast, Lan lived in a one-room house with a family with a lower wealth index at both time points. In addition, Lan's head of household had never been to school while Tam's household head had completed primary school.

At 5 years of age, when the girls were expected to make transition to school, they had a very similar level of understanding of quantitative concepts and both had low life satisfaction (Table 4.12). However, Lan had a vocabulary score that was only half the mean score for her peers without a disability, while Tam's vocabulary was similar.

Despite having more disadvantaged material circumstances and a more limited vocabulary on her transition to school, after three years of schooling, Lan achieved higher scores for both vocabulary and mathematics than Tam (Table 4.12). Lan could write without difficulty or errors, and could make basic mathematical calculations. In contrast, Tam, who did not attend school, was illiterate. She could not read or write and was unable to count. With regard to life satisfaction, the situation was similar. Lan’s life satisfaction had increased from 1 to 4 within three years, while Tam’s rating decreased from 3 to 2.

Table 4.12: Summary of comparative data for two children with a disability who did and did not attend school

	WI at 1 year	WI at 5 years	PPVT at 5 years	PPVT at 8 years	CDA_Q at 5 years	Maths at 8 years	EGRA at 8 years	SWL at 5 years	SWL at 8 years
Lan	0.25	0.31	19	65	12	15	386.32	1	4
Tam	0.45	0.49	32	49	10	4	NK	3	2
Disabled	0.38	0.48	25.44	71.78	9.60	14.25	290.31	3	5.20
Non-disabled	0.41	0.50	37.14	94.59	9.78	17.59	300.23	4.22	6.03

Note. WI = wealth index, PPVT = *Peabody Picture Vocabulary Test-III*, CDA\_Q = Quantitative subtest of the *Cognitive Development Assessment*, EGRA= *Early Grade Reading Assessment*. SWL = Satisfaction with life. NK = Unknown.

Although there was a general tendency across the case studies for cognitive development to be greater in the context of school attendance, the case studies for Lan and Tam were particularly good examples of the power of schooling. In the cases of Lan and Tam, gender, disability type, and growth were similar, and Tam had greater access to material capital.

Apart from material and education effects, there was also a tendency for children with physical disabilities to have larger vocabularies and greater life satisfaction than those with visual disabilities. However, there were several exceptions to this pattern.

## 4.6 Discussion

The longitudinal case studies used quantitative data from the *Young Live* study to provide insights into the developmental contexts, developmental trajectories, and psychosocial wellbeing of Vietnamese children with visual and physical disabilities. Consistent with Bronfenbrenner and Morris’s eco-biological framework, the current study examined multiple domains of the children’s developmental context and multiple developmental outcomes over time to provide rich descriptions that allowed an “understanding development and child outcomes as an interaction between the developing child, his/her environmental context, and

the timing of the particular process being examined". However, the case study design precluded conclusions about the specific environmental and individual factors that contributed to these. Despite this, a number of patterns and themes emerged from variable-focused and person-focused analyses. In particular, three themes were observed. These concerned low levels of development, resilience and schooling.

First, several developmental indices highlighted a pattern in which most children with disabilities had low levels of development when their scores were interpreted with reference to the mean for their peers without a disability. The majority of children with a disability showed growth faltering at one or more time points and had a small vocabulary size, and low skills in reading and mathematics when their scores were interpreted with reference to the mean for peers without a disability. Very few children with a disability had high developmental outcomes when their scores were interpreted with reference to those of their non-disabled peers. This pattern is consistent with previous research documenting the high prevalence with which children with disabilities show poorer developmental outcomes than their peers without disabilities (Wolman, Resnick, Harris, & Blum, 1994).

Second, the patterns of results often suggested resilience, despite the difficult living conditions most of the children experienced. The majority of children with a disability lived with extreme material deprivation, lacking facilities to meet their basic needs, such as access to electricity and a toilet. As a result, most showed growth faltering that did not recover over time. At school, children with a disability also faced obstacles such as unsafe travel and the risk of physical punishment. Despite these odds, the majority of children with a disability attended both pre-school and school at appropriate ages. This is consistent with both parents and children's educational expectations. The children expected, and were expected by their parents, to complete a level of education. In addition, most children who attended school made progress. Thus, one of the most salient findings of the current study was that although children with disabilities experienced many difficulties, most showed resilience in several dimensions of development.

The final pattern suggested the importance of schooling. Exploration of data for individual case studies (the person-focused analyses) suggested a link between formal education and some domains of cognitive development. This finding is consistent with previous studies documenting the power of formal education in cognitive development (Farfel et al., 2013; Seifert, 2004).

## 4.7 Strengths and Limitations

Study 1 presented a series of case studies to provide insights into the lived experience of Vietnamese children with disabilities. They introduced the reader to the context of development of children with disabilities in Vietnam prior to adolescence. The combined parent-reports of “The child has a long-term problem” and “He/she cannot see” or “He/she cannot walk/cannot move one or more arms or legs” identified children with severe visual disabilities, and children with many, but not all, types of severe physical disability. However, this means of identifying children with a disability had several limitations. First, none of the case studies are likely to involve children with moderate or mild disabilities and therefore Study 1 provides no insights into the living conditions or developmental trajectories of these children. Second, physical disabilities can lead to impaired functioning other than problems with walking or limb movements. Children who had physical disabilities (e.g., due to clubfoot, curvature of the spine) that did not prevent them from walking or moving one or more arms or legs were excluded, and therefore Study 1 provides no insights into the living conditions or developmental trajectories of these children. Third, when offered only “Yes/No” response alternatives to the screening questions, it is likely that some parent-reports may under-reported the severity of disability while other parent-reports may have over-reported this. The shortcomings that result from methods of identifying children with a disability that rely on parent-report and that do not assess the severity of their disability were overcome in Study 2. Indeed, that study explore the possibility that severity of disability is a predictor of wellbeing. Fourth, it is unclear what 5- and 8- year-old children understood of the item “Where on the ladder do you feel you personally stand at the present time?” or what domains of their lives they considered when deciding on their ratings. Such concerns are common in secondary data analyses (Brooks-Gunn, Phelps, & Elder, 1991). Fifth, it is also understood that the focus of Young Lives study is poverty in childhood, not children with disability. Their target sample were children living in rural and remote areas. Therefore, living experience and developmental circumstance described in Study 1 may not represent for children with disabilities living in big cities in Vietnam. Sixth, the use of the disability questions had its own limitations:

- None of the case studies are likely to involve children with moderate or mild disabilities and therefore Study 1 provides no insights into the living conditions or developmental trajectories of these children.

- Other forms of physical disabilities other than walking were not also covered in the study. Children who had physical disabilities (e.g., due to clubfoot, curvature of the spine) that did not prevent them from walking or moving one or more arms or legs were excluded, and therefore Study 1 provides no insights into the living conditions or developmental trajectories of these children.
- Participants who have mild or moderate level of difficulty in seeing or walking were missed. No severity of disability was mentioned. This is the major limitation in Study 1 when it is known that, in reality, the quality of lived experience depends very much on at which level of disability one person suffer: from not severe at all to extremely severe. The findings were therefore only considered as some outline about lived experience about this population in Vietnam.
- The parent-reported based data also may not reflect the correct level of difficulty experienced by their children.

## 4.8 Conclusion

This is the first study to report longitudinal data on the psychological development and well-being of children with visual and physical disabilities in LAMICs. The findings are limited by the case study design and must be interpreted with caution while they await confirmation by research using large, representative samples. Despite this, the present findings draw attention to the many everyday challenges that children with disabilities and their families face due to material deprivation, and the high cost these children often pay as a consequence, in faltering physical growth, delayed cognitive development, and poor psychosocial well-being. The case studies also point to the likely importance of ensuring that children with a disability are able to attend school and of improving their families' material circumstances in any attempt to improve the quality of life and developmental outcomes for these children. The study documents both the uniqueness of each child's circumstances, but also highlights patterns observed across children. One of the most salient of these was that although children with disabilities experienced many difficulties, most showed resilience in several domains of development. In summary, this study provided information about the developmental context for Studies 2 and 3, which focused on the psychosocial well-being of Vietnamese adolescents with visual and physical disabilities, and aided the interpretation of their findings.

# CHAPTER 5 - STUDY 2: QUANTITATIVE STUDY OF PSYCHOSOCIAL WELL-BEING AMONG VIETNAMESE ADOLESCENTS WITH VISUAL AND/OR PHYSICAL DISABILITIES

*“Adolescence is a time in life that harbors many risks and dangers, but also one that presents great opportunities for sustained health and well-being”* (Kleinert, 2007, p. 1057)

## 5.1 Orientation

The previous chapter described the developmental contexts and trajectories of children with visual and physical disabilities in Vietnam. The insights it provided about the poor living circumstances and physical development of children with a disability warrant concern about their well-being when they reach adolescence. However, it is also possible that their opportunities for education could compensate for other disadvantages to allow them to experience well-being in adolescence. This chapter will report the results of a cross-sectional quantitative study investigating well-being among Vietnamese adolescents with visual and physical disabilities. In particular, this large-scale study examined the level of well-being in a range of negative and positive domains and sought to identify predictors of these outcomes. Moderators for the relationship between severity of disability and these outcomes are also examined.

## 5.2 Abstract

Adolescence is usually considered to be a challenging period in development. Adolescents with disabilities face additional challenges that may place them at risk of poor well-being. Most research about the well-being of people with a disability has been conducted in high-income countries and has focused on intellectual disability. However, most adolescents with disabilities live in LAMICs where visual and physical disabilities are most common. This research addresses this gap in the literature by examining well-being among adolescents who are doubly disadvantaged by having a physical or visual disability and growing up in a LAMIC (Vietnam) in which there is limited access to support.

Bronfenbrenner and Morris’s bio-ecological framework informed the development of a research model that identified biosystem (severity of disability), individual (optimism, social support, adaptive coping) and microsystem factors (discrimination, out-of-home care) with the

potential to predict or moderate outcomes in positive (satisfaction with life, flourishing, prosocial behaviour, positive affect) and negative domains of well-being (depression and anxiety symptoms, conduct problems, negative affect). This model was tested in a sample of visually ( $n = 94$ ) and physically ( $n = 112$ ) disabled adolescents (aged 10-19 years) drawn from four sites in rural, regional and urban centres in Vietnam.

Adolescents with disabilities reported a high mean level of symptoms of depression and anxiety (three and four times higher than expected in the general population in Western country (Lovibond & Lovibond, 1995)). However, they also reported moderate levels of satisfaction with life, flourishing and positive affect. The research model explained more than 25% of the variance in five out of eight well-being outcomes. Discrimination was the strongest independent predictor for mental health problems, while social support made the largest independent contribution to most of the positive domains of well-being. There was little evidence that the predictor variables moderated the relationship between severity of disability and well-being outcomes. Severity of disability made an independent contribution to only a few well-being outcomes.

### **5.3 Introduction**

The transition from childhood to adulthood during adolescence often lasts for more than ten years, and is marked by many physical, psychological and social changes that may be sources of stress. It involves changes in both external appearance and internal self-image. An additional potential source of stress is the increasing mismatch between sexual and psychological maturity during adolescence (Kleinert, 2007; Patton & Viner, 2007). In many countries, adolescence is also a time of increased academic demands, career choices, increased responsibility and more complex social roles. Adolescents respond differently to the stressors they encounter. Although some are able to thrive, others develop emotional or behavioural problems. The prevalence with which mental health problems emerge during adolescence is higher than in any other period in the lifespan (Arnett, 1999).

In high-income countries, having a disability is positively related to poor emotional well-being (Wolman et al., 1994), mental health problems, including depression (Gureje, Ademola, & Olley, 2008), and behavioural problems (Gortmaker et al., 1990). In such countries, adolescents with physical disabilities experience higher levels of anxiety and depression than their peers without a disability (da Silva et al., 2011a).

Adolescents with disabilities, especially those living in LAMICs, are also likely to be at risk of poor psychosocial well-being because they face additional challenges. Material deprivation, low access to education, poor access to health services, high unemployment rates, and insecure living conditions, are common problems for young people with disabilities in LAMICs (The World Bank, 2006; UNICEF, 1999, 2013; United Nations, 2012b). Both present stressors, and anticipated future stressors, may contribute to these adolescents' psychological problems and increase the risk of poor psychosocial well-being.

However, the small amount of available research on psychosocial well-being among young people with a disability has produced inconsistent results. Some studies have found a positive relationship between psychosocial problems and disability among young people (Gortmaker et al., 1990) while others have found no difference in psychological well-being between adolescents with and without a disability (Berntsson et al., 2007; Cappelli et al., 1989; Kellerman et al., 1980; Orr et al., 1984). Such inconsistent findings make it likely that there are environmental and/or personal factors that are capable of magnifying or reducing the relationship between disability and well-being. In order to promote well-being among young people with disabilities in LAMICs, it is necessary for research to identify these risk and protective factors.

No previous studies have directly compared well-being among adolescents with two different types of disabilities in LAMICs. Research from high-income countries suggests that adolescents with different types of disabilities may differ in their well-being. For example, results suggest that adolescents with physical disabilities experience higher levels of anxiety and depression than their peers without a disability (Silva et al., 2011a), whereas those with speech and language impairment have mental health and well-being comparable to that of their peers without a disability (Gutman et al., 2010). Thus, an important first step in developing policies and interventions to support the well-being of adolescents with a disability living in LAMICs is to determine whether different types of disability are systematically associated with different levels of well-being, and to identify the factors that are associated with these outcomes. The current study aimed to investigate levels and predictors of well-being among Vietnamese adolescents with two types of disability: visual and physical.

There are also a number of other gaps in the current literature on the well-being of adolescents with a disability in LAMICs. First, most disability research has concentrated on negative domains of well-being. In particular, two mental health problems, anxiety and depression have often been the focus (da Silva et al., 2011a; Kellerman et al., 1980). There are

several disadvantages to this approach. First, such research perpetrates an association between persons with a disability and deficits and negative attributes. Second, we know little about other outcomes in the negative domains of psychosocial wellbeing, such as antisocial behavior and negative affect. Third, such research ignores the level of resilience widely documented among people with a disability (e.g., Amtmann et al., 2015). That is, there has been limited research on the positive domains of well-being in the context of disability, and most of this has focused on a single outcome, satisfaction with life. As a result, we also know little about many of the outcomes in the positive domain of psychosocial wellbeing, such as flourishing, prosocial behavior and positive affect, that have been widely studied in research on other adolescent populations. In addition, the focus on only a small number of domains of well-being in any individual study limits our knowledge of the pattern of positive and negative well-being outcomes experienced by young people with a disability in LAMICs. This study will address this gap in the literature by investigating four outcomes in both negative (depression, anxiety, antisocial behavior and negative affect) and positive domains of well-being (life satisfaction, flourishing, prosocial behavior and positive affect) in adolescents with visual and physical disabilities in one middle-income country, Vietnam.

Much of the research that has examined the predictors of well-being among adolescents with visual and physical disabilities has focused on demographic variables (Table 2.2). However, many people with disabilities have access to a wide range of psychological and environmental resources that can support their well-being. For example, women with intellectual disability show resilience and positive well-being if their strengths are enhanced in a supportive context (Conder, Mirfin-Veitch, & Gates, 2015). Despite such evidence, there is very limited research on the psychological assets (e.g., optimism, adaptive coping), environment resources (e.g., social support), or environmental risks (discrimination, out-of-home care) have been widely studied in research on well-being in other adolescent populations. This study will address this gap in the literature by investigating the way both negative and positive domains of well-being are related to protective (optimism, social support, adaptive coping) and risk factors (discrimination, out-of-home care) among adolescents with visual and physical disabilities in Vietnam.

### **Theoretical framework: Bronfenbrenner and Morris's bio-ecological theory**

Study 2 used Bronfenbrenner and Morris's bio-ecological framework (Bronfenbrenner & Morris, 2006) to organize the variables in the theoretical framework that guided the research. The predictors in the theoretical framework included one biosystem factor (severity of

disability), two individual system protective factors (optimism, adaptive coping), one microsystem protective factor (social support) and two microsystem risk factors (discrimination, out-of-home care) (Figure 5.1). The predicted relationships between these factors and outcomes in positive and negative domains of psychosocial well-being are summarized in the research framework in Figure 5.2.

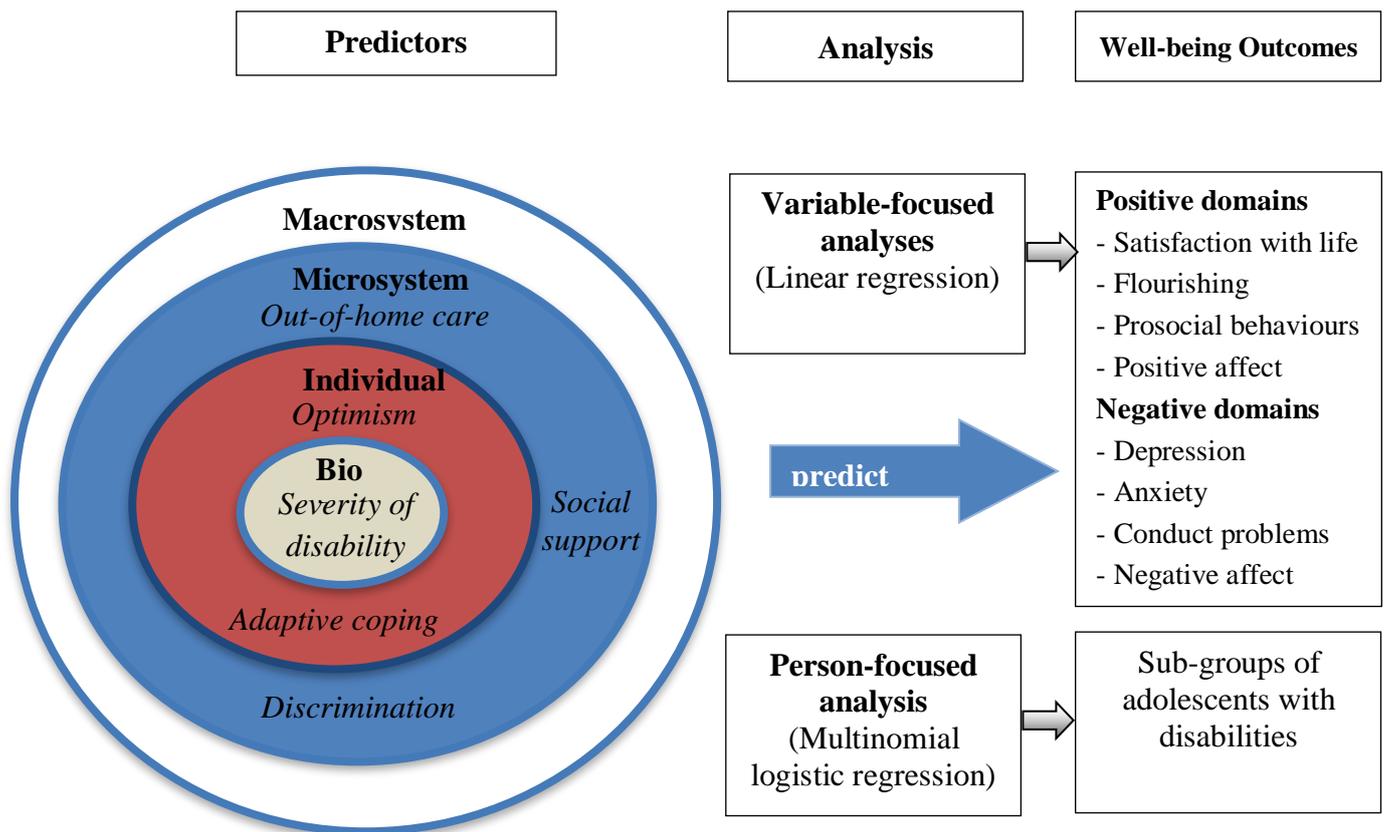


Figure 5.1: Theoretical framework: Showing predictor variables in Study 2 in the context of Bronfenbrenner and Morris’s bio-ecological framework and the analyses used to explore their relationships with well-being outcomes

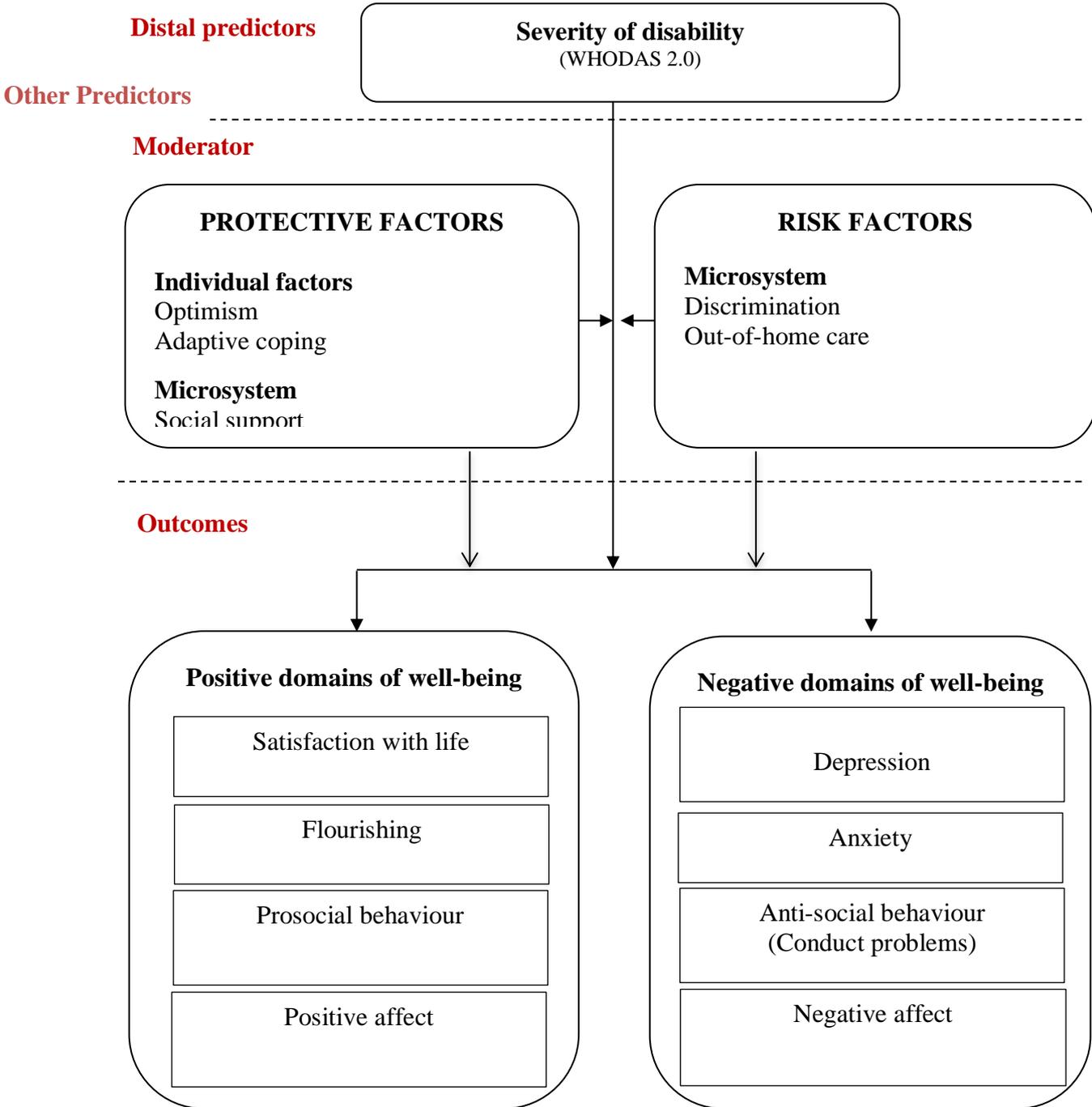


Figure 5.2: Research framework: Showing direct and moderating relationships between variables in Study 2

## 5.4 Aims and hypotheses

The present study had six aims:

1. To document the level of well-being among Vietnamese adolescents with visual and physical disabilities in
  - a. Four positive domains: satisfaction with life, flourishing, prosocial behaviour, positive affect.
  - b. Four negative domains: depression, anxiety, anti-social behaviour (conduct problems), negative affect.
2. To investigate whether type of disability influences adolescents' level of well-being in these domains
3. To examine the relationship:
  - a. Between severity of disability and these domains of wellbeing
  - b. Between other predictors (optimism, social support, adaptive coping, discrimination, out-of-home care) and these domains of wellbeing
4. To identify factors that may moderate the relationship between severity of disability and these domains of wellbeing.
5. To identify clusters of participants with similar patterns of well-being outcomes
6. To identify factors that predict membership in these clusters.

Aims (3) and (4) were addressed by testing the following hypotheses:

1. Severity of disability will be:
  - a. Negatively related to four positive domains of well-being:
    - i. Satisfaction with life
    - ii. Flourishing
    - iii. Prosocial behaviour
    - iv. Positive affect
  - b. Positively related to four negative domains of well-being:
    - i. Symptoms of depression
    - ii. Symptoms of anxiety
    - iii. Anti-social behaviour (conduct problems)
    - iv. Negative affect
2. Three protective factors, consisting of two psychological assets (optimism and adaptive coping) and one environmental resource (social support), will be

- Positively related to the four positive domains of well-being
  - Negatively related to the four negative domains of well-being
3. Two environmental risk factors (discrimination and out-of-home care) will be
    - Negatively related to the four positive domains of well-being
    - Positively related to the four negative domains of well-being
  4. The relationship between severity of disability and well-being will be moderated by
    - a. The three protective factors
    - b. The two risk factors

In terms of statistical techniques, aims (1) (2) (5) and (6) were addressed by exploratory analyses since no relevant previous research was available to guide hypothesis generation. To be more specific, descriptive statistics and between-groups multivariate analysis of variance (MANOVA) were used for aim 1 and 2 respectively (Pallant & Pallant, 2011). Cluster analyses were used for aim (5) and (6).

For aim (3) and (4) which had 4 hypotheses, there were three statistical techniques used to address these hypotheses. First, hypotheses 1 were investigated using Pearson product-moment correlation coefficient as this technique is used to describe the strength and direction of the linear relationship between two variables. Second, Hypotheses 2 and 3 were examined using multiple regression as this technique is used to investigate how well a set of variables is able to predict a particular outcome (Pallant & Pallant, 2011). Third, hypothesis 4 was tested using Pearson product-moment correlations (PROCESS macro for SPSS) (Hayes, 2013).

## 5.5 Method

### 5.5.1 Data collection

#### 5.5.1.1 *Sampling plan*

The present study focuses on adolescents with the most common types of disabilities in LAMICs, physical and visual disabilities. However, it was impossible to randomly or proportionally sample from all adolescents with these disabilities in Vietnam. First, no comprehensive statistics about the number and location of adolescents with disabilities is available from the national or provincial government agencies, even though some government departments record the number of adolescents with disabilities in specific categories. In addition, NGOs that provide services to adolescents with disabilities did not allow random or purposeful sampling among their clients/students. As a result, although every effort was made to recruit participants from diverse geographical, socio-economic, and service contexts, the

sample obtained in the present study is not nationally or regionally representative. This should be noted when interpreting the results of the study.

**Diverse service contexts.** Vietnamese adolescents with a disability may receive support from diverse formal service providers including Buddhist pagodas, churches, specialist schools, orphanages, charitable organizations and other agencies. However, some adolescents with a visual or physical disability receive only informal support from their families. Formal services can be managed by either government or NGOs.

Service providers in each geographic location were initially identified through internet searches and the researcher's professional networks. Snowball sampling techniques then provided information about additional services. These service providers were classified into four main types:

1. Specialist government schools, orphanages and other associated with the national Department of Labor, Invalids, and Society.
2. Specialist schools, orphanages and other agencies operated by non-government organizations such as pagodas, churches, international charity organizations, vocational training, communal home and child's families.
3. The third type of support service involved public-private partnerships (i.e., they were sponsored by both government and non-government sources).
4. Families are the only service provider for adolescents with disabilities who are not able to afford other types of support, or live far away from other sources of support sources, or may have a disability so severe that they are not eligible to receive other forms of support.

**Multiple sites.** Research sites were chosen to capture contextual differences in geography, socio-economic status and levels of exposure to the legacy of war found in Vietnam to the extent that this was possible in a three-year research project. These contexts should include (1) an urban city where many disability service providers are located, (2) a rural area in which family members may be the only source of support for many adolescents with disabilities (3) a region characterized by socio-economic diversity and in which ethnic minorities are represented and (4) a site with an elevated prevalence of disability due to a legacy of Agent Orange. To achieve this, data were collected in four sites: Ho Chi Minh City (major metropolitan centre), Ben Tre province (an inland regional site with few disability centres), Thua Thien Hue province (a coastal region with high levels of socio-economic and ethnic diversity) and Da Nang city (a site with a high prevalence of disability due to Agent

Orange). Da Nang and Ben Tre were also research sites in the *Young Lives* study, on which Study 1 was based. The deliberate overlap in research sites between the *Young Lives* study and the current study was designed to facilitate comparisons between Study 1 and Study 2. The location of the research sites is illustrated in Figure 5.3.



Figure 5.3: The location of research sites in Study 2

### **5.5.1.2 Sampling strategies**

A mix of sampling strategies, including purposive, proportional and snowball sampling, were employed to recruit service providers and participants. Service providers were first selected by purposive sampling to ensure the diversity of service types in the study in terms of type and the size of service providers, gender and type of disability of clients. Then, permission from those service providers to recruit adolescent participants for this study was requested.

Participants who were not in contact with any formal service providers were identified by a snowball technique. Service providers were asked if any clients/students who used their services in the past had withdrawn (e.g., because they were unable to pay the fees). In addition, when one family that was not in contact with a formal service provider was located, members of that family were asked if they knew of other adolescents with disabilities who were in a similar situation.

### **5.5.1.3 Recruitment**

To capture the well-being of diverse Vietnamese adolescents with disabilities, recruitment was conducted in the seven types of sites in which Vietnamese adolescents with disabilities live (family households, special schools, vocational training centres, Buddhist pagodas, churches, orphanages and private support centres) and in four different geographic locations across South and Central Vietnam. The recruitment process was designed to ensure that potential participants felt no pressure to consent to the study. When adolescents were living in institutions, a third person, who had no prior direct contact with prospective participants, delivered the introduction letter and consent forms. This ensured that adolescents' decisions would not be affected by the researcher or supervisors in the institution. In addition, all invited persons living in institutions, including those who did not agree to participate, were asked to return their consent forms to a sealed drop box. This box was placed in a convenient public area in their service centre. This procedure ensured that adolescents' decisions about whether or not to participate remained confidential. This was a second technique aimed at ensuring that there was no pressure on their decision. All participants, including those with visual disability, answered the questionnaire delivered orally in an interview form. Only those who are able to read and write and willing to answer the survey by paper and pen were allowed to do as they wished.

Although the sample in this study captured the diversity in the Vietnamese population, it was not nationally or regionally representative. Participants were drawn from four research sites all of which were only in Southern Vietnam. The implication for this is that data from this

study cannot be used as the basis for estimates of the prevalence of particular outcomes for any positive or negative domain of well-being. For example, the data can not be used to estimate the national, regional or provincial prevalence of severe or very severe symptoms of anxiety or depression among Vietnamese adolescents with a visual or physical disability.

The study used a cross-sectional design in which two field trips were carried out. The first field trip in January 2014 aimed to (1) locate disability service providers and (2) conduct a pilot test with a small sample of adolescents with a visual or physical disability to examine the relevance of the measures that were planned to use in the study. The second field trip in January - March 2015 collected data from the participants from the located service providers.

***Disability status.*** Because the aims of Study 2 did not require the use of archival data, it was possible to use the WHO ICF framework to define disability and the WHO DAS 2.0 to assess the disability status of potential participants. Unlike the screening questions used to identify visual and physical disabilities, the WHO DAS 2.0 allows assessment of the severity of impaired functioning. This allowed the inclusion of adolescents with moderate disabilities, and for severity of disability to be included as a predictor of psychological well-being. Identifying the types of impairment and the extent to which this limited their participation in life activities involved two separate procedures: recruitments of service providers and recruitments of adolescent participants.

### **Recruitments of services providers**

Most of the service providers that had been identified in the first field trip were reconnected as sites for recruitment in the second field trip. Recruitment took place through a total 12 service providers and 15 families across four research sites.

It was impossible to recruit an equal number from each type of service providers in each of the research sites, because individual service providers usually focus on providing support for young people with one type of disability. For example, one Church-based disability centre provided care primarily for young people with intellectual disabilities and orphans. Thus, only one participant was eligible and recruited from this service provider. In contrast, it was easier to find adolescents with visual and physical disabilities in vocational training centres. Because many disability services in Vietnam are centralized, and draw clients from other parts of the country, the largest single site for recruitment was Ho Chi Minh City (Table 5.1).

Table 5.1: The number of participants recruited in four sites

Service provider type	Number of participants			
	Hue	Da Nang	Ho Chi Minh	Ben Tre
Government	0	41	29	0
Non-government				
Specialist school	4	0	0	0
Pagoda	18	0	15	0
Church	0	1	0	0
Vocational training centre	0	0	28	0
Communal home	0	0	5	0
Public - private partnerships	23	0	0	26
Families	5	4	1	5
<b>Total</b>	<b>51</b>	<b>46</b>	<b>78</b>	<b>31</b>

Note. n = Number of participants.

### **Recruitment of adolescent participants**

The researcher first created a list of service providers identified during the first field trip. After that, the researcher made telephone contact with the Heads or Managers and asked for a face-to-face appointment during which she provided an explanation about the study and requested their permission for a third person, who was not directly involved with the prospective participants to deliver information letters and consent forms to young people with visual or physical disabilities who receive support from their service.

The number of introduction letters suggested by the service provider were then delivered. All invited persons, including those who did not agree to participate, were asked to return their consent forms to a sealed drop box. This box was placed in a convenient public area in their service centre. This procedure ensured that prospective participants' decision of whether or not to participate remained confidential. The response rate for participation was 93% (224/240).

Adolescents who had been identified as having a visual or physical disability by a service provider or by their family, who gave consent to participation, and who had a parent or guardian who gave consent to participation (if they were under 18 years of age), underwent a screening test to determine whether they meet the eligibility criteria.

- Children's age was determined from birth certificates (or from their guardian's estimate of their age if a birth certificate is not available)

- Disability status was determined by administration of the WHODAD 2.0 by the principle researcher or the research assistant.
- The ability to understand the Vietnamese language sufficiently to provide valid data was informally checked via conversation with the researcher.

As a result, the sample consisted of Vietnamese adolescents who satisfied three inclusion criteria: aged 10-19 years; have visual or physical disability, and are able to use and understand verbal or written Vietnamese.

Consent for participation was obtained from the young person, and from their parents if they were under 18 years of age and lived at home, or from their guardian if they lived in a residential facility far from their parents, or if their parents were illiterate. Guardians were the people who had been given permission by the adolescents' parents to have the main responsibility for decisions affecting the adolescents' welfare, and who were acknowledged by law as the adolescents' guardians.

All adolescent participants, including the younger ones, answered the questionnaire verbally in the interview format, unless they were capable and willing to do this in pen-and-paper format. All questionnaires that were completed by interview were delivered by one of two individuals: the principal researcher or a research assistant, who was a bilingual Vietnamese expert in the disability field. The research assistant received prior training in all research procedures from the principal researcher, and had the opportunity to obtain feedback on her performance. She was responsible for delivering the questionnaire by interview to about one-quarter of the participants.

Participants were provided with the opportunity to organize the meetings with the principle researcher at a safe and secure location outside their residence or at any location in which they feel comfortable and in which confidentiality could be maintained. All location in which interviews took place prevented the interview and the responses being overheard by others. It was possible for a trusted adult to accompany participants to the interview, but they were not allowed to hear the conversation. All participants and their parents/guardians preserved the right to stop the interview at any time.

#### **5.5.1.4 Derivation of the sample**

After personal consent forms (from 18 to 19-year-old participants) or guardian's consent forms (from those who were younger than 18 years of age) were received agreeing to participation, adolescents were contacted and to schedule the screening tests that checked their

eligibility. The twelve prospective participants who failed to meet inclusion criteria were thanked for their time but took no further part in Studies 2 and 3. Those who met inclusion criteria about age, disability and language were invited to complete the survey in either a written or a one-to-one interview format. Most participants answered the questionnaire by interview due to either their poor literacy in Vietnamese or the fact that it was not possible to make a Braille version of the questionnaire available.

To minimize the burden, the questionnaire was divided into three parts. Each part took approximately 45 minutes to complete. Participants who met the inclusion criteria could choose to complete one, two or all three parts of the questionnaire. All participants agreed to complete all three parts. However, there were two participants who had low level of communication during the interview and their data were excluded. Thus, there were 210 participants (data of 206 participants were kept for analysis after data were cleaned). The high response rate and participation rate resulted in a sample that was inclusive even though it was not representative.

### **5.5.2 Sample characteristics**

Participants were recruited via their service providers. Therefore, before describing characteristics of adolescent participants with visual and physical disabilities, an insight into these service providers is provided.

### **5.5.3 Characteristics of the sources of support for young people with a disability**

**Variety in funding and management.** The 12 providers of support that were recruited to the study represented different types of management and funding. First, some were funded and managed by the Vietnamese. Second, other service providers were small NGOs with a specific function. One example is a vocational training centre that was established and managed by a man with a physical disability primarily to teach adolescents with physical disabilities how to fix electronic devices. Another type of service provider consisted of small-scale private communal homes that charged a fee to provide care for young people with a specific type of disability. The fourth type of service provider consisted of specialist schools for young people with disabilities were sponsored by international charitable Organizations. Most of the schools of this type are in good condition and provide a variety of types of support. The fifth type of service provider consisted faith-based disability centres such as those offered by Buddhist pagodas, and organizations sponsored by Christian churches that provide basic care and

specialist support for young people with disabilities. Most of the adolescents assisted by these organizations are orphans. The sixth type was the public-private partnership in service providers. Examples of such a “mixed” model were providers for which the location had provided free of charge by government while funds to build and then maintain the centres came from either international NGOs or from self-sustaining economic activities such as a bakery, restaurant, massage service, toothpick and incense production. This category also included a service provider that received support from a large number of different sources in addition to receiving regular financial support from the government.

Lastly, adolescents’ own families were often the most important, or only provider of care and support.

**Variety in material environments and quality of service.** By visual inspection, it could be seen that the quality of the physical environments showed considerable variability across service providers (Figure 5.5). Some of service providers were very well-resourced and were able to provide separate areas for recreation, accommodation, vocational training, and income-generating activities. In contrast, other centres were in poor condition. The type of activities and support provided by these service providers varied accordingly. Self-sustainable activities such as growing vegetables, selling incense, drawing, painting and making handcraft products were relatively common in well-resourced services (Figure 5.4). In addition, well-resourced centres often supported young people’s well-being by paying attention to the aesthetic characteristics of the centre (Figure 5.5), and by providing opportunities for physical exercise, yoga, music and other creative activities (Figure 5.6 and Figure 5.7). In contrast, other centres provided either a single service (e.g., vocational training or residential service) or no support for extra-curricular and social activities.



Figure 5.4: Photographs showing income-generating activities at some disability centres



Figure 5.5: Photographs showing the contrast in aesthetic characteristics between two disability centres

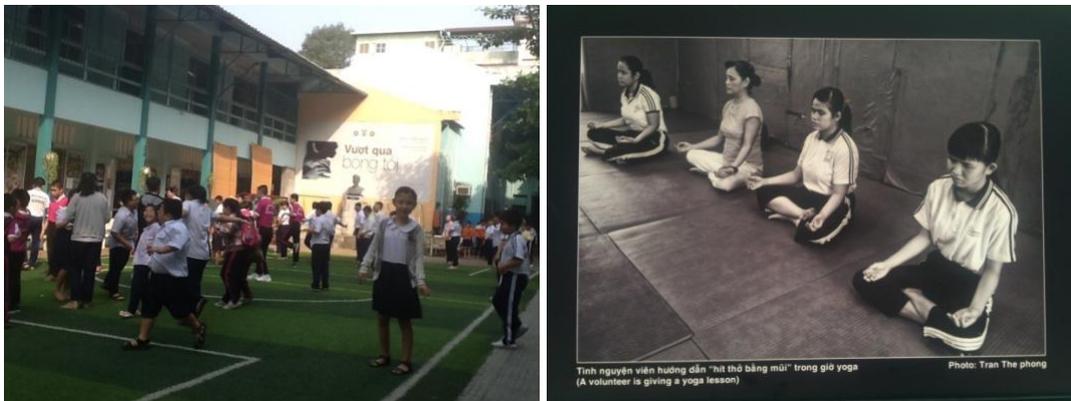


Figure 5.6: Group exercise and meditation activities to promote well-being offered at disability centres



Figure 5.7: A library of Braille books and group activities provided for leisure activities. Black and white photos: Tran The Phong

The 15 families included in the study each had their own unique living circumstances. However, the quality of housing and the quantity and quality of household possessions

indicated that many families, especially those in rural settings, experience financial hardship. One of the 15 families recruited to the study was caring for two adolescents with disabilities.

In short, it can be seen that service providers involved in this study were diverse in many aspects. This was the result of a sampling plan that attempted to capture the range of service providers available to young people with a disability in Vietnam. Understanding the characteristics of these services provided a foundation for understanding the results of this study.

### ***Adolescent participants' characteristics***

**Pooled sample.** The whole sample included 206 adolescents with either visual or physical disabilities aged 10-19 years old ( $M = 15.2$ ,  $SD = 2.5$ ) across four provinces in Vietnam (rural: 55.8%, urban: 44.2%). Despite their age, many participants had completed a relatively few years of schooling ( $M = 5.66$  years,  $SD = 4.0$ ) (Table 5.2). The greatest disparity in schooling was seen between participants from government services and participants whose main support was their families (Government:  $M = 8.02$ ,  $SD = 2.65$ ; Families:  $M = 3.81$ ,  $SD = 5.23$ ) (Table 5.3). Consistent with current communist ideology and traditional Vietnamese culture, most participants reported either that they had no religion (55.3%) or were Buddhist (33%). Ho Chi Minh City which is the largest city in Vietnam contributed the most participants (37.9%).

The majority of participants were judged to have a disability of moderate severity. Such participants commonly reported difficulty in self-care and joining social activities. Most disabilities were congenital (61.2%), and it is likely that some were attributable to ongoing environmental contamination by Agent Orange. Despite the passage of 40 years since the end of the Vietnam War, landmines accounted for one in ten disabilities (10.2%). As is the case in other LAMICs, traffic accidents (14.1%) and other types of injury were also significant contributors to participant's disabilities. The percentage of the sample who were male (62.1%) is similar to the percentage of all Vietnamese children with a disability who are male (57.1%) (UNICEF & MOLISA, 2009).

Table 5.2: Demographic statistics of the pooled sample

Variables	n = 206	%	95% CIs	
			Lower	Upper
<b>Age in years</b>				
10-14 (early adolescence)	79	38.3	31.6	45.1
15-19 (late adolescence)	127	61.7	54.9	68.4
<b>Site of care</b>				
In-home care	61	29.6	23.8	35.9
Out-of-home care	145	70.4	64.1	76.2
<b>Level of disability</b>				
Mild	4	1.9	0.5	3.9
Moderate	195	94.7	91.3	97.6
Severe	7	3.4	1.0	5.8
<b>Education level</b>				
No schooling	45	24.3	18.4	30.8
Grade 1-5	37	20.0	14.6	26.5
Grade 6-9	62	33.5	26.5	40.5
Grade 10-12	41	22.2	16.2	28.6
No response	21	11.0		

Note. n = Number of participants, % = Percentage, CIs = Confidence intervals.

Table 5.3: Demographic characteristics of the pooled sample (n = 206) by type of service providers

	Male (%)	Physical disability (%)	Mean age (SD)	Years of school (SD)
Government services n = 70	57.8	28.1	16.52 (2.2)	8.02 (2.7)
Non-government service n = 87	74.4	64.1	16.95 (2.1)	5.08 (4.3)
Public-private partnership n = 49	67.3	55.1	14.69 (2.7)	6.49 (3.5)
Families n = 16	62.5	75.0	14.44 (2.5)	4.00(5.1)
Total n = 206	62.1	54.9	15.21 (2.5)	5.66 (4.0)

Note. n = Number of participants

**Sample by type of disabilities.** The demographic characteristics of with each type of disability are presented in Table 5.4. Both groups of adolescents were biased in favour of males, older adolescents and disabilities of moderate severity. Although the mean age of adolescents in both groups was older than 15 years, a large percentage of them had not yet completed primary school. Adolescents with physical disabilities who had never been to school were almost double that of their peers with visual disabilities. The vast majority of participants with a visual disability were currently receiving support in an urban area. In contrast, this was true of less than half of the participants with a physical disability. Many participants (over 45%) in both groups lived out-of-home. Almost 90% of participants with physical disability were in out-of-home care.

Table 5.4: Demographic characteristics of the sample according to type of disability

Variables	Visual (n = 93)		Physical (n = 113)	
	n	%	n	%
Gender				
Male	58	62.4	70	61.9
Female	35	37.6	43	38.1
Age in years				
10-14 (early adolescence)	39	41.9	40	35.4
15-19 (late adolescence)	54	58.1	73	64.6
Level of disability				
Mild	4	4.3	0	0
Moderate	89	95.7	106	93.8
Severe	0	0	7	6.2
Education level				
No schooling	16	17.6	29	30.9
Grade 1-5	18	19.8	19	20.2
Grade 6-9	35	38.5	27	28.7
Grade 10-12	22	24.2	19	20.2
Location				
Urban	69	74.2	46	40.7
Rural	24	25.8	67	59.3
Sites of care				
In-home care	49	52.7	12	10.6
Out-of-home care	44	47.3	101	89.4

Notes. n = Number of participants.

#### 5.5.4 Refinement of the measures

The cultural and developmental appropriateness of the planned measures and their suitability for persons with a visual or physical disability were assessed by examining their relevance, acceptability and psychometric properties in a pilot test. This was necessary, because even though the planned measures were selected because they had previously been used in research involving adolescents and/or Asian populations, none had been previously been used in research involving Vietnamese adolescents with disabilities. For example, the *Satisfaction with Life Scale* has been used successfully in a sample of Asian young people (Pavot & Diener, 2013), and among adults with disabilities (Chwalisz, Diener, & Gallagher, 1988), including those in Vietnam (Takahashi et al., 2011), but has not been used in research on disabled young people in Vietnam. The Asian adaptation of the *Ways of Coping Checklist* has proven useful in research in many Asian countries, including those adjacent to Vietnam (Sawang et al., 2010). However, it had not previously been used with young people in Vietnam. The relevance, acceptability and psychometric properties of measures that I planned to use in Study 2 were examined in a pilot study.

##### 5.5.4.1 Pilot study

First, the researcher created a list of service providers for young people with disabilities via internet searches and academic networking. After contacting and obtaining permission from the service providers' Heads or District Officers, a third person, who was not a teacher or school principal for the participant, sent invitations and consent letters to prospective participants. Adolescents agreed to participate were contacted by the researcher to check their eligibility. Participants who met inclusion criteria then completed the questionnaires in writing or by interview.

The questionnaire contained demographic questions and twelve measures:

- (1) Screening disability test from *WHO Disability Assessment Schedule 2.0* (World Health Organization, 2013c)
- (2) Satisfaction with life from *the Satisfaction with Life Scales* (Diener, Emmons, Larsen, & Griffin, 1985)
- (3) *Flourishing Scale* (Diener et al., 2009)
- (4) The prosocial behaviour and conduct problems from *the Strengths and Difficulties Questionnaire* (Goodman, Meltzer, & Bailey, 1998)
- (5) The positive and negative affects subscale from *the Positive and Negative Affect Schedule* (PANAS) (Watson, Clark, & Tellegen, 1988).

- (6) Depression and anxiety subscale from *Depression, Anxiety and Stress Scale - 21* (Lovibond & Lovibond, 1995)
- (7) Optimism sub-scale from *The Revised Life Orientation Test* (Scheier, Carver, & Bridges, 1994)
- Social support from *The Expanded Vaux Social Support Record* (Vaux, 1988)
- (8) Discrimination from *The Everyday Discrimination Scale* (Lewis et al., 2012 & Fitchett, 2012)
- (9) Adaptive coping from *The coping flexibility* (Kato, 2012)

These measures were translated into Vietnamese with the back translation process.

After completing each of the above tests, the respondent was asked to complete a brief valuation form (Appendix C). The ten questions in the evaluation form asked for participants' opinion about the level of difficulty, clarity of language, time-taken and relevance of the items in the measure relevance and content relevance (Stephen, 1952) The questionnaire was in Vietnamese, which then underwent the back translation process to English.

#### **5.5.4.1.1 Pilot study sample**

Participants were adolescents with a visual or a physical disability (n= 28, Male: 57.1%, Physical disability: 57.1%). Their mean age was 15.07 (SD = 2.99) but on average they had completed only six years of schooling (M = 6.86, SD = 3.27). The participants were drawn from ten service providers located in four provinces.

#### **5.5.4.1.2 Results of the pilot study**

**Internal consistency reliability.** The internal consistency of each of the measures was determined using Cronbach's alpha coefficient after reversing negative items. Alpha coefficients were higher than 0.78 for all except three measures: the *Positive and Negative Affect Schedule* (Cronbach's  $\alpha = 0.64$ ), the *Coping Flexibility Scale* (Cronbach's  $\alpha = 0.51$ ) and *The Revised Life Orientation Test* (Cronbach's  $\alpha = 0.60$ ) (Appendix G).

The measure which had the lowest internal consistency was The Revised Life Orientation Test, Cronbach's  $\alpha = 0.60$ . However, the number was still in the acceptable range, given that there are only ten items in the scale and the small number of participants involved in the pilot test (George & Mallery, 2003).

As the *Positive and Negative Affect Schedule* consists of 20 items which are opposite in meaning (10 items for positive affect and 10 items for negative affect) and the overall Cronbach's  $\alpha$  was low (Cronbach's  $\alpha = 0.64$ ), a reliability analysis was run to test these subscales

separately. The result indicated that they had high reliabilities, Cronbach's  $\alpha = 0.78$  and  $0.81$  for positive and negative affect subscale respectively.

The Coping Flexibility Scale ( $0.51$ ) had very low reliability (Cronbach's  $\alpha = 0.51$ ), thus decision was made to replace it with the subscale from *The Ways of Coping Checklist Scale* (Sawang et al., 2010).

In the absence of a suitable alternative, *The Revised Life Orientation Test* (Cronbach's  $\alpha = 0.60$ ) was retained despite its low internal consistency. In addition, this number is still in the acceptable range, given that there are only 10 items in the scale (George & Mallery, 2003).

**Participants' feedback.** Many participants expressed concerns about answering the items in *The Everyday Discrimination Scale*. They confessed that they did not feel comfortable sharing their bad experiences of discrimination with a stranger, especially in a face-to-face interview. It was clear that participants were avoiding or reducing prevalence and/or severity of discrimination and victimization. The participants' feedback is consistent with Hillman's concept about self-protective mechanism used among disadvantaged adolescents (Hillman, Wood, & Sawilowsky, 1998). This phenomenon has previously been recorded among other population with disabilities (Green, Davis, Karshmer, Marsh, & Straight, 2005). To overcome this thread to validity of the data, the wording of the lead question was changed so that the referent was no longer "you" but "your friend who has the same type and level of disability like you". This change in wording was informed by research on the "personal group discrimination discrepancy": a phenomenon in which minority group member perceive that other members of their group, but not themselves, to be the target of discrimination (Wright, Taylor, Moghaddam, & Lalonde, 1990).

In summary, the majority of measures showed high internal consistency reliability and therefore could be used in the main study. One planned measure was eliminated (*the Coping Flexibility Scale*) and another planned measure needed a small change (*the Everyday Discrimination Scale*). Based on these results, the final measures for the main study in this thesis were finalized.

#### **5.5.4.2 Final Measures used in Study 2**

The description of the measures is organised into three categories: demographic, predictor and outcome variables. One variable, severity of disability had multiple roles: the basis for an inclusion criterion, a demographic variable, and the principal predictor variable. It is described with the other demographic variables. An overview of the measures is provided in Figure 5.8.

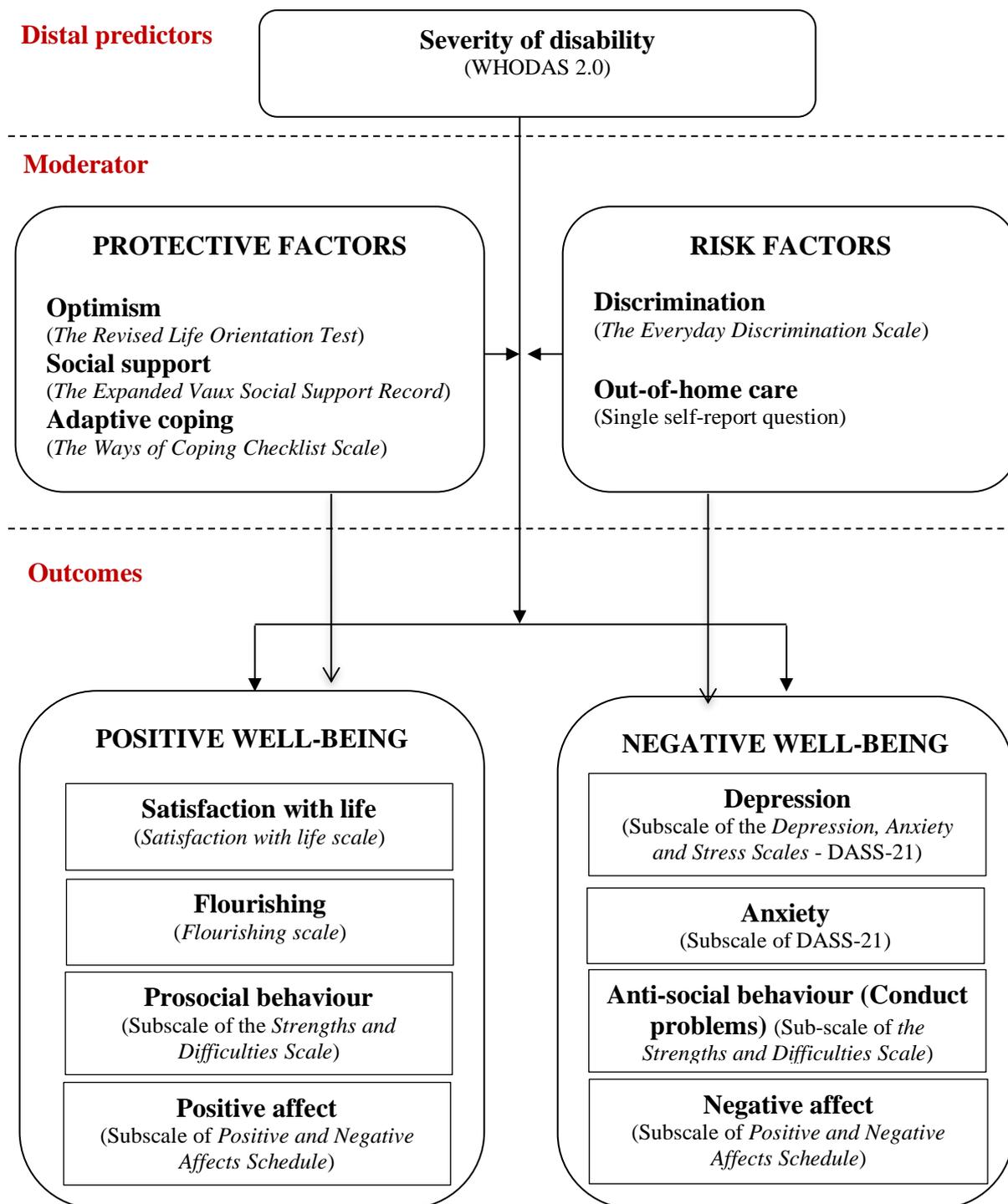


Figure 5.8: Measures in Study 2 in the context of the research model

#### **5.5.4.2.1 Demographic variables**

Information was gathered concerning ten demographic characteristics of the participants (severity of disability, type of disability, source of the disability, ethnicity, age, gender, level of education, rural/urban location, religion, and type of service provider).

#### **5.5.4.2.2 Severity of disability**

The 12-item short form of *The World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0)* was used to assess the severity of participants' disabilities (World Health Organization, 2013c). This measure uses the *International Classification of Functioning, Disability and Health (ICF)* as its theoretical framework, and therefore considers three factors, impairment, activity limitation and participation, into account when assessing severity of disability level (World Health Organization, 2013c). Thus, the philosophical perspective underlying this measure is consistent with that adopted in this research.

The WHO DAS 2.0 evaluates disability in six domains of life: cognition, mobility, self-care, getting along, life activities and participation. Each of the 12 items is rated on a five-point scale: (1) for 'none', (2) for 'mild', (3) for 'moderate', (4) for 'severe' and (5) for 'extreme'. Thus, the range of possible scores is 12 to 60.

Previous research suggests that the WHODAS 2.0 was broad cross-cultural applicability (World Health Organization, 2010; Üstün et al., 2003), and good test-retest reliability at the item (intra-class coefficient = 0.69-0.89), domain (intra-class coefficient = 0.93- 0.96), and overall levels (intra-class coefficient = 0.98). The 12-items short form of WHO DAS 2.0 explains 81% of the variance of the full 36-item version. In this study, the internal consistency of the measure was satisfactory (Cronbach's  $\alpha = 0.70$ ).

#### **5.5.4.2.3 Other demographic variables**

Information concerning type of disability, source of the disability, age, gender, level of education, rural/urban location, religion, ethnicity and type of service provider were collected using single-item self-report measures (Appendix H).

#### **5.5.4.2.4 Other predictors of well-being**

Severity of disability was the main predictor variable. There were also five other predictor variables. Three of these were protective factors: optimism, adaptive coping and social support. Two were risk factors: discrimination and out-of-home care.

**Optimism.** The optimism subscale from the *Revised Life Orientation Test (LOT-R)*, was used to measure optimism (Scheier et al., 1994). Participants completed all 10 items on the test, which includes three items measuring optimism, three items measuring pessimism and four items that serve as fillers. Participants rated each item on a five-point scale: from 0 (strongly disagree) to 4 (strongly agree). The optimism score is the sum of the three optimism items (Herzberg, Glaesmer, & Hoyer, 2006). Despite the very small number of items, in the current study the internal consistency of the measure was satisfactory (Cronbach's  $\alpha = 0.64$ ).

**Adaptive coping.** The problem-focus and support-seeking subscale of the Asian adaptation of *The Ways of Coping Checklist Scale* was used to measure adaptive coping (Sawang et al., 2010).

The 20 items reflecting adaptive coping strategies used in this study consisted of fourteen problem-focus items and six support-seeking items, which were each rated on a four-point scale from 0 (does not apply and/or not used) to 3 (used a great deal). Sample items include: *Accepted my strong feelings but didn't let them interfere with other things too much, changed or grew as a person in a good way* (problem-focus), *talked to someone to find out about the situation, accepted sympathy and understanding from someone, asked someone I respected about how I was feeling* (support-seeking). The adaptive coping score was the sum of the 20 items. Although Vietnam was not included in the validation study for this scale, this adapted version has previously proved useful in many nearby countries such as Indonesia, Sri Lanka, Singapore and Thailand (Sawang et al., 2010). In this study, the measure had high internal consistency (Cronbach's  $\alpha = 0.82$ ).

**Social support.** This was measured by *The Expanded Vaux Social Support Record*, which is an adaptation of the Vaux Social Support Record (Vaux, 1988). The expanded scale consists of 15 items that assess four types of support (companionship, emotional, informational, instrumental) from three sources (staff at their school, family members and peers). Each item is rated on a three-point scale: 0 (none), 1 (a few), 2 (many). The social support score is the sum of all social support items. Sample items include: *There are people in my family I can talk to, who give me good advice about my problems. At school, there are adults I can talk to who care about my feelings and what happens to me.* In the current study, the social support scale had high internal consistency (Cronbach's  $\alpha = 0.80$ ).

**Discrimination.** Experiences of discrimination were assessed by an adaptation of the 9-item *Everyday Discrimination Scale* (Lewis et al., 2012; Fitchett, 2012). As a result of the pilot test, wording of the lead question was changed from "you" to "your friends who have visual or

physical disabilities'. Sample items are: *Your friends are treated with less courtesy than other people are, your friends are treated with less respect than other people are, people act as if they are afraid of your friends, your friends are called names or insulted etc.* The items in the scale are rated on a 6-point scale: 6 (almost everyday), 5 (at least once a week), 4 (a few times a month), 3 (a few times a year), 2 (less than once a year), 1 (never).

The appropriateness of this measure was examined in a wide range of adult population aged 18 and older in the study of Kim and Ford (2014). The participants included 884 non-Hispanic Whites, 4,950 Blacks, 2,733 Hispanics/Latinos, and 2,089 Asians. Findings indicated that, except for Item 7 ("People act as if they're better than you are") the measure was invariant across four racial/ethnic groups. It was concluded that this measure is likely to be appropriate for use in Asia (Kim & Ford, 2014). So far, there is no measure of discrimination that has been validated for Vietnamese adolescents. This study was the first to determine its appropriateness for this population. After changing the subject, the modified scale seems to demonstrate better internal consistency (Cronbach's  $\alpha = 0.86$ ). In the pilot study when the original wording was used, this measure had a Cronbach's  $\alpha$  of 0.78.

**Out-of-home care.** Information on this variable was collected from a single self-report question.

#### **5.5.4.2.5 Well-being outcomes**

Eight domains of well-being were assessed. Four of these were positive domains of well-being (satisfaction with life, flourishing, prosocial behaviour, positive affect). The other four were negative domains of well-being (symptoms of depression and anxiety, antisocial behaviour, and negative affect). Four positive domains of well-being outcomes were assessed:

**Satisfaction with life (SWL).** This was measured using the *Satisfaction with Life Scale* (Diener et al., 1985 & Griffin, 1985). This scale contains 5 items that are rated on a seven-point Likert-style scale. The score is the sum of ratings across of five items. Possible scores range from 5 to 35 and can be classified into 6 categories: extremely dissatisfied (5-9), dissatisfied (10-14), slightly below average in life satisfaction (15-19), average in life satisfaction (20-24), satisfied (25-29) and extremely satisfied (30-35).

This scale has been proven to have satisfactory validity and reliability. They have high test-retest reliability (two-week interval and four-year interval of the scale are 0.83 and 0.54 respectively Beuningen, 2012).

Since introduced in 1985, the scale has been employed in a numerous studies and proven as a satisfactory measure (Pavot & Diener, 2013). Test-retest reliability for a two-week interval and four-year interval of the scale are 0.83 and 0.54 respectively. Internal reliability ranges between 0.80 and 0.89. Furthermore, the association of the Satisfaction with Life scale with other measures of health attitude and subjective wellbeing such as Rosenberg Self-Esteem Scale, Marlowe-Crowne Social Desirability Scale showed this scale has sufficient construct validity (Beuningen, 2012; Diener et al., 1985). Nomological and discriminant validity was also evident in the study of Beuningen (2012). In terms of affected factors, except marital status which is not involved in this study; sex, age, social desirability, education level, health insurance status do not seem to affect scores (Dijkers, 1999; Pavot & Diener, 2013). All these good indicators of SWL scale were resulted from studies in various samples and contexts all over the world including young people with disabilities (Pavot & Diener, 2013).

Young people with disabilities were found as target populations in at least two studies that used the SWL scale (Allman & Diener, 1990; Chwalisz, Diener, & Gallagher, 1988). Although the number of disabled youth in previous studies of Allman and Diener (1990), and Chwalisz et al (1988) was relatively small (32 and 29 respectively), the result provided insight into life satisfaction of young people with disabilities and the relevance of using the SWL scale among this population. Two groups of students with disabilities in the two separate studies had mean of the Satisfaction with Life score were 20.8 (SD=8.4) and 24.3 (SD=7.4) showing average life satisfaction level (Allman & Diener, 1990; Chwalisz, Diener, & Gallagher, 1988; Pavot & Diener, 1993).

Within my scope of searching, at least one study used the SWL scale in the sample of Vietnamese with physical disability those were over 18 years of age (Takahashi et al., 2011). The SWL scale was the main measure along with another one used in this study. Mean score of the scale was below 20 in all subset of the sample. The result from study of Takahashi et al. (2011) and positive reviews from previous studies demonstrated that SWL score is reliable and valid to use for adolescents with visual and physical disabilities in Vietnamese context. Therefore, the present study used the SWL scale showing high consistency with the alpha coefficient was 0.89.

**Flourishing.** This was measured by *the Flourishing Scale* (Diener et al., 2009). This scale consists of eight items that measure a person's perception of his/her level of success in six domains including engagement, relationships, self-esteem, meaning and purpose, and

optimism. Participants rate each item on a seven-point scale from 1 (lowest score) to 7 (highest score). Sample items included: *I lead a purposeful and meaningful life, I am a good person and live a good life, people respect me.* The flourishing score is the sum across all items. Possible scores range from 8 to 56. Higher scores indicate higher levels of flourishing.

So far there has been no controversial about the validity and reliability of Flourishing Scale. Many studies confirmed the relevance of this scale in measuring positive wellbeing (Duan & Xie, 2016; Howell & Buro, 2015; Sumi, 2014). Although Flourishing Scale was not adopted in Vietnam, it has been evident that this scale works well for the Asian population, such as Japanese (Sumi, 2014) and Chinese adolescents (Duan & Xie, 2016). The current study reported the excellent internal consistency reliability for the Vietnamese adolescents with disabilities (Cronbach's  $\alpha = 0.90$ ).

**Prosocial behaviour.** This was measured using prosocial behaviour sub-scale from the adolescent self-report form of *The Strengths and Difficulties Questionnaire (SDQ)* (Goodman et al., 1998). This scale contains 5 items that are rated on a three-point scale (0 = not true, 1 = somewhat true, 2 = certainly true). Sample items are: *I try to be nice to others, I am kind to young children.* The prosocial score is the sum of the ratings across items. Higher scores indicate higher levels of prosocial behaviour. The SDQ has been used successfully in a wide range countries including Vietnam (Research and Training Center, 2006). Its validity and reliability have been reported in many studies (Goodman, 1999, 2001; Shojaei, Wazana, Pitrou, & Kovess, 2009). In this study, the prosocial behaviour showed satisfactory internal consistency despite the small number of items (Cronbach's  $\alpha = 0.64$ ). Cut scores are available for scores within the normal, borderline and clinical ranges.

**Positive affect.** This was measured using positive affect sub-scale from *The Positive and Negative Affect Scale (PANAS)* (Watson et al., 1988). This sub-scale contains 10 items that assess present mood and are rated on a five-point scale from 1 (very slightly or not at all) to 5 (extremely). Sample items are: *Interested, inspired, strong, proud.* The positive affect score is the sum of the scores across items. Higher scores indicate higher levels of positive affect. Previous research has shown the reliability and validity of this scale to be moderately good (Crawford & Henry, 2004; Watson et al., 1988).

So far, there have still been a few concerns about the PANAS scale. The most controversial characteristic is the independence of its subscale. As it has been expected to show negatively relation, positive and negative affect scales was reported low correlation in many

studies, even in the study of its own initiative (Chen, Dai, Spector, & Jex, 1997; Spector, & Jex, 1997; Mehrabian, 1998; D. Watson et al., 1988). In addition, the absence of items reflecting typical human moods such as “happy” and “sad” in the scale has also raised concern about its validity and coverage.

However, it has been argued that positive and negative affects in fact are opposite vectors of the same dimension and should treat them as two independent factors (Russell & Carroll, 1999). If employing this perspective, positive affect and negative affect in PANAS could be considered as a bipolar structure of overarching happiness-sadness dimension. Thus, even “happy” or “sad” emotion are not explicitly included among items in PANAS, other levels of these emotions are covered. In addition, reliability and validity of this scale were moderately good (Crawford & Henry, 2004; D. Watson et al., 1988). The Cronbach Alpha coefficient for positive and negative affect scale was 0.86 to 0.90 and 0.84 to 0.87 respectively with the “right now” time frames (D. Watson et al., 1988). Similarly, good internal consistency reliability for the sub-scales was found in the present study (Cronbach’s  $\alpha = 0.76$  and  $0.85$  for positive and negative affect, respectively). Therefore, PANAS was considered a relevant measure to collect data for the two dependent variables in the current study: Positive affect and negative affect. Suggestion for cut-off score of “right now” positive affect was mean scores =  $29.7$  ( $SD = 7.9$ ); for negative affect was mean score =  $14.8$  ( $SD = 5.4$ ) (D. Watson et al., 1988). So far, there is no measure of depression and anxiety that has been validated for Vietnamese adolescents. This study was the first to determine its appropriateness for this population. The sub-scale had satisfactory internal consistency reliability in the current study (Cronbach’s  $\alpha = 0.76$ ).

**Symptoms of Depression.** Symptoms of depression were measured using the depression sub-scale from the 21-item short form of the *Depression, Anxiety and Stress Scales (DASS-21)* (Lovibond & Lovibond, 1995). The depression sub-scale contains 7 items, each of which is rated on a four-point scale from 1 (did not apply to me at all over the last week) to 3 (applied to me very much or most of the time over the past week). Sample items are: *I couldn’t seem to experience any positive feeling at all, I felt that I have nothing to look forward to.* The score is the sum of the ratings. Because the DASS-21 is the short form version of the 42-item DASS, the final score of the sub-scale was multiplied by two (x2) to allow interpretation of the severity of symptoms: 0-9 (normal), 10-13 (mild), 14-20 (moderate), 21-27 (severe), 28+ (extremely severe) (Lovibond & Lovibond, 1995).

**Symptoms of Anxiety.** These were measured using the anxiety sub-scale of the 21-item

short form of the *Depression, Anxiety and Stress Scale (DASS-21)* (Lovibond & Lovibond, 1995). The number of items and rating scale are the same as those previously described for the depression subscale. A sample item is *I was worried about situations in which I might panic and make a fool of myself*. The total score of the sub-scale was multiplied by two (x2) to allow interpretation of the severity of symptoms: 0-7 (normal), 8-9 (mild), 10-14 (moderate), 15-19 (severe), 20+ (extremely severe) (Lovibond & Lovibond, 1995).

It is clear from the literature that the DASS-21 is a well established instrument for measuring depression, anxiety and stress (two of them: depression and anxiety were investigated in the current study) among adult in the Western culture (Henry & Crawford, 2005; Jihan S.R. Mahmoud, Lynne A. Hall, & Staten, 2010 2010). However, there have been concerns relating to:

- (1) using the sub-scales from DASS-21 to measure depression, anxiety and stress separately (Duffy, Cunningham, & Moore, 2005 2005),
- (2) using for adolescent population (Patrick, Dyck, & Bramston, 2010 2010),
- (3) and using among Asian population (Oei, Sawang, Goh, & Mukhtar, 2013 & Mukhtar, 2013).

It is evident that although DASS-21 failed to support three-factor model (Duffy et al., 2005), the depression and anxiety sub-scales were found still robust and applicable (Szabó, 2010; Tully, Zajac, & Venning, 2009 2009). Only the validity of stress items in the measure raised question and needs further refinement (Szabó, 2010). DASS-21 has been one of the most useful measures for distinguishing between depression and anxiety (Jihan S.R. Mahmoud et al., 2010). These sub-scales in DASS-21 have good validity, reliability, internal consistency and excellent psychometric properties (Tully et al., 2009). In addition, it was evident that this measure, particularly depression and anxiety sub-scales, work well for adolescents as much as for adult population (Szabó, 2010). Therefore, although the utility of the whole DASS21 for adolescents may be a concern, using the sub-scales of depression and anxiety should not a problem.

Regarding the utility of the DASS-21 among Asian population, there was a suggestion that the 18-item version might be more suitable than the 21-item version (Oei et al., 2013). However, the items excluded in the revised version were three items in the stress sub-scale so using depression and anxiety sub-scales would not be a big issue among Asian population. In addition, Tran, Tran & Fisher (T. Tran et al., 2013) recently validated the DASS-21 among Vietnamese women in primary health care. The result showed that in general this measure is

culturally sensitive enough to detecting symptoms of common mental disorders among Vietnamese in the research setting. In the current study, depression and anxiety sub-scale showed high internal consistency reliability (Cronbach's  $\alpha = 0.67$  and  $0.71$  respectively). Altogether, the sub-scales of DASS-21 appear to be useful for screening depression and anxiety among Vietnamese adolescents.

As depression and anxiety were two important variables in the negative well-being outcomes, I was aware that the use of DASS 21 needed to be make sure in terms of its validity and reliability for the target population. Therefore, this study conducted confirmatory factor analysis to evaluate this measure for the Vietnamese adolescents with disabilities. The result is presented below.

The fourteen anxiety and depression items from the DASS-21 were subjected to principle components analysis using SPSS version 23. Inspection of the correlation matrix revealed the presence of many co-efficient of .3 and above, therefore a promax rotation was used. The factorability of the matrix was shown by a Kaiser-Myer-Olkin value of 0.76 and a significant value for Bartlett's Test of Sphericity ( $\chi^2(91) = 607.6, p < .001$ ). The two-component solution explained a total of 37.5% of the variance, with component 1 contributing 26.9% of the variance and component 2 contributing 10.6% of the variance. The Eigen values for both components were above 1.0.

The pattern matrix resulting from the promax rotation revealed the presence of a simple structure (Thurstone, 1947). The interpretation of the two components was consistent with the design of the DASS-21: with all seven depression items loading on component 1 and four of the anxiety items and no depression items loading on component 2. There was a moderate correlation between the two factors ( $r = .37$ ). The results of this analysis support the use of depression and anxiety items as separate scales, as suggested by the scale authors (Lovibond & Lovibond, 1995).

In summary, it is considered to be relevant to use depression and anxiety sub-scales of the DASS-21 to measure these problems among Vietnamese adolescents with disabilities.

**Antisocial behaviour.** This was measured using the conduct problems sub-scale from the adolescent self-report version of *The Strengths and Difficulties Questionnaire (SDQ)* (Goodman et al., 1998). The number of items, rating and scoring are the same as that described for the prosocial behaviour sub-scale. Sample items from the conduct problems sub-scale are: *I steal from home, school or elsewhere, I often lie or cheat*. In this study, the conduct problems sub-scale showed satisfactory internal consistency for a measure containing few items

(Cronbach's  $\alpha = 0.60$ ). Cut scores are available for scores within the normal, borderline and clinical ranges.

**Negative affect.** This was measured using the negative affect sub-scale of *The Positive and Negative Affect Scale (PANAS)* (Watson et al., 1988). The number of items, time frame, ratings and scoring were the same as those reported for the positive affect sub-scale. Sample items are: *upset, guilty, scared*. In this study, the negative affect sub-scale showed high internal consistency (Cronbach's  $\alpha = 0.85$ ).

## 5.6 Results

Two software programs were used to analyse data from Study 2: the PROCESS macro was used to examine moderation effects (Hayes, 2013) while SPSS version 23 was used for all other analyses. The results are presented in three main sections, which report the findings from the preliminary analyses, variable-focused analyses, and person-focused analyses, respectively. Two complementary methods of statistical analysis were used to identify the relationship between predictor variables and well-being. First, a variable-focused approach was used to identify the variables that contributed to individual differences between participants in each of the eight domains of well-being assessed in the study. This approach used correlation and regression statistical analyses. Second, a person-focused approach sorted the participants into groups based upon their scores for the eight domains of well-being. Then an examination identified distinctive patterns of predictor variables that distinguished between these groups. This approach used cluster analyses. The aim was to seek confirmation of findings, and gain fresh insights, through viewing the same dataset through different statistical lenses.

The results from variable-focused analyses are presented in four sub-sections:

- (1) *Descriptive statistics*, which addressed the level of well-being in positive and negative domains reported by adolescents with visual and physical disabilities (Aim 1),
- (2) *Multivariate analyses* that compared the levels of well-being reported by adolescents with visual and physical disabilities (Aim 2),
- (3) *Correlation analyses* that identified the direction and strength of relationships between severity of disability, other predictor variables and well-being outcomes among adolescents with disabilities (Aim 3),
- (4) *Regression analyses* that identified predictor variables that explained independent variance in well-being outcomes and any predictors that moderated the relationship between disability severity and well-being (Aim 4).

In the last section of the results, findings from the person-focused analyses are reported in two sections: cluster analysis and multinomial logistic regression.

### 5.6.1 Preliminary analysis

Preliminary analyses identified errors and missing data, and examined the distribution of data (Pallant & Pallant, 2011).

**Errors.** The dataset, which initially contained data for 210 participants, was checked for errors made by participants in self-completed questionnaires and by the researcher during data entry. Errors by participants were identified by searching for scores falling outside the possible range ( $n = 0$ ). Errors during data entry were identified by having two independent people (the principle researcher and a supervisor) compare randomly selected cases and scores within the dataset with the original responses recorded on the questionnaires. The very small number of errors that were detected were corrected.

**Missing data.** Participants who had missing data for five or more items on a single instrument, or ten or more items in total ( $n = 4$ ) were removed from the dataset. For cases with lower levels of missing data (1.9 %,  $n = 4$ ), missing items were imputed using person mean substitution (if missing one item per scale) and hot deck imputation (if missing more than one item per scale) (Hawthorne & Elliott, 2005; Tabachnick & Fidell, 2007; van Ginkel, van der Ark, & Sijtsma, 2007 2007). There did not appear to be any pattern in the missing data or in the characteristics of the participants with missing data.

**Distribution of data.** Visual inspection of histograms and statistics for skewness and kurtosis indicated that there was no marked deviation from normality for any variable. All the continuous variables had skewness  $\leq |1|$  and kurtosis  $\leq |2|$  (Appendix A). Therefore, the planned parametric analyses could proceed.

In summary, the data set was cleaned, four participants were removed from the dataset due to missing data, and the data for the remaining 206 participants were used in subsequent analyses. Due to the large sample size, a criterion of  $\alpha = .01$  was used to identify statistically significant results.

## **5.6.2 Variable-focused analysis**

### **5.6.2.1 Descriptive statistics**

There was no evidence of floor or ceiling effects for any variable for either group of adolescents. It can be seen by visual inspection of Table 5.5 that the mean scores were near the middle of the possible range for most measures for participants with both types of disability. Therefore, subsequent analyses could be conducted without transforming the data.

An exploratory analysis was run to investigate the possibility that the main analyses should include gender as a covariate. Results indicated that there was no statistically significant difference between males and females on predictor variables or well-being outcomes ( $F_{(30, 366)}$

= 0.60,  $p = .95$ , Wilks' Lambda = 0.91,  $\eta^2 = .047$ ). Therefore, gender was not included as a covariate in the main analyses.

### **5.6.2.2 Level of well-being among adolescents with disabilities**

Data for level of well-being are organized into positive and negative domains. First, the results are presented for the pooled sample. Then the results are presented separately for visually and physically disabled adolescents.

**Positive domains of well-being.** Adolescents with disabilities showed well-being in several positive domains. Mean scores were above mid-point for three of the four positive domains of well-being: satisfaction with life, flourishing and positive affect (Table 5.5). In contrast, the mean score for prosocial behavior was low. Indeed, more than two thirds of the participants met the criteria for clinically significant deficits in prosocial behaviour and another 15.5% were in the borderline category (Table 5.7).

**Negative domains of well-being.** Despite evidence of well-being in some positive domains, the mean scores for the two measures of mental health problems were high (Table 5.5). Indeed, more than one third of the participants had symptoms of depression and anxiety that could be classified as severe or extremely severe (Table 5.6). This is four times higher than the rate expected in a general population of adolescents in Western countries (Lovibond & Lovibond, 1995). Participants were more likely to have severe or extremely severe levels of anxiety and low levels of depression than they were to have low levels of anxiety and severe/extreme level of depression (McNemar test  $\chi^2_{(1, N = 206)} = .065$ ).

In contrast, the mean score for conduct problems was within the normal range (Table 5.5). Despite this, one in five participants could be classified as having conduct problems that were within the clinical range (Table 5.7). The mean score for the fourth negative domain of well-being, negative affect, was very near the midpoint of the scale.

Table 5.5: Descriptive statistics for continuous variables for the pooled sample (n = 206)

Variable	M	SD	95% CIs	
			Lower	Upper
Distal predictor				
Disability severity	37.62	5.91	36.80	38.40
Other predictors				
Optimism	17.19	2.77	16.78	17.54
Social support	15.68	4.05	13.28	14.48
Adaptive coping	30.59	7.95	29.54	31.67
Discrimination	23.35	7.94	22.68	25.21
Positive domains of wellbeing				
Satisfaction with life	20.31	6.38	19.45	21.21
Flourishing	38.06	7.93	36.90	39.10
Prosocial behaviour	5.83	1.95	5.56	6.09
Positive affect	28.45	5.60	27.72	29.59
Negative domains of wellbeing				
Depression	12.94	6.40	12.04	13.88
Anxiety	15.21	7.28	14.25	16.24
Conduct problems	2.86	1.53	2.62	3.12
Negative affect	23.29	6.92	22.46	24.70

Note. n = Number of participant, M = Mean, SD = Standard deviation.

Table 5.6: Severity of depression and anxiety symptoms in the combined sample (n=206)

Level	Depression			Anxiety		
	Scores	n	(%)	Scores	n	(%)
Normal	0-9	52	(25.2)	0-7	21	(10.2)
Mild	10-13	63	(30.6)	8-9	21	(10.2)
Moderate	14-20	23	(11.2)	10-14	72	(35.0)
Severe	21-27	42	(20.4)	15-19	33	(16.0)
Extremely Severe	28-42	26	(12.6)	20-42	59	(28.6)

Note. n = Number of participants, % = Percentage of the sample.

Table 5.7: Categories of prosocial behaviour and conduct problems in the combined sample (n=206)

Category	Prosocial behaviour			Conduct problems		
	Score	n	(%)	Score	n	(%)
Normal	6-10	45	(21.8)	0-3	134	(65.0)
Boderline	5	32	(15.5)	4	28	(13.6)
Clinical range	0-4	129	(62.6)	5-10	43	(20.9)

Note. n = Number of participants, % = Percentage of the sample.

### 5.6.2.3 *Difference in well-being between visually and physically disabled adolescents*

A between-groups multivariate analysis of variance (MANOVA) was performed to investigate differences in psychosocial well-being between adolescents with visual and physical disabilities (Table 5.8).

**Difference in well-being.** Overall, adolescents with a visual disability had higher levels of well-being than adolescents with a physical disability ( $F_{(9,193)} = 6.04, p < .001$ , Wilks' Lambda=.78,  $\eta^2 = 0.22$ ). Children with a visual disability had higher scores for three of the four positive domains of well-being outcomes: flourishing, prosocial behaviour and positive

affect (flourishing:  $F_{(1)} = 16.72$ ,  $p < .001$ ,  $\eta^2 = 0.077$ ; prosocial behaviour:  $F_{(1)} = 20.00$ ,  $p < .001$ ,  $\eta^2 = 0.091$ ; positive affect:  $F_{(1)} = 14.73$ ,  $p < .001$ ,  $\eta^2 = 0.068$ ). Effect sizes for all three were small to moderate (Pallant, 2011).

The pattern of relationships between variables for visually disabled participants was compared by visual inspection with that for physically disabled participants. The patterns were judged to be highly similar. This was confirmed by a test of concordance, which indicated that the number of similarities in the pattern of findings was highly unlikely to be due to chance ( $\chi^2_{(1, n = 206)} = 13.2$ ,  $p = .0003$ ).

This result affected the way in which the results addressing Aims 2 and 3 were presented. In order to maximize the power of statistical analyses examining relationships between the variables, the two groups of adolescents with disabilities were pooled. That is, correlation and regression analyses are reported for the whole sample, rather than separately for visually and physically disabled participants. There was no age difference between visually disabled and physical disabled participants (Visual:  $M = 14.95$ ,  $SD = 2.33$ ; Physical:  $M = 15.43$ ,  $SD = 2.62$ ;  $t(204) = -1.39$ ,  $p = .16$ , two-tailed).

**Difference in severity of disability.** Post-hoc analyses explored differences in predictor variables between the two groups of adolescents. Adolescents with a physical disability had a more severe disabilities than their peers who had a visual disability ( $F_{(1,204)} = 18.6$ ,  $p < .001$ ,  $\eta^2 = 0.083$ ).

**Difference in other predictors.** Adolescents with visual and physical disabilities also differed on other predictor variables ( $F_{(5,197)} = 13.17$ ,  $p < .001$ , Wilks' Lambda=0.75,  $\eta^2 = 0.25$ ). Adolescents with a visual disability had higher scores on two of the three protective factors (optimism and adaptive coping) (optimism:  $F_{(1)} = 9.92$ ,  $p = .002$ ,  $\eta^2 = 0.047$ ; adaptive coping:  $F_{(1)} = 14.28$ ,  $p < .001$ ,  $\eta^2 = 0.066$ ). The effect sizes for all differences were small to medium (Pallant, 2011).

The two groups also differed on the categorical risk factor out-of-home care ( $\chi^2_{(1, n=206)} = 43.3$ ,  $p < .001$ ). More adolescents with a physical disability (70 %) than with a visual disability (30%) lived out-of-home care.

**Covarying for severity of disability.** Because differences between the two groups could be an artefact of differences in the severity of disability between these groups, the analyses were rerun with severity of disability as a co-variate. The pattern of findings remained unchanged. Overall, adolescents with a visual disability had higher levels of positive well-being

than adolescents with a physical disability ( $F_{(9,193)} = 5.11, p < .001, \text{Wilks' Lambda} = 0.78, \eta^2 = 0.19$ ). Adolescents with a visual disability still had higher scores for three positive outcomes: flourishing, prosocial behaviour and positive affect (flourishing:  $F_{(1)} = 10.87, p \leq .001, \eta^2 = 0.051$ ; prosocial behaviour:  $F_{(1)} = 18.88, p < .001, \eta^2 = .086$ ; positive affect:  $F_{(1)} = 13.41, p < .001, \eta^2 = 0.063$ ). Again, there was no difference between the two groups for negative domains of well-being.

Similarly, when disability severity was used as a covariate, post-hoc analyses found that adolescents with visual and physical disabilities still also differed on the predictor variables ( $F_{(5,198)} = 11.97, p < .001, \text{Wilks' Lambda} = 0.77, \eta^2 = 0.23$ ). Adolescents with a visual disability still had higher scores on two of three protective factors (optimism, adaptive coping) and lower score on one risk factor (out-of-home care) (optimism:  $F_{(1)} = 11.17, p = .001, \eta^2 = 0.052$ ; adaptive coping:  $F_{(1)} = 10.74, p = .001, \eta^2 = 0.05$ ; out-of-home care:  $F_{(1)} = 42.77, p < .001, \eta^2 = 0.175$ ).

Since the pattern of findings did not change when severity of disability was used as a covariate, it was concluded that adolescents with a visual disability are advantaged over their peers with a physical disability in several positive domains of well-being and in a number of predictor variables.

Table 5.8: Mean and standard deviation in continuous variables across type of disability

Variables	Disability					
	Visual (n= 93)		Physical (n=113)		Possible range	
	M	SD	M	SD	Min	Max
<b>Predictor</b>						
Disability severity	35.74	5.83	39.16	5.84	13	100
<b>Protective factors</b>						
Optimism	17.90	3.01	16.61	2.42	0	24
Social support	14.16	4.24	13.72	4.27	0	30
Adaptive coping	32.98	7.72	28.64	7.62	0	60
<b>Risk factors</b>						
Discrimination	14.44	8.54	22.49	7.35	9	54
<b>Positive domains of well-being</b>						
Satisfaction with life	20.39	5.87	22.25	6.79	5	35
Flourishing	40.55	6.78	36.01	8.25	8	56
Prosocial behaviour	6.45	1.95	5.32	1.80	0	10
Positive affect	30.08	5.10	27.13	5.65	10	50
<b>Negative domains of well-being</b>						
Depression	11.78	6.13	13.89	6.47	0	21
Anxiety	14.32	7.64	15.95	6.92	0	21
Conduct problems	2.63	1.86	3.05	1.79	0	10
Negative affect	23.74	7.87	22.93	6.05	10	50

#### **5.6.2.4 Correlation between predictors and well-being outcomes among adolescents with visual and physical disabilities**

Despite differences in the level of well-being between adolescents with visual and physical disabilities, the pattern of relationships between the predictors and well-being outcomes in the two groups was highly similar (Appendix B). In addition, a one-sample Chi square test indicated that the extent to which similar findings was observed was highly unlikely to be due to chance (Continuity correction  $\chi^2_{(1, n=206)} = 13.2, p = .0003$ ). Therefore, the two samples were combined in subsequent analyses to achieve greater statistical power. The relationship between predictors and well-being outcomes for the combined sample is shown in Table 5.9.

Table 5.9: Pearson product-moment correlations between predictors and well-being outcomes in the combined sample (n=206)

Scale	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Severity of disability													
<b>Protective factors</b>													
2. Optimism	-.01												
3. Social support	-.24**	.18*											
4. Adaptive coping	-.18*	.00	.35**										
<b>Risk factors</b>													
5. Discrimination	-.02	-.01	.02	.23**									
6. Out-of-home care	.20**	-.02	-.09	-.41**	-.19**								
Positive domains of well-being													
7. Satisfaction with life	-.10	.18*	.55**	.14	.17*	.09							
8. Flourishing	-.24**	.33**	.45**	.19**	.26**	-.27**	.45**						
9. Prosocial behaviour	-.07	.33**	.49**	.33**	.05	-.19**	.39**	.42**					

10. Positive affect	-.06	.27**	.21**	.37**	.21**	-.22**	.27**	.32**	.43**				
Negative domains of well-being													
11. Depression	.22**	-.24**	-.15*	.08	.38**	.06	.02	-.08	-.03	-.04			
12. Anxiety	.20**	-.21**	-.22**	.00	.22**	.04	-.22**	-.10	-.03	.03	.53**		
13. Conduct problems	.01	-.37**	-.23**	-.03	.16*	-.10	-.23**	-.18*	-.32**	.24**	.25**	.29**	
14. Negative affect	.12	-.19**	-.44**	-.01	.31**	-.04	-.27**	-.17*	-.26**	-.04	.31**	.37**	.28**

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Note. n = 206, \*\* p < .001 (2-tailed), \* p < .01(2-tailed).

**Severity of disability.** Severity of disability was related to only three of the eight domains of well-being. It showed a small negative correlation with one positive domain of well-being (flourishing), and small positive correlation with both mental health problems. It was also related to three other predictors. These included two protective factors (social support, adaptive coping) and one risk factor (out-of-home care). In all cases, the size of the effect was small (Table 5.9).

**Other predictors.** Two protective factors, optimism and social support, were positively associated with all the positive domains of well-being (satisfaction with life, flourishing, prosocial behaviour, positive affect) and negatively correlated with all the negative domains of well-being (depression, anxiety, conduct problem, negative affect). The effect sizes were small to moderate (Table 5.9).

The risk factor out-of-home care was negatively associated with three of the four positive domains of well-being: flourishing, prosocial behaviour and positive affect. No correlation was found between this factor and any negative domain of well-being (Table 5.9).

In contrast, the risk factor discrimination had a positive association with all four negative domains of well-being. The effect sizes were from small to moderate. However, a surprising finding was that discrimination was also positively associated with life satisfaction, flourishing and positive affect. The effect sizes were small.

#### **5.6.2.5 *Testing the direct relationships in the research model and identifying independent predictors of well-being***

One or more predictor variables that explained independent variance were identified for each well-being outcome. However, the number of such predictors and the magnitude of their relationships with well-being differed across domains (Table 5.10).

No predictor variable explained independent variance in all domains of well-being. However, all the predictors had an independent relationship with at least one domain of well-being. Both optimism and discrimination were independently related to six of the eight domains of well-being. Social support was independently related to four of the eight domains of well-being. It is noteworthy that severity of disability showed independent relationships only with the two types of mental health problems.

Taken together, the variables in the research model explained a significant amount of the variance in every well-being outcome (Table 5.10). The total amount of variance accounted for by the predictor variables indicated the usefulness of the research model in predicting individual differences in each domain of well-being. The research model accounted for more than 25% of the variance in three positive domains (satisfaction with life, flourishing and prosocial

behaviour) and one negative domain of well-being (symptoms of depression). However, it had considerably lower predictive power for some other outcomes. In particular, the amount of variance in symptoms of depression explained by the research model was twice more than that for symptoms of anxiety (Table 5.10).

Table 5.10: Results of regression analyses identifying independent relationships between predictor variables and eight well-being outcomes

Variables	Adjusted R <sup>2</sup>	b	B	SE	95% CI	t value	P value
<b>Positive outcomes</b>							
Satisfaction with life	.36						
Disability severity		.02	.02	.07	(-.11, .15)	.31	.76
Optimism		.07	-.17	.14	(-.12, .42)	1.13	.27
Social support		.56	.15	.09	(.66, 1.03)	8.84**	.005
Adaptive coping		-.03	.84	.05	(-.14, .08)	-.46	.67
Discrimination		.16	-.03	.04	(.03, .19)	2.63*	.001
Out-of-home care		.18	.11	.89	(.78, 4.35)	2.83**	.01
<b>Flourishing</b>							
Flourishing	.36						
Disability severity		-.09	-.12	.08	(-.28, .04)	-1.14	.26
Optimism		.24	.69	.17	(.36, 1.01)	4.16**	.00
Social support		.39	.72	.12	(.49, .95)	6.18**	.00
Adaptive coping		-.10	-.10	.07	(-.23, .04)	-1.44	.78
Discrimination		.22	.18	.05	(.08, .28)	3.60**	.001
Out-of-home care		-.21	-3.55	1.11	(-5.73, -1.37)	-3.21*	.05
<b>Prosocial behaviour</b>							
Prosocial behaviour	.39						
Disability severity		.08	.03	.02	(-.01, .07)	1.50	.13
Optimism		.24	.17	.04	(.09, .25)	4.08**	.00
Social support		.40	.18	.03	(.13, .24)	6.22**	.00
Adaptive coping		.17	.04	.02	(.01, .08)	2.45*	.05
Discrimination		-.04	-.01	.01	(-.03, .02)	-.49	.62
Out-of-home care		-.08	-.34	.28	(-.89, .21)	-1.23	.89
<b>Positive affect</b>							
Positive affect	.16						
Disability severity		.03	.03	.08	(-.12, .17)	.35	.24
Optimism		.21	.49	.15	(.18, .79)	3.14**	.001
Social support		.05	.08	.11	(-.13, .31)	.83	.23
Adaptive coping		.24	.20	.06	(.07, .32)	3.08**	<.001
Discrimination		.09	.06	.05	(-.03, .16)	1.32	.12
Out-of-home care		-.10	-1.46	1.02	(-3.56, .53)	-1.46	.86

<b>Negative outcomes</b>							
Depression	.28						
Disability severity		.24	.25	.07	(.12, .39)	3.75**	.01
Optimism		-.22	-.51	.14	(-.78, -.23)	-3.61**	.01
Social support		-.08	-.13	.10	(-.32, .07)	-1.27	.06
Adaptive coping		.11	.09	.06	(-.03, .20)	1.48	.07
Discrimination		.45	.30	.04	(.22, .38)	7.06**	.01
Out-of-home care		.10	1.36	.94	(-.49, 3.12)	1.45	.19
Anxiety	.13						
Disability severity		.19	.23	.09	(.06, .40)	2.71*	.05
Optimism		-.18	-.46	.18	(-.81, -.12)	-2.66*	.05
Social support		-.19	-.33	.12	(-.51, -.02)	-2.12	.06
Adaptive coping		.04	.04	.07	(-.09, .19)	.69	.07
Discrimination		.24	.18	.05	(.09, .30)	3.62**	.01
Out-of-home care		.04	.65	1.18	(-2.16, 2.47)	.13	.96
Conduct problem	.19						
Disability severity		.00	.00	.02	(-.04, .04)	.04	.26
Optimism		-.33	-.22	.04	(-.30, -.13)	-5.05**	.01
Social support		-.16	-.07	.03	(-.13, -.01)	-2.28	.06
Adaptive coping		-.05	-.01	.02	(-.05, .02)	-.70	.06
Discrimination		.24	.05	.01	(.02, .07)	3.62**	.01
Out-of-home care		-.12	-.49	.29	(-1.05, .07)	-1.72	.51
Negative affect	.25						
Disability severity		.04	.06	.09	(-.11, .23)	.69	.26
Optimism		-.10	-.29	.18	(-.63, .06)	-1.62	.32
Social support		-.36	-.67	.12	(-.92, -.43)	-5.41**	.01
Adaptive coping		.05	.05	.07	(-.09, .19)	.69	.06
Discrimination		.33	.28	.05	(.17, .38)	5.18**	.01
Out-of-home care		-.06	-1.02	1.18	(-3.34, 1.30)	-.87	.50

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Note. n = 206, \*\* p < .001 (2-tailed), \* p < .01(2-tailed).

In summary, the predictive power of individual variables and of the research model showed marked differences across well-being outcomes. Despite this, one protective factor (optimism) and one risk factor (discrimination) were independently related to six of the eight domains of well-being outcome. Social support was independently related to half of the well-being outcome in this study (four domains), and in each case it was the strongest independent predictor.

### **5.6.2.6 Identifying risk and protective factors that moderate the relationship between severity of disability and well-being outcomes**

The research model also predicted that the relationship between severity of disability and well-being outcomes would be moderated by five predictors (optimism, social support, adaptive coping, discrimination and out-of-home care). However, severity of disability was related to only two domains of well-being (depression and anxiety). Therefore, this prediction could be tested for only these two domains. The moderating effect of the predictors was tested using the PROCESS macro for SPSS (Hayes, 2013). One of the advantages of this software is that it eliminates calculation errors by automatically centering the predictors, computing the interaction term and displaying the simple slopes.

Among the five predictors, only adaptive coping had a moderating effect. None of the five predictors moderated the relationship between severity of disability and symptoms of depression (Table 5.11, Figure 5.9). However, adaptive coping served as a buffer in the relationship between severity of disability and anxiety symptoms (Table 5.12, Figure 5.10). When levels of adaptive coping were low (1 SD below the mean) or at the mean, there was a positive relationship between severity of disability and anxiety symptoms, (Low:  $b = 0.41$ , 95% CI [0.26, 0.56],  $t = 5.44$ ,  $p < .001$ ; At the mean:  $b = 0.25$ , 95% CI [0.10, 0.41],  $t = 3.32$ ,  $p < .001$ ). However, when levels of adaptive coping were high (1 SD above the mean), there was no relationship between severity of disability and anxiety symptoms ( $b = 0.10$ , 95% CI [-0.12, 0.31],  $t = 0.89$ ,  $p = .37$ ). Graph 5.1 plots the simple slopes for this interaction.

Table 5.11: Findings from the PROCESS analyses testing whether predictor variables moderated the relationships between severity of disability and symptoms of depression

Predictors	b [95% CI]	SE B	t	p
<b>Optimism</b> R <sup>2</sup> = 0.09, SME = 37.90				
Optimism	- 0.48 [-0.81, -0.15]	0.17	-2.82*	< .01
Disability	0.21 [0.06, 0.35]	0.07	2.78*	< .01
Interaction	-0.02 [-0.07, 0.04]	0.03	-0.67	.50
<b>Social support</b> R <sup>2</sup> = 0.05, SME = 39.30				
Social support	-0.15 [-0.36, 0.07]	0.11	-1.37	.17
Disability	0.20 [0.06, 0.34]	0.07	2.75*	.01
Interaction	0.00 [-0.03, 0.03]	0.02	0.10	.92
<b>Adaptive coping</b> R <sup>2</sup> = 0.27, SME = 38.42				
Adaptive coping	0.12 [0.00, 0.24]	0.06	1.9*	< .01
Disability	0.26 [0.13, 0.40]	0.07	3.78*	< .01
Interaction	-0.01 [-0.02, 0.01]	0.01	-1.21	.05
<b>Discrimination</b> R <sup>2</sup> = 0.23, SME = 31.93				
Discrimination	0.30 [0.18, 0.42]	0.06	4.92*	< .01
Disability	0.28 [0.15, 0.41]	0.07	4.33*	< .01

Interaction	0.00 [-0.01, 0.02]	0.01	0.28	.78
<b>Out-of-home care</b> R <sup>2</sup> = 0.05, SME = 39.30				
Out-of-home care	-0.28 [-2.31, 1.76]	1.03	-0.27	.79
Disability	0.26 [0.12, 0.39]	0.07	3.83*	< .01
Interaction	0.21 [-0.09, 0.50]	0.15	1.39	.17

\* p < .01

Table 5.12: Findings from the PROCESS analyses testing whether predictor variables moderated the relationships between severity of disability and symptom of anxiety

Predictors	b [95% CI]	SE B	t	p
<b>Optimism</b> R <sup>2</sup> = 0.08, SME = 49.39				
Optimism	- 0.52 [-0.84, -0.20]	0.16	-3.17*	< .01
Disability	0.20 [0.05, 0.36]	0.08	2.57*	.01
Interaction	-0.04 [-0.10, 0.01]	0.03	-1.71	.09
<b>Social support</b> R <sup>2</sup> = 0.07, SME = 50.18				
Social support	-0.29 [-0.51, 0.07]	0.11	-2.57*	.01
Disability	0.19 [0.04, 0.34]	0.08	2.51*	.01
Interaction	-0.02 [0.04, 0.01]	0.01	-1.25	.21
<b>Adaptive coping</b> R <sup>2</sup> = 0.06, SME = 50.29				
Adaptive coping	0.04 [-0.11, 0.19]	0.07	0.54	.59

Disability	0.25 [0.10, 0.41]	0.08	3.32*	< .01
Interaction	-0.02 [-0.03, -0.01]	0.01	-2.93*	< .01
<b>Discrimination</b>				
R <sup>2</sup> = 0.10, SME = 47.38				
Discrimination	0.20 [0.10, 0.30]	0.05	3.83*	< .01
Disability	0.27 [0.12, 0.42]	0.08	3.55*	< .01
Interaction	0.00 [-0.01, 0.01]	0.01	0.30	.76
<b>Out-of-home care</b>				
R <sup>2</sup> = 0.04, SME = 51.62				
Out-of-home care	-0.76 [-3.39, 1.86]	1.33	-0.57	.57
Disability	0.26 [0.11, 0.41]	0.08	3.44*	< .01
Interaction	0.10 [-0.23, 0.43]	0.17	0.62	.54

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\* p < .01

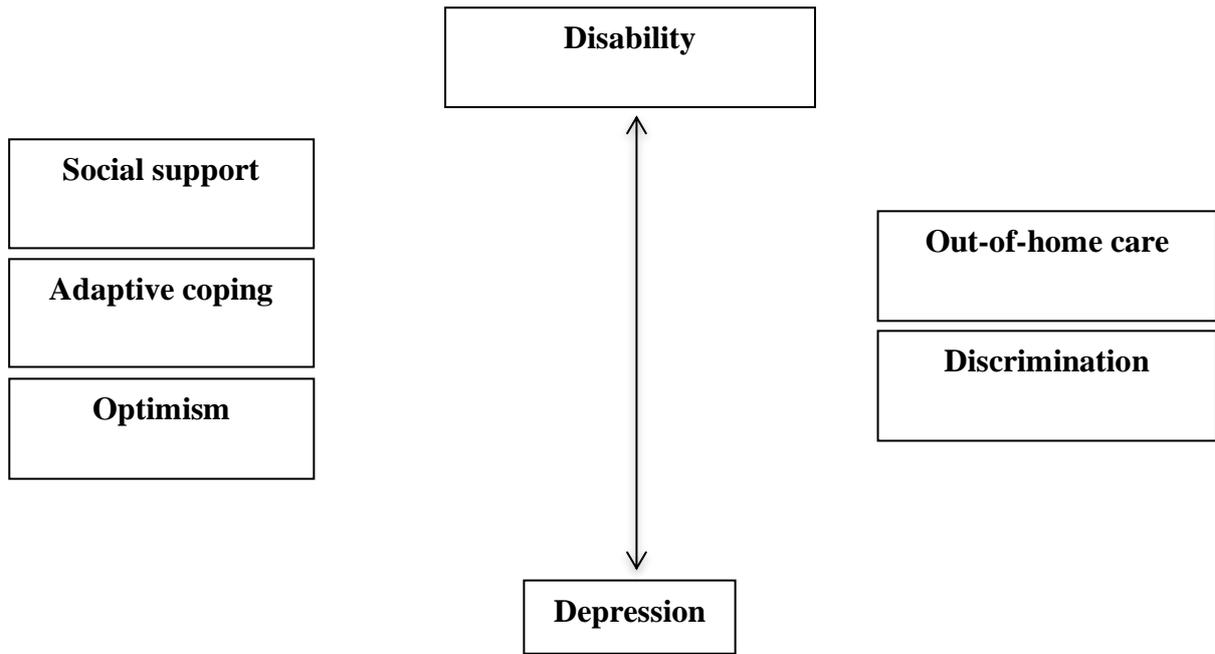


Figure 5.9: Visual summary of the results of the PROCESS analyses investigating the possible moderating role of predictor variables in the relationship between disability severity and symptoms of depression

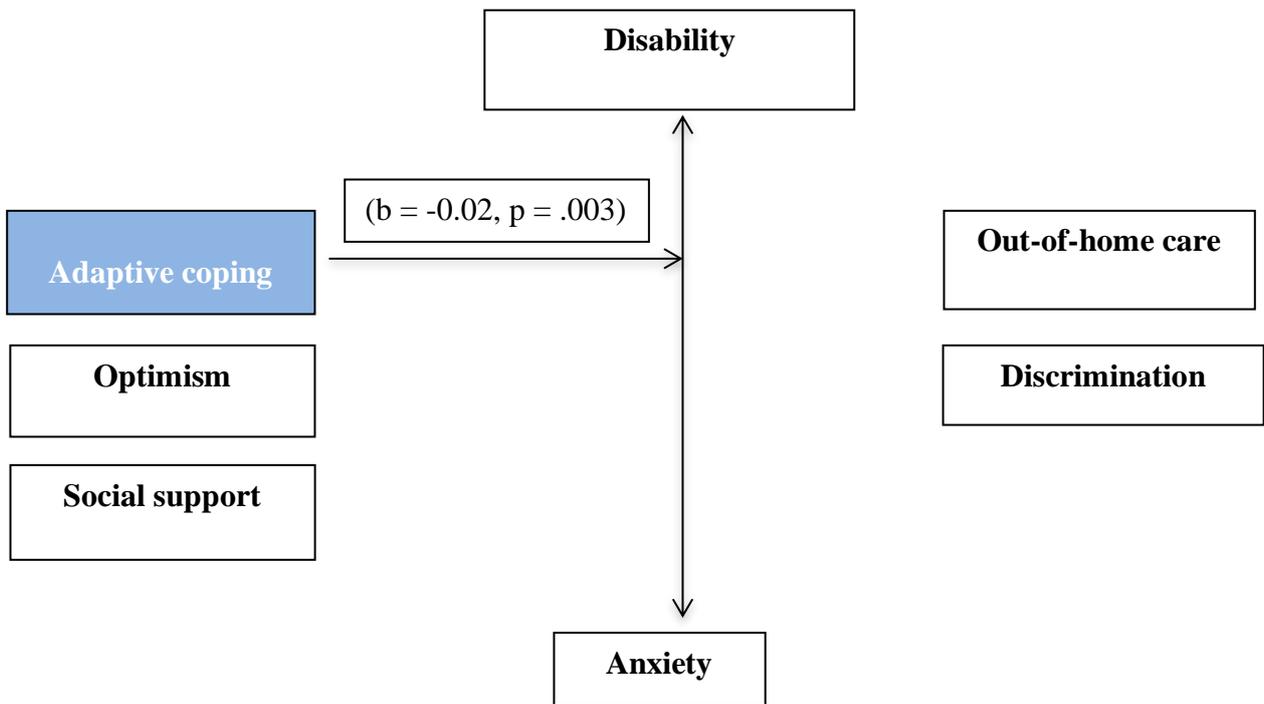
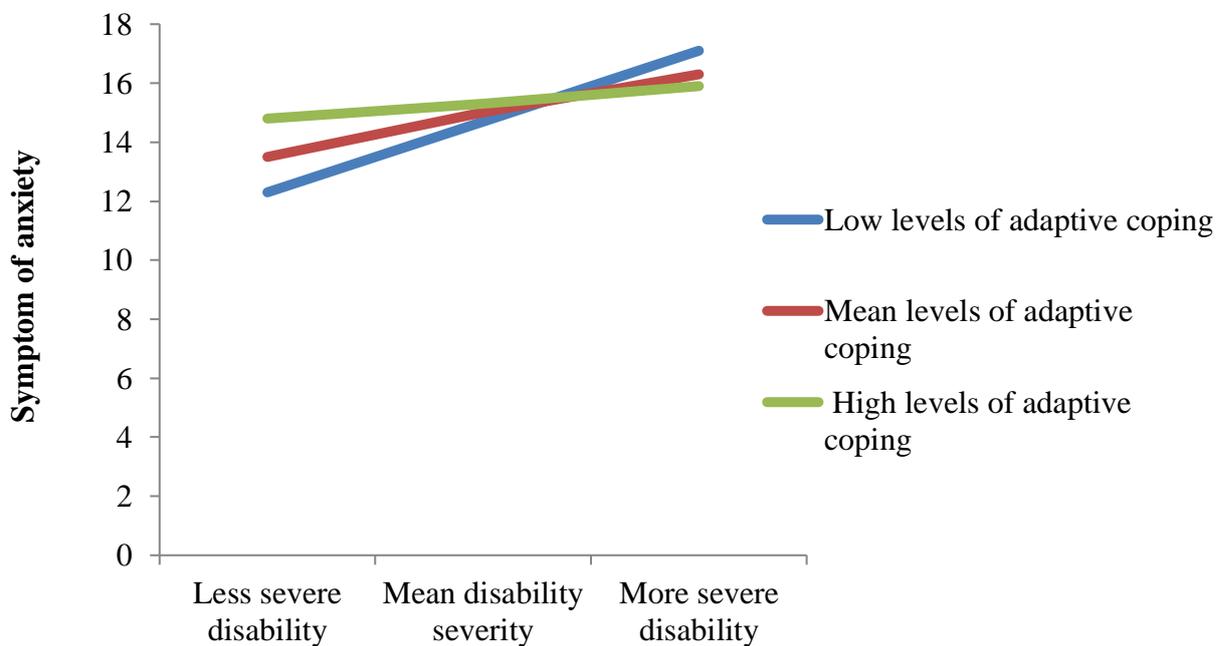


Figure 5.10: Visual summary of the results of the PROCESS analyses investigating the possible moderating role of predictor variables in the relationship between disability severity and symptoms of anxiety



Graph 5.1: Simple slopes showing the moderation by adaptive coping of the relationship between severity of disability and symptoms of anxiety

### 5.6.3 Person-focused analyses

Although it was expected to explore the mechanism that underlies the relationship between severity of disability and well-being outcomes, mediation analyses were not performed due to some certain reasons. There are prerequisite conditions that a model must satisfy in order to run mediation analyses. The first condition is that independent variable must be related to dependent variable (Statistics solution, 2013). However, in the current study, there are only two dependent variables (depression and anxiety) out of 8 well-being outcome domains related to independent variable (severity of disability). This model, therefore, was likely not a helpful model to seek to identify the mechanism or process for the relationship between the two variables.

Instead of running mediation analyses after moderation, it was believed that it would be helpful to explore how the whole sample of adolescents with disabilities was classified on the basis of the eight well-being outcomes, and then determine the extent to which the predictors (optimism, social support, adaptive coping, discrimination, and out-of-home care) influenced membership in the classified clusters. Therefore, person-focused analyses were performed after the moderation analyses but not mediation analyses as normally expected order.

#### 5.6.3.1 Identifying clusters of participants

A cluster analysis explored sub-groups of adolescents with disabilities classified on the basis of the eight well-being outcomes (satisfaction with life, flourishing prosocial behaviour, positive affect, depression, anxiety, conduct problems and negative affect). A two-step analysis procedure, in which the number of groups was unrestrained, identified three clusters:

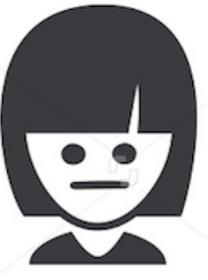
- The largest cluster (n = 111; 54.4% of the sample) showed a pattern across well-being outcomes that could be classified as “global resilience”, because members had high scores for most positive well-being outcomes, low levels of negative affect, and showed only mild symptoms of depression and mild or moderate levels of anxiety.
- The smallest cluster showed a pattern across well-being outcomes that could be classified as “domain-specific resilience” (n = 25; 12.3% of sample). The members were characterized by very poor mental health, shown by very high scores for symptoms of depression and anxiety. The scores were twice as high as those in other groups and were within the severe and extremely severe range, respectively. They also reported low life satisfaction (below the mid-point on the scale) and high negative affect (at the midpoint on the scale). Despite this, they reported high levels of flourishing and a moderate level of positive affect.

- The third cluster accounted for one third of the participants (n = 68; 33.3% of the sample) and showed a pattern across well-being outcomes that led them to being named the “surviving group”. This group’s members reported only mild symptoms of depression and mild or moderate levels of symptoms of anxiety. However, their scores for positive domains of well-being were low and their antisocial behaviour (conduct problems) was within the normal range. However, this group had the lowest scores for flourishing and positive affect (both below the midpoint on the scale) (Table 5.13).

The quality of this cluster model was fair (on a scale of poor, fair and good) (average Silhouette = 0.3, ratio of sizes = 4.44). The outcomes that played the greatest role in determining cluster group membership were satisfaction with life, symptoms of anxiety and prosocial behaviour (Table 5.13).

The cluster analysis was then repeated with two variables added: severity of disability and type of disability. The results remained the same, and type of disability and severity of disability were the variables with the least importance in determining cluster membership (predictor importance = 0.14 and 0.07, respectively).

Table 5.13: Characteristics of three clusters of participants and the importance of predictors

	Cluster label and size		
			
	Global resilience group (n = 111)	Surviving group (n = 68)	Domain-specific resilience group (n = 25)
Predictors (in rank order)	 54.4% (111)	 33.3% (68)	 12.3% (25)
Satisfaction with life	M = 24.19	M = 15.59	M = 16
PI = 1	(above midpoint)	(below midpoint)	(below midpoint)
Anxiety symptoms	M = 12.77	M = 14.88	M = 27.36
PI = 0.89	(moderate)	(severe)	(extremely severe)
Prosocial behavior	M = 6.81	M = 4.26	M = 5.76
PI = 0.75	(normal range)	(normal range)	(normal range)

Flourishing	M = 41.91	M = 31.71	M = 38.04
PI = 0.72	(above midpoint)	(at midpoint)	(above midpoint)
Depression symptoms	M = 11.64	M = 11.47	M = 22.80
PI = 0.69	(mild)	(mild)	(severe)
Conduct problems	M = 2.12	M = 3.34	M = 4.48
PI = 0.53	(normal range)	(normal range)	(normal range)
Negative affect	M = 20.73	M = 24.85	M = 32.60
PI = 0.48	(below midpoint)	(below midpoint)	(at midpoint)
Positive affect	M = 30.26	M = 25.34	M = 30.52
PI = 0.24	(below midpoint)	(below midpoint)	(at midpoint)

Note. n = Number of participants. M = Mean. PI = Predictor importance.

### **5.6.3.2 Identifying predictors that differentiated the clusters of participants**

A post-hoc analysis using multinomial logistic regression was conducted to determine the extent to which the predictors (optimism, social support, adaptive coping, discrimination, and out-of-home care) influenced membership in the three clusters (global resilience, surviving group and domain-specific resilience group). Results indicated that the set of predictors reliably distinguished between the three clusters ( $\chi^2 = 137.89$ ,  $p < .001$  with  $df = 10$ ) with a moderate effect size (Nagelkerke's  $R^2 = .580$ ). Both the global resilience and domain-specific resilience groups were more likely to have higher scores on optimism and adaptive coping than the surviving group (Domain-specific resilience group: Exp (B) = 1.02 and 1.08, respectively; Global resilience group: Exp (B) = 1.44 and 1.04, respectively). Optimism and social support were significant predictors for membership of the global resilience group, but they were not for the domain-specific resilience group (Domain-specific resilience group: Optimism: Wald  $(1) = 0.03$ ,  $p = .86$ , social support: Wald  $(1) = 0.08$ ,  $p = .78$ ; Global resilience group: Optimism: Wald  $(1) = 17.05$ ,  $p < .001$ , social support: Wald  $(1) = 35.59$ ,  $p < .001$ ). Discrimination was the only significant predictor of membership in both the global resilience and domain-specific resilience groups that distinguished them from members of the surviving group (Table 5.14).

In summary, the combined sample of 206 adolescents with disabilities in this study could be classified into three clusters regardless of their disability type and severity. The majority of participants showed resilience across many domains of well-being. Participants in the globally resilient cluster could be distinguished from the members in the surviving cluster on the basis of

their high scores for two protective factors (optimism, social support) and their lower score on one risk factor (discrimination).

Table 5.14: Multinomial logistic regression analyses showing the factors that distinguished participants in the two “resilient” clusters from those in the surviving cluster

Cluster	Predictor	B	SE	Wald	df	Sig	Exp(B)	95% Confidence Interval	
								Lower	Upper
Domain-specific resilience group	Intercept	-8.75	2.65	10.89	1	.00			
	Optimism	.02	.12	.03	1	.86	1.02	.81	1.29
	Social support	-.03	.09	.08	1	.78	.98	.82	1.16
	Adaptive coping	.08	.04	2.95	1	.09	1.08	.99	1.17
	Discrimination	.21	.05	18.86	1	<.001	1.23	1.12	1.35
	Out-of-home care	.39	.64	.37	1	.55	1.48	.42	5.20
Global resilience group	Intercept	-10.0	2.37	34.83	1	<.001			
	Optimism	.36	.09	17.05	1	<.001	1.44	1.21	1.71
	Social support	.40	.07	34.59	1	<.001	1.49	1.30	1.70
	Adaptive coping	.04	.03	1.54	1	.22	1.04	.98	1.11
	Discrimination	.09	.03	7.50	1	.01	1.09	1.03	1.16
	Out-of-home care	-.98	.57	2.95	1	.09	.38	.12	1.15

Note. (a) The reference category is the “Surviving group”.

## 5.7 Conclusion and discussion

Previously, most studies conducted in high-income countries have found that people with disabilities have high scores for mental health problems and other negative domains of well-being (Gortmaker et al., 1990; Sobol, 1990; Gureje et al., 2008; Wolman et al., 1994; Blum, 1994). However, it remained unclear whether this precluded them also showing high scores for positive domains of well-being. It also remained unclear whether type of disability and severity of disability predict well-being, and what other factors also predict well-being and/or moderate the relationship between severity of disability and well-being. This is the first study investigating these issues in a sample of adolescents with visual and physical disabilities a LAMIC.

It is note worthy that both the recruitment sites and the recruitment processes used in this study have a number of implications for the interpretation of the findings. Although the recruitment strategy produced a larger and more diverse sample of adolescents with disabilities than most previous research, the sample is not representative of adolescents with visual and physical disabilities in Vietnam. It has three shortcomings in this respect. First, none of the recruitment sites were in Northern Vietnam. Second, none of the recruitment sites were in very remote locations on the Western border of Vietnam, which have the highest concentration of people from ethnic minorities. Third, in order to gain a clear picture of the consequences of two specific types of disabilities (visual and physical), the study excluded adolescents who had multiple disabilities. Therefore, the findings of the study cannot be generalised to all adolescents with a visual or physical disability in Vietnam, and as a result, applications of the findings to policy and practice need to be done with caution.

### **Well-being among adolescents with visual and physical disabilities.**

In high-income countries, adolescents with disabilities are at an elevated risk of experiencing poor psychosocial well-being (da Silva et al., 2011; Eapen, Al-Gazali, Bin-Othman, & Abou-Saleh, 1998; Ezpeleta et al., 2007; Fuhr & De Silva, 2008; Honey et al., 2011; Orr, Weller, Satterwhite, & Pless, 1984; Weder, 2010). However, under some conditions, adolescents with a disability also appear to be able to achieve levels of well-being similar to those of peers without a disability (Berntsson et al., 2007 & Hellström, 2007).

Findings from the current study confirm that adolescents with disabilities in LAMICs are vulnerable to mental health problems. It is noteworthy that the prevalence of severe and extremely severe symptoms of depression and anxiety in this study were three and four times

higher, respectively, than that expected in the general population. If this finding can be replicated in other LAMICs, there would be many important implications in terms of economic development for those countries. The economic burden of mental health problems should make it an ongoing target for public health interventions, especially among vulnerable populations such as adolescents with disabilities.

However, it was also noteworthy that adolescents with disabilities reported levels of satisfaction with life, flourishing and positive affect that were above the midpoints on the relevant scales. This finding allows a more nuanced understanding of their well-being and may help to overcome deficit models of disability that perpetrate stigma. Practitioners and policy makers may benefit from considering both positive and negative domains of well-being when designing support services for young people with a disability. In particular, an understanding of positive domains of well-being would allow a strengths-based approach to interventions.

### **Measurement issues**

Because it assesses the severity of disability by focuses on impaired functioning in the key domains of life, the 12-item WHO DAS 2.0, contains one question about emotional impact, “How much have you been emotionally affected by your health problems”. This may have conceptual overlap with one or more domains of well-being. However, the non-specific nature of the question and the number of other items in the WHO DAS 2.0 makes it unlikely that the associations between severity of disability and either positive or negative domains of well-being were inflated. Indeed, severity of disability was not positively correlated with negative affect, symptoms of anxiety, or conduct problems and showed only a weak positive correlation with symptoms of depression (accounting for less than 5% of variance). Similarly, it was not negatively correlated with positive affect, prosocial behaviour, or satisfaction with life and showed only a weak correlation with flourishing (accounting for about 5% of variance). There is therefore very little evidence to suggest that any conceptual overlap between severity of disability and positive or negative domains of well-being artificially inflated the association between these.

There was also partial conceptual overlap between some of the predictor variables. This has two sources. First, most predictor variables reflected subjective judgements made by the same individual. Second, high levels of some predictor variables (e.g., optimism) were likely to motivate behaviours likely to contribute to other predictor variables (e.g., flourishing). Such correlations between predictor variables may artificially inflate evidence of moderated relationships in regression analyses. Although inter-correlations between predictor variables

were found, tests of multicollinearity indicated that these were not of sufficient magnitude to affect the results of the regressions. Moreover, in analyses in which the possible moderating effects of five predictor variables (optimism, social support, adaptive coping, discrimination and out-of-home care) on eight well-being outcomes (satisfaction with life, flourishing, prosocial behavior, positive affect, depression, anxiety, conduct problems, negative affect) were examined, only one moderated relationship was found (adaptive coping served as a buffer in the relationship between severity of disability and anxiety symptoms) and this had a very small effect size. Therefore, there was very little evidence that any conceptual or measurement overlap between predictor variables inflated the magnitude of moderated relationships.

### **Differences in well-being and predictors according to type of disability and demographic variables.**

Very few previous studies have compared levels of well-being across young people with different types of disability (Silva et al., 2011a; Gutman et al., 2010). This study hypothesized that because young people with visual and physical disabilities encounter unique psychosocial challenges, they may also show unique patterns of psychosocial well-being. The findings suggest that this may be the case for some positive domains of well-being. Adolescents with a visual disability had higher mean scores than adolescents with a physical disability for three positive outcomes: flourishing, prosocial behaviour and positive affect. However, no differences were found between the two groups on any negative domains of well-being. In particular, there was no difference in mental health problems between visually and physically disabled adolescents. However, it is unclear whether this finding should be attributed to type of disability. Adolescents with a visual disability had higher levels of two protective factors (optimism, adaptive coping) and a lower prevalence of one risk factor (out-of-home care). It should be noted that these differences remained after controlling for another confounding factor, the severity of disability. Thus, the most plausible explanation appears to be that adolescents with a visual disability might be less adversely affected by disability than those with physical disabilities as they have greater access to assets that protect against adversity, and less exposure to external risks than their peers with a physical disability. However, this explanation awaits confirmation by future research.

Living in out-of-home care appears to be an important factor related to the difference in well-being between adolescents with visual disability and their peers with physical disability. The percentage of adolescents who lived in out-of-home care differed dramatically by type of disability, with many more adolescents with a physical disability living out-of-home than adolescents with a visual disability. Out-of-home care shows strong negative relationships with

some domains of well-being. In the USA and other Western countries there are active attempts to eliminate the circumstances in which young people with disabilities live in this type of facility (Friedman & Kalichman, 2014). At present, out-of-home care seems to be the optimal option for many young people, especially those with physical disabilities living in rural areas who wish to pursue an education or obtain employment in Vietnam and other LAMICs.

In addition, data concerning out-of-home care illustrates the shift from rural to urban areas among adolescents with disabilities. The legacy of Buddhist traditions in Vietnam (UNICEF, 2010) has led to a widespread stigma concerning disability. The legacy of the Buddhist tradition in which disability is viewed as a punishment for mistakes caused by parents, or by the person with disability in a previous life, leads many rural families with children with a disability to avoid shame by keeping these children at home out of the public eye. In addition, the low income of many rural families prevents them from affording the cost of sending their children to special schools or support centres, especially because these are often only available in urban areas. As a result, until recently, many disabled children in Vietnam did not attend school. In 2010, it was reported that only one in four children with a disability could go to school and almost half of these children aged 6-17 were illiterate (Rosenthal, 2009; UNICEF, 2010). However, the increasing urbanization of Vietnam appears to be allowing greater access to services for young people with a disability. In the current study, three-quarters of adolescents with a visual disability lived in urban areas did not need to move out of their home for schooling or vocational training. In contrast, the vast majority of adolescents with a physical disability were from rural backgrounds and therefore needed to live out-of-home in order to access these opportunities.

Gender is often a demographic characteristic associated with psychosocial well-being outcomes. In many LAMICs, female teenagers face additional challenges resulting from gender inequalities and discrimination (Pearson, 1995; Yu & Sarri, 1997). Therefore, it was predicted that they might have poorer well-being than boys. However, in this study, contrary to this expectation, no difference was found between male and female adolescents in either positive or negative domains of well-being.

### **The association between severity of disability, risk and protective predictors and well-being outcomes.**

All of the predictor variables in the research model explained independent variance in at least one domain of well-being. However, while some predictors were related to many domains of well-being, the predictive power of others was more domain-specific. One of the noteworthy

findings of the current research was that severity of disability was found to make an independent contribution to the variance in only two of the eight domains of well-being (symptoms of depression and anxiety), and it was not the strongest independent predictor in either case. That is, disability did not determine the destiny of these young people. These results are consistent with the theoretical framework used in the current study, in which well-being is viewed as an outcome that has multiple determinants, only some of which are directly related to disability.

It is noteworthy that three predictor variables, optimism, social support and discrimination, explained independent variance in many domains of well-being. They were also the largest contributors to explaining variance in some domains of well-being. These findings are consistent with previous studies about the positive influence on well-being of optimism (Wrosch & Scheier, 2003), and social support (Turner & Noh, 1988; Abubakar et al., 2013) and negative impact of discrimination (UNICEF, 2013). The unexpected and counter-intuitive results of the simple correlations showing that discrimination was positively associated with three positive well-being outcomes (life satisfaction, flourishing and positive affect), awaits replication and explanation in future research.

In general, the research model can be considered to have utility. The distal predictor (severity of disability), protective factors (optimism, social support, adaptive coping), risk factors (discrimination, out-of-home care) included in the model all contributed independent variance to least one domain of well-being. Two protective factors, optimism and social support, were positively associated with many domains of well-being (six and four domains, respectively).

#### **Moderators for the relationship between disability and well-being outcomes.**

The research model proposed that the other predictor variables would moderate the relationship between severity of disability and each of the well-being outcomes. However, there was little evidence that this was the case. Only one instance of moderation was found. There was evidence that adaptive coping served as a buffer between the severity of disability and symptoms of anxiety among adolescents with disabilities. This finding is consistent with many previous studies showing the positive role of adaptive coping for well-being among other vulnerable populations (e.g., Huijgevoort, 2002; Bryden, 2015).

The current study also highlights the context-dependent nature of findings. In the Vietnamese context, there was no evidence that optimism, social support, and discrimination, moderated the relationship between disability and any well-being outcomes. However, such moderating relationships have been found in earlier research in both Western (Honey et al., 2011) and Asian contexts (Ho, Cheung, & Cheung, 2010).

### **Three clusters of adolescents with disabilities**

Regardless of severity and type of disability, the participants in this study could be classified into three clusters with unique characteristics. Most participants showed resilience in some domains of well-being. Nevertheless, many of the participants were struggling with significant challenges of mental health problems. These findings are consistent with those from the variable-focused analyses in which a large number of participants reported severe and extremely severe symptoms of depression and anxiety and yet means scores for some positive domains of well-being were above the midpoint on the scale.

## **5.8 Limitations and future research**

The current study had several limitations and knowledge in the field will be advanced if these limitations can be addressed in future research. Although the multi-site, multi-sectorial sampling strategy used in this study was designed to capture diversity in the population of Vietnamese adolescents with a disability, no attempt was made to obtain a nationally or regionally representative sample. The absence of any comprehensive national register of adolescents with a disability precluded this possibility. Although the four research sites captured rural and urban, and inland and coastal contexts, all were in Central and Southern Vietnam. As a consequence, data from this study cannot be used as the basis for estimates of national or regional prevalence rates for particular positive or negative well-being outcomes. For example, the data cannot be used to estimate the national, regional or provincial prevalence of severe or very severe symptoms of anxiety or depression among Vietnamese adolescents with a visual or physical disability. Moreover, the results of the analyses identifying predictors of well-being cannot be meaningfully translated into national or regional odds-ratios. In summary, the research findings can more usefully be applied to psychology than to epidemiology.

Second, the study used a cross-sectional observational research design. Therefore, no inferences about causal relationships were appropriate. The research model examined in this study showed a direction of effect from severity of disability to well-being that was informed by evidence from previous research (Lucas, 2007). It has been argued, however, that the direction of effect could be reversed. In particular, poor well-being in domains of mental health may magnify the severity of disability (Beekman et al., 2002). Longitudinal and experimental research is needed to help us understand the causal processes underlying the current results.

Third, the study did not explore differences in community attitudes towards the two types of disability or towards young people with congenital and acquired disabilities. A traditional belief in many Asian countries, including Vietnam, is that congenital disability is a punishment

for bad behavior in a previous life (Ngo et al., 2012). It is unclear whether this attitude is also held towards young people who acquire their disability as a result of illness, injury or war (Shiloh, Heruti, & Berkovitz, 2011). It may be important for future research to access community beliefs and attitudes towards different sources of disability, the extent to which these beliefs and attitudes are accepted and adopted by young people with a disability, and the way these attitudes influence their well-being.

Fourth, the research model did not predict a clinically significant amount of variance in two domains of well-being: positive affect and symptoms of anxiety. In order to improve prediction of these outcomes, it is necessary for future research to identify variables with stronger predictive power for these outcomes and incorporate these into the model.

Fifth, it is likely that that specific type of service provider and its quality can affect well-being of adolescents with disabilities. Findings about well-being of adolescents with disabilities were not taken these factors into account. Future study should investigate possible predictors that were not included in the model such as type of service provider, its quality, years of staying in a service provider, poverty, cause of disability and blaming attitude

Sixth, the absence of parallel data from peers without a disability (from a control group in the present study, or from previous research) limited the interpretation of the descriptive statistics. For example, it was not possible to make judgements about whether the participants' access to resources, exposure to risks, or well-being outcomes were higher or lower than those of other Vietnamese adolescents. The ability to make such judgements would have strengthened the fulfillment of Aim 1.

Seventh, participants were recruited via their principal service provider, which may have been their own families, Buddhist pagodas, churches, specialist schools, orphanages, charitable organizations, or a government or non-government agency. One implication is that service providers may have biased the sample through the extent to which they encouraged or dissuaded their clients to become involved. The purposeful sampling strategy used to ensure a diverse sample also introduced biases. As with most other qualitative research, the aim was not to obtain a nationally or regionally representative sample as a basis for making generalizations about a population. Therefore, caution should be used when applying the findings in similar contexts and it is inappropriate to generalise the findings, for example about the percentage of participants who encountered specific challenges, to a population.

Several strategies were used to avoid the participants' responses being biased due to the power of the service providers. First, all adolescents who met the inclusion criteria and were receiving services from a service provider who agreed to co-operate with the research received an

invitation to participate. Second, a third person, who was not directly involved with the prospective participants was assigned the task of delivering the information letters and consent forms to young people with visual or physical disabilities. Third, the use of the same drop box to collect consent forms from all invited persons, including those who did not agree to participate, was designed to preclude service providers and peers becoming aware of which adolescents had agreed (and declined) to participate. Evidence of the effectiveness of these strategies in reducing bias in the sample was a high participation rate (93 percent; 224/240).

In addition, in order to reduce bias in responses, the interviews took place in a safe and comfortable place that precluded the conversation being observed or overheard by anyone associated with the service provider.

## **5.9 Conclusion**

In conclusion, despite its limitations, the present study provided some new insights into both the level of well-being among a large and diverse sample of young people with a disability in a LAMIC. It was the first study to document multiple outcomes in both positive and negative domains of well-being. It was therefore the first study to show that young people with visual and physical disabilities are able to maintain moderate levels of well-being in several positive domains while also experiencing the challenges of very significant mental health problems. In addition, the inclusion of young people with two types of disabilities was a distinctive feature of the research. It is the first study to show that young people with a visual disability enjoy somewhat higher levels of well-being in some positive domains than their peers with a physical disability. The current study identified risk and protective factors and tested them in a research model on multiple outcomes. It is noteworthy that the protective role of social support is evident for many domains of well-being among Vietnamese adolescents with disabilities. The next study focused on exploring this factor from the participants' perspective.

# CHAPTER 6 - STUDY 3: QUALITATIVE STUDY EXPLORING PERCEPTIONS OF CHALLENGES TO WELLBEING AND SUPPORT NEEDS HELD BY VIETNAMESE ADOLESCENTS WITH A VISUAL OR PHYSICAL DISABILITY

*“There is no such thing as a worthless conversation, provided you know what to listen for.”*  
Miller (1965, p. 5)

## 6.1 Abstract

Visual and physical disabilities have a high prevalence among children in low- and middle-income countries, and have a profound effect on these children’s developmental trajectories. For most of these children, having access to appropriate informal and formal support is a prerequisite to realize their potential, achieve quality of life, and contribute to their community. However, in low- and middle-income countries support services are typically limited in both quality and quantity. The current study aimed to gain insight into the developmental contexts of Vietnamese adolescents with a visual or physical disability by exploring their perceptions of the everyday challenges they face, their evaluations of current support services and their perceptions about the types of support services that would allow them to thrive. Data were collected from in-depth individual semi-structured interviews, which were conducted with adolescents (aged 10-19 years) with a visual (n=12) or physical (n=9) disability drawn from diverse rural, regional and urban sites in Vietnam. An audio recording was made of each interview to allow verbatim transcription by the researcher. A content analysis was conducted, and the findings were organized using Bronfenbrenner and Morris’s bio-ecological framework. Both groups of adolescents reported five similar challenges: mobility limitation, problems relating to social relationships, the very few pathways available to them to make the developmental transition to adult status with a career and financial independence, current financial stress and limited opportunities for recreational activities. It is noteworthy that the participants associated these challenges with their microsystems, rather than directly with their physical impairments. The adolescents’ greatest unmet needs were for vocational and psycho-social support. However, there was also an unmet need for information: Most participants were unaware of the full range of support services that were available to them. The types of support services that participants perceived to be ideal were directly related to the five challenges they identified. Their ideas about ideal support focused on three main aspects of service quality: physical characteristics (convenient location, accessible, aesthetically pleasing), infrastructure (space, areas, useful equipment) and staff characteristics (friendly, dedicated and highly

competent). Responses from all participants were integrated to create a model to guide the development and reform of services to support the development of Vietnamese adolescents with a visual or physical disability.

## **6.2 Introduction**

For many people with disabilities, support providers serve as a ‘bridge’ that connects them with their community and allows them to succeed. The provision of material support, such as assistive devices, may allow young people with disabilities to participate in social activities, work, and live in their community independently (Green et al., 2005). The provision of psychosocial support may allow also improvement in quality of life (Kokoric, Berc, & Rusac, 2012). Without such support, many young people with disabilities are likely to be socially isolated, unable to engage in meaningful activities, or dependent on others (Takamine, 1998).

People with disabilities seek diverse types of support from diverse types of service providers. Types of support include environmental adaptation (e.g., assistive devices), communication support, social engagement strategies, education, employment, advocacy, respite, assistance animals (e.g., guide dogs), therapeutic interventions, information and advice. These can be provided by formal or informal service providers.

Each type of service provider has its own strengths and weaknesses. Formal support providers encompass agencies of the State and non-government organizations (e.g., faith-based organizations, international charities). Formal support services usually employ professional staff and have a clear mission to maximize the benefit for people with disabilities. With stable funding and a duty to implement disability laws, formal service providers play an important role in setting standards for interventions and other support services for people with disabilities. Formal services may also provide training and guidance for informal support providers, such as family and friends, so that they are better able to care for the person with a disability. When formal support is appropriate and accessible, the demands that care places on informal support providers are reduced. Such service providers not only reduce the physical and psychological challenges on families with a member with a disability, but can also reduce the financial pressure, as caregivers who are freed from caregiving are able to participate in income-generating activities (World Health Organization, 2011).

Despite these potential advantages, some models of formal service provision may not lead to positive well-being outcomes. In particular, formal service providers providing institutional care for young people with disabilities have been widely criticized (Borbasi, Bottroff, Williams, Jones, & Douglas, 2008; Parmenter, 2008). Historically, many providers of

specialist institutional care have delivered only basic amenities (e.g., housing, food). They also often focus on children who have been abandoned by their families. But even under the best conditions, institutional care is likely to limit opportunities for community engagement, include human rights abuses and fails to provide individualized care and autonomy (World Health Organization, 2011; Disability Rights International, 2016). In LAMICs, these shortcomings of institutional care are often exacerbated by poor living conditions, inadequate staffing, shortage of food, and lack access to appropriate medicines and rehabilitation (World Health Organization, 2011). In addition, people with disabilities in institutional care perceive that they have very little power or control over their own lives (Freidson, 1970). As a result, for more than 20 years, stakeholders have promoted models of non-institutional formal care for young people with disabilities (Chiriacescu, 2008).

Informal support providers encompass family members, friends and other members of the communities in which persons with disabilities live. These provide most of the support received by young people with disabilities, even in high-income countries, where formal support services for people with disabilities are available (World Health Organization, 2011). In particular, immediate family members and friends provide most of the emotional, material and instrumental help for young people with disabilities. As a result, young people with a physical disability in Western countries reported that the help provided by family and friends is more important to their quality of life than the support they receive from formal support services, such as social welfare departments (Leutar & Štambuk, 2007). The strengths of informal support are that it is provided in the flexible context of ongoing attachment relationships, characterized by reciprocity and a deep knowledge of the preferences and challenges of each young person with a disability (Kokoric et al., 2012). The weakness of informal support is that family members and friends often lack relevant professional knowledge and the specialized skills needed to provide the best possible care for young people with a disability. They may also not have the knowledge and resources to prevent or reduce disability. Many children become disabled, or their disability becomes more severe because family members fail to access necessary medical interventions for their children (World Health Organization, 2004). In addition, informal support providers usually have limited access to specialist resources (e.g., assistive devices). In summary, each type of service provider has its own advantages and disadvantages. Acknowledging those is important in 'top-down' decision-making about service provision.

Effective service provision is responsive to the needs of the people it serves. This requires a bottom-up approach in which the voices of the end users are taken into account (Dobrzyńska, Rymaszewska, & Kiejna, 2008; Fortune, 2013). Services that are perceived to be

irrelevant, inaccessible or unacceptable are likely to be underused. There are many examples of services in high-income countries that have been designed from the top-down and that have not been utilized because they do not meet the needs of the target clients (Bigby, 2010; Lunenborg, Nakken, Van der Meulen, & Ruijssenaars, 2011). In contrast, when there is a deep understanding of the challenges faced by people with a specific disability, sometimes a single well-chosen support can help to overcome many problems (Sarason, Shearin, Pierce, & Sarason, 1987). Therefore, it is important to document the opinions of young people with visual and physical disabilities to inform the development of support service for them. The current study aims to capture the voices of young people with disabilities who receive support from diverse providers (faith-based care centres, government specialist centres, non-government care centres, family) as they discuss their perceptions of the challenges to their well-being and their support needs, evaluate current support services, and identify the characteristics of service providers that influence their well-being.

While research in high-income countries has provided children and adolescents with disabilities with opportunities to share their experiences and expectations about support services (Watson et al., 2000), few adolescents with disabilities in LAMICs have been given this chance. However, even in high-income countries, the development and improvement of support services for people with disabilities is usually based on perceptions and expectations of parents or caregivers rather than that of young people with a disability (Maloni et al., 2010; O'Brien, Whitehead, Jack, & Mitchell, 2012). This may be due to the assumption that their parents or caregivers are more aware of their problems and the support they need than the young people themselves. In addition, even in high-income countries, attempts to document the opinions of young people with disabilities often fail to include voices from rural areas. The current study aims to bridge an important gap in research by capturing the voice of adolescents with disabilities in diverse contexts (rural/urban) who are receiving support from diverse service providers (religious support centres/specialised schools/in-home care) in a LAMIC. The objective was to develop a culturally relevant model that summarized the characteristics of an ideal service provider for adolescents with visual and physical disabilities in the Vietnamese context.

Vietnam has a large number of young people with a visual and physical disability (UNICEF, 2000), however, services to support their participation and well-being are still limited in both quantity and quality (Mensch et al., 2003; UNICEF, 2010). For example, one survey showed that up to 60% of young people with disabilities did not receive any form of formal support services (UNICEF & MOLISA, 2004). Until very recently, this situation showed little

evidence of improvement (The Department of United Nations Population Investigation in Vietnam, 2011). There continues to be a gap in the provision of disability-specific support services and in the provision of services outside the main urban centres (UNICEF & MOLISA, 2004). It is hoped that the findings from the current study will provide insights to inform the improvement of service provision for Vietnamese adolescents with visual and physical disabilities.

### **6.3 Research aims**

Study 3 had three aims:

(1) To identify:

- common challenges facing Vietnamese adolescents with visual and physical disabilities;
- the challenges for which participants believed that they needed support from external sources.

(2) To capture the evaluations of current support services made by Vietnamese adolescents with visual and physical disabilities

(3) To explore the characteristics of service providers that influenced the well-being of Vietnamese adolescents with visual and physical disabilities by capturing the qualities of an ideal service provider.

### **6.4 Method**

#### **6.4.1 Participants**

A subset of 21 participants from Study 2 participated in this study (visual disability:  $n = 12$ , physical disability:  $n = 9$ ; male = 11, female = 10) (Table 6.1). The participants were recruited by purposive sampling to preserve the diversity of the sample in terms of age, gender, type of disability, level of disability, in-home/out-of-home care and geographic location; and to include participants with high and low satisfaction with life, and high and low levels of optimism. The age of participants ranged from 11 to 19 years ( $M = 15.48$  years). About half of the sample had been disabled since birth ( $n = 10$ ); one quarter ( $n = 5$ ) had acquired their disability postnatally as a result of a traffic accident or illness, and the remainder did not know how or when they became disabled because they were abandoned by their parents at a young age ( $n = 6$ ). Participants were recruited by purposive sampling to preserve the diversity of the sample in terms of age, gender, type of disability, level of disability, in-home/out-of-home care and geographic location; and to include participants with high and low satisfaction with life, and high

and low levels of optimism. One outcome of considering such a large number of factors in a small sample was that only one or two adolescents were drawn from many contexts. For example, only one of the participants lived in their family home, only one attended a church-funded special school, and only two were cared for by Buddhist monks in a pagoda (Table 6.1)

Table 6.1: Demographic characteristics of participants in Study 3

ID	Gender	Age	Education*	Type of disability	Cause of disability	Type of accommodation
1	Male	16	Special class*	Visual	Illness at 1.5 years	Government holistic care centre
2	Male	14	8	Visual	Congenital	Government holistic care centre
3	Female	16	0	Physical	Congenital	In care of monks at Buddhist Pagodas
4	Male	16	Special class*	Visual	Traffic accident at 12 years of age	Government holistic care centre
5	Male	16	0	Visual	Congenital	Government holistic care centre
6	Female	17	11	Visual	Congenital	Government holistic care centre
7	Female	19	0	Physical	Congenital	In care of monks at Buddhist Pagoda
8	Female	12	Special class*	Visual	Brain tumour at 6 years old	Government holistic care centre
9	Male	12	5	Visual	Not known	Family
10	Female	10	0	Physical	Not known	In care of monks at Buddhist Pagodas
11	Male	14	9	Visual	Congenital	Specialist school
12	Male	15	9	Visual	Congenital	Government specialist school
13	Male	17	9	Visual	Not known	Government specialist school
14	Male	17	9	Visual	Congenital	Government specialist school
15	Female	15	10	Physical	Traffic accident at 15 years of age	NGO specialist school
16	Female	18	6	Physical	Not known	NGO specialist school
17	Male	19	6	Physical	Fever at 2 years of age	NGO specialist school
18	Female	19	11	Physical	Not known	NGO specialist school
19	Male	17	9	Visual	Not known	Government specialist school
20	Female	11	11	Physical	Congenital	Government specialist school
21	Female	15	1	Physical	Congenital	Church-funded special school

Note. "Special class" refers to an ungraded class that does not follow the mainstream school curriculum.

## 6.4.2 Recruitment

First, service providers were asked for permission to approach potential participants to invite them to be involved in one or both of Studies 2 and 3. Then, on the basis of their responses in Study 2, a subset of participants was given a Letter of Introduction (Appendix H) and consent form for Study 3 (Appendix I). When participants were under 18 years of age, informed consent was sought using a two-step process. First, a Letter of Introduction and consent form were sent to their parents or guardians (Appendix J). Second, participants under 18 years of age were provided with an oral explanation of the information in the Letter of Introduction and were asked to give verbal assent. Participants and their parents/guardians were allowed sufficient time to consult with friends, family members and the researcher before making their decisions about participation. The response rate was 92% (22/24 adolescents who were approached agreed to participate), however one of these was unable to complete the interview. Thus, a total of 21 participants completed Study 3.

## 6.4.3 Interviews

All data were collected from in-depth individual semi-structured interviews conducted by the principle researcher. The participants' words were audio-recorded, and pens and large sheets of paper were provided to allow participants express their ideas graphically.

The semi-structured interviews were organized around eight main questions, which explored information relevant to the three research aims. After establishing rapport with each participant, the interview was introduced: *The ultimate aim of this research is to improve the services provided to young people with a disability to help them overcome their challenges/difficulties. In order to do that, I am, first of all, very interested in understanding the challenges you face in your life. Everyone encounters challenges in their lives. Many of the challenges faced by young people with a disability may relate to the same issues as those faced by other young people (e.g., problems concerning finance, friendship, health, family, transport, communication, harmonious living, sport activities, love, career, sexuality etc...). Other challenges faced by young people may relate to their disability.*

The interview began with four questions that aimed to identify the most common and significant challenges faced by Vietnamese adolescents with visual and physical disabilities (Aim1).

***Question 1:*** *Could you share with me the kinds of challenges that you have encountered in the last month?*

**Question 2:** *Now, I would like to ask you about an imaginary situation. Imagine that you had a magic wand that could help you change three things. You could not change your disability, but you could change anything else, what would you change? And why?*

**Question 3:** *Now I would like you to think about the real world. I am interested in gaining a better understanding of your perceptions of what would help you overcome the challenges you face. What are challenges that you think you can solve yourself?*

**Question 4:** *What other challenges are there for which you think you need external support?*

The next three questions explored the participants' evaluation of their current support providers (Aim 2).

**Question 5:** *Is there anything about currently available support services that you think is not effective or unhelpful for you, and why?*

**Question 6:** *What kinds of services do you want to be available, but do not currently exist?*

**Question 7:** *Is there anything that should be changed or improved in order for these current support services to be more effective?*

The last question explored the participants' perceptions concerning the qualities of an ideal support provider.

**Question 8:** *What characteristics do you think that an ideal support service would have?*

In addition to these eight main questions, the semi-structured interview format allowed the use of follow-up questions to either (1) seek clarification to ensure that the participants' experience and views were accurately documented, or (2) to allow a deeper understanding of the issues the participants had raised (Dahlgren, Emmelin, & Winkvist, 2004). In addition, a list of available services was used to ensure that participants were given the opportunity to comment on each. In order to maintain a natural conversational tone, minor changes to the wording of questions were made across interviews to respond to differences in context. This proved to be an important advantage of the semi-structured interview format when working with this population who had no prior involvement in research.

Most interviews were completed in 20-35 minutes. An audio recording was made of each interview to allow verbatim transcription by the researcher. Then, an independent expert in disability who is bilingual in English and Vietnamese provided translation from Vietnamese into English for most of the interviews (n = 14) while the remaining interviews were translated by the researcher, who is also bilingual in Vietnamese and English (n = 7).

At the end of the interview, each participant received a list of support services and the researcher's contact details in case they needed assistance.

## **6.4.4 Data analysis**

### **6.4.4.1 Inductive content analysis**

Interview data were analyzed through inductive content analysis (Elo & Kyngäs, 2008). There is consensus that content analysis is an appropriate method for analysing verbal, written or visual information in qualitative research ( Cole, 1988; Elo & Kyngäs, 2008; Vaismoradi, Turunen, & Bondas, 2013). There are two approaches to content analysis: inductive and deductive. Inductive content analysis enables researchers to identify key concepts and themes derived from the data, rather than from prior theories (Elo & Kyngäs, 2008). This was particularly appropriate in the current research, because there are few previous studies about support services for Vietnamese young people with disabilities that would allow a focus on predefined categories of responses. In addition, inductive content analysis is the most relevant approach for capturing the original ideas of the participants to provide new insights into an issue. Inductive content analysis allowed the perceptions of participants with disabilities to be documented regardless of whether these perceptions were consistent with available empirical evidence. The results of the analysis were used as the basis for the development of a model that summarized desired characteristics of service providers for Vietnamese adolescents with visual and physical disabilities.

### **6.4.4.2 Coding process**

The inductive content analysis was conducted using the five-step method proposed by Graneheim and Lundman (2004) and specific coding methods proposed by Saldaña (2016). In the first step, the recorded interviews were translated from Vietnamese into English. The English transcripts were used as the data because English-speaking researchers needed to be able to complete an independent analysis to check the accuracy and reliability of results. In the second step, an iterative process was used to divide the transcripts into meaning units. In the third step, the meaning units were coded based on multiple coding methods and consideration of the differences and similarities between identified codes. In the fourth step, the codes were grouped into categories and then classified into sub-themes. Finally, themes relevant to challenges, need for external support, and desired characteristics of a good service provider were formed from the sub-themes (Graneheim & Lundman, 2004).

Transforming information from meaning units into codes is one of the most important stages in inductive content analysis (Saldaña, 2016). Coding methods proposed by Saldaña (2016) were used to enhance the accuracy and objectivity of coding. The most commonly used methods in the study were: attribute coding (e.g., age, gender), magnitude coding (e.g., positive,

negative), simultaneous coding (e.g., one meaning unit that was relevant to two issues required more than one code), and descriptive/topic coding (which used a noun code). In some cases, *in vivo* coding, which preserves the participants' verbatim responses was also used (Saldaña, 2016).

Four steps were followed to apply these methods. First, ten transcripts were sampled; and draft codes, categories, subthemes and themes were inductively developed. These formed the basis of a draft codebook. Second, a pilot test was conducted in which an independent researcher attempted to apply the codebook to each of five transcripts on two separate occasions. Third, the results of the pilot test were used to refine the draft codebook. Fourth, the final codebook (Appendix K) was used to code all 21 transcripts.

As recommended by Saldaña (2016), I regularly wrote analytic memos as a part of the qualitative analysis process. The purpose was to document and reflect on various aspects of the analysis, such as code choices, research objectives, emergent concepts, patterns, categories, the extent to which the responses could be synthesized, how I personally related to the participants and other personal thoughts that could have contributed to bias in the codes, categories, themes and the conclusions I drew. This writing task was very helpful in scrutinizing the process of data analysis and minimizing bias (Saldaña, 2016).

#### **6.4.4.3 Pilot analysis**

Five out of the twenty-one available transcripts were used for a pilot analysis. The preliminary pilot analysis had two aims: to determine

- (1) if the translations were equivalent in terms of the codes, categories, subthemes and themes they generated;
- (2) if the draft codes could be applied reliably by coders other than the researcher.

A three-step process was used in the pilot study. First, the researcher and a qualified translator independently translated five transcripts from Vietnamese into English. As a result, two sets of independent translations of five transcripts were available. Then, the two transcripts for each participant were coded in random order by an independent researcher at four-week intervals. Differences in the codes that were assigned to the two transcripts from the same participant were identified (Table 6.2).

Table 6.2: Differences in coding in different translations of the same interview

Participant ID	Time	Meaning units identified	Codes assigned	Differences in coding
A	1 <sup>st</sup>	32	38	0
	2 <sup>nd</sup>	33	38	
B	1 <sup>st</sup>	20	20	1
	2 <sup>nd</sup>	20	21	
C	1 <sup>st</sup>	48	48	0
	2 <sup>nd</sup>	48	48	
D	1 <sup>st</sup>	39	41	6
	2 <sup>nd</sup>	43	46	
F	1 <sup>st</sup>	24	24	5
	2 <sup>nd</sup>	27	28	

Note. n = number.

A quantitative analysis showed that there were few differences in the number of units identified or the number of codes that were assigned across the two translations for the first three participants. However, for other two participants (D and F), the difference in number of codes was large (6 and 5, respectively) (Table 6.2).

A detailed examination of the nature of each discrepancy was undertaken by the researcher. Two issues were identified. First, most discrepancies could be attributed to a lack of clarity in the codebook that affected data for codes but not data for subthemes or themes. For example, the meaning unit ‘People go quickly, I walk very slowly’ as assigned the code ‘Challenges/ Freedom of movement/ challenges compared to others’ at one time and ‘Challenges/freedom of movement/comparison to others’ at the other time. Both codes captured a challenge relating to freedom of movement. The codebook was edited to avoid further trivial discrepancies in coding. Second, other discrepancies between codes could be attributed to small differences in the meaning units that were identified. For example, at one time the sentence “*I wish I studied to know letters and learn numbers to recognize the value of notes, how to use money*” was broken into two units: “*I wish I studied to know letters*” and “*learn numbers to recognize the value of notes, how to use money*”. These were assigned the codes ‘Wish and Desire/Education/Literacy’ and ‘Wish and desire/Education/Numeracy and finance’ respectively. However, at the second time point, the same sentence was broken into two meaning units: “*I wish I studied to know letters and learn numbers*” and “*to recognize the value of notes, how to use money*”, which were coded as ‘Wish and Desire/Education/literacy and numeracy’ and ‘Wish and desire/Education/Finance’, respectively. The codebook was revised to avoid future

trivial differences in identification of meaning units that had consequences for the assignment of codes.

Overall, the differences in the transcripts and the codes that were assigned to these transcripts were very minor. They did not affect the sub-themes or themes that were identified. It was therefore concluded that there was a high level of agreement between the two sets of translations and that the translations were equivalent in terms of the themes they generated. The pilot analysis led to some refinements for the codebook that clarified the rules for dividing transcripts into meaning units to improve the clarity of the distinction between codes. Thus, the revised codes were judged to allow reliable coding by coders other than the researcher.

## **6.5 Results**

The results are organized according to the three research objectives: common challenges; demand for, and evaluation of, existing support services; and the perceived characteristics of an ideal service provider. Many adolescents with disabilities raised similar issues, which resulted in several themes being identified with a high frequency. For brevity, only one or two quotations were selected as examples for each theme and subtheme. Because of the small number of participants, no attempt was made to compare themes between adolescents with the two types of disabilities.

### **6.5.1 Topic 1 - Challenges to well-being faced by Vietnamese adolescents with visual and physical disabilities**

Findings regarding the challenges faced by Vietnamese adolescents with visual and physical disabilities were drawn from three sources: (1) responses to participants the question about challenges participants encountered in the last month, (2) issues raised indirectly in responses to the prompt about what they wished they could change for their lives, (3) challenges identified indirectly when participants responded to the prompt about the qualities of an ideal service provider. The results showed that concern about three broad challenges was very prevalent. These related to freedom of movement, social relationships and pathways to a career (e.g., barriers to education, vocational training and employment). Additional themes that were raised by a minority of the participants included financial problems, discrimination and lack of contact with family members.

### 6.5.1.1 Freedom of movement

Almost all participants, regardless of the type or severity of their disability, identified freedom of movement to be a significant challenge. Moreover, it was usually the first challenge they mentioned. The lack of independent mobility resulted in a heavy dependence on other people.

*Due to the impairment, I have difficulty going to school, or even helping my parents do housework. I just sit and wait for them. I cannot do anything by myself. (Participant 15, 17-year-old girl with a physical disability)*

*When I go out with friends, my friends have to take my hands and guide me. (Participant 4, 16-year-old boy with a visual disability)*

The challenge of mobility not only limited participants' daily activities, but also placed them in danger from traffic and from other hazards. It was noteworthy that many participants faced these difficulties and dangers on a daily basis when they travelled to and from their school and the market.

*I have only one method of moving. That is walking on foot. You know, I face risk from traffic accidents on my way every day. (Participant 6, 17-year-old girl with a visual disability)*

*When I go out in the streets, I have to use a stick. It is a bamboo stick but used as a white cane. People go quickly, I go very slowly. I sometimes hit a chair or a motorbike. (Participant 14, 19-year-old boy with a visual disability)*

It was also clear that restrictions on independent movement limited the participants' participation in social and recreational activities:

*I have no big problem with moving around but I cannot play football very well. Because of not seeing clearly, I sometimes cannot pass the ball to other players. I mainly play based on the sound of the ball bell [a small bell put into a ball so that children with visual disabilities can follow the movement of the ball by sound and the red colour of the ball]. (Participant 5, 16-year-old boy with a visual disability)*

Difficulties with independent movement were also a resource challenge on the participants' families. Because adolescents with disabilities needed supervision when they travelled, other members of their family needed to forego income-generating activities or household tasks in order to accompany them.

*I need support from others in travelling... My parents have to be with me most of the time. (Participant 18, 19-year-old girl with a physical disability)*

One of the main reasons for participants' restricted movement appears to be the absence of disability accessible infrastructure, such as ramps and walking lanes. This is particularly true in rural areas:

*There have to be always two people to help me travel every time I go to my hometown because the infrastructure there is very poor. It is easy to trip in the road. I cannot go without help there. (Participant 8, 12-year-old boy with a visual disability)*

In summary, limitations on independent movement are a common challenge to the well-being of participants. It poses a threat to their safety, limits their participation, and is a source of burden for their families.

### **6.5.1.2 Social relationships**

Another challenge that was widely reported by the participants was the difficulty of initiating and maintaining positive social relationships. For adolescents with disabilities, social relationships are also an important resource to support wider participation in their communities. Thus, it is not surprising that participants expressed their desire for a greater quantity and quality of social relationships.

*I want to have more friends, more close friends. (Participant 3, 14-year-old boy with a visual disability)*

However, they encountered challenges in both existing and new relationships. For existing relationships, the challenges came from their lack of confidence in maintaining friendships, and their small number of friends and disrupted romantic relationships.

*I find maintaining friendships is a challenge. Finding a friend is difficult and maintaining this friendship is even more difficult. (Participant 9, 12-year-old boy with a visual disability)*

Some participants lacked confidence in their ability to achieve friendships, and explained how this might result in losing friends:

*If people [friends] are close, there are also problems...I doubt my ability... Even though I do not do anything, they [my friends] may think or be afraid that I can discomfort them or do a bad thing for them. I am having fewer and fewer friends than before. (Participant 1, 16-year-old boy with a visual disability)*

Romantic relationships during adolescence are relatively rare as only two out of 21 participants reported that they had ever had a boyfriend/girlfriend. Both indicated that they kept their romantic relationship a secret and had little hope that it would become a long-term

relationship. In one case, the participant attributed the break-up of her romantic relationship to acquiring her disability (as a result of a car accident).

*Regarding “that person” [laughing], since I had the accident, he gradually left me. Maybe he was embarrassed because of me, I don’t know... (Participant 15, 15-year-old girl with a physical disability)*

Participants also reported that initiating conversations with others as a strategy to widen their social relationship was also a challenge, even when they were among their classmates. They attributed their difficulties to a range of issues, including a lack of interest or trust in others, lack of social skills needed to make friends, and lack of communication skills. Adolescents’ own behaviours therefore, may contribute to their marginalization.

*I rarely talk to others, unless they ask me. In the inclusive class, I do not know anyone to communicate with. I am afraid that they dislike or have contempt for me. I do not feel comfortable talking with others. The ones who came to talk to me might be just curious about me (Participant 1, 16-year-old boy with a visual disability)*

*...I also need assistance to have more friends. I do not know how to start a conversation with a new person... By that, I hope I can make friends easily and have more friends. I think I should put more effort on communicating with others. (Participant 2, 16-year-old girl with a physical disability)*

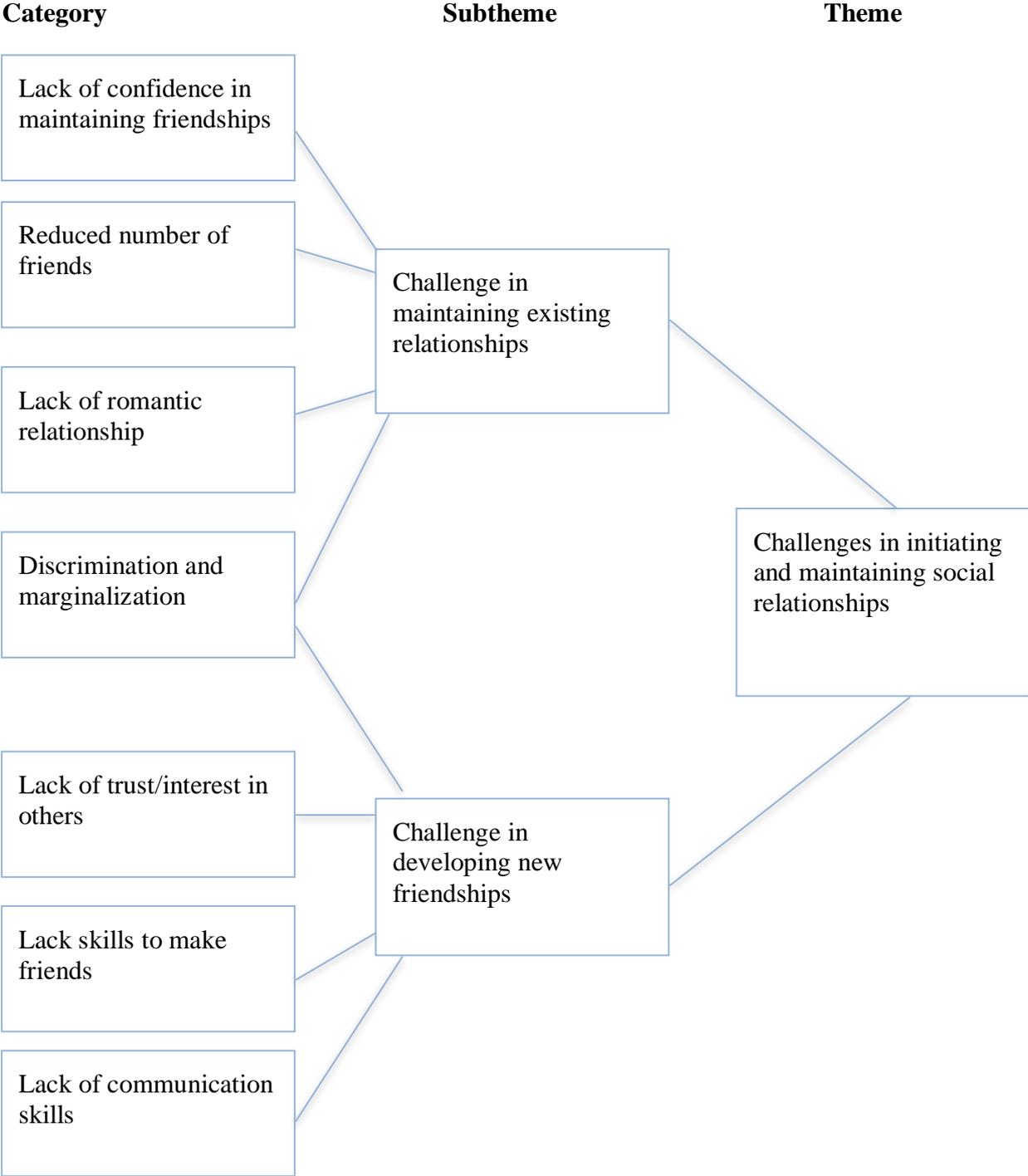
Other adolescents with disabilities reported discrimination and/or social exclusion.

*From the beginning to the end of the school year, there were a few persons coming to me. It has been so sad that I have not talked with many friends in class. Since I was not able to come and talk with them, they thought I was “autistic”. They did not read homework/studying tasks for me. They did not notice my existence. I wish they were friendlier and talked to me. (Participant 1, 16-year-old boy with a visual disability)*

The sources to which young people attributed their difficulties in social relationships are summarized in Figure 6.1.

In summary, adolescents with visual and physical disabilities encountered challenges in both developing and maintaining social relationships. This was most often mentioned in the context of friendships with peers. These challenges were attributed to their own deficiencies (lack of social skills, communication skills, social confidence) and external barriers (such as discrimination and marginalization by others). Difficulties with social relationships were often linked to other challenges, such as limited social participation and career opportunities.

Figure 6.1: Categories leading to challenges in social relationships among Vietnamese adolescents with visual and physical disabilities



### 6.5.1.3 Pathway to career

The theme ‘pathway to career’ captured two subthemes: education and vocational training. These two issues were common concerns across participants with the two types of disabilities.

The most common response to the question about what they would change “if they had a magic wand” was that they would be able to study more effectively so that they could achieve a higher level of education.

*I only wish that I could study well. That’s all. I do not need anything other than that. (Participant 15, 15-year-old girl with a physical disability)*

*As disabled people, only few students can enter college and university. The majority are not able to do so. I am a girl with only average grades at school; I will find it very difficult to continue my studies after I graduate from high school. (Participant 18, 19-year-old girl with a visual disability)*

The significance attributed to education reflected a belief that a good education provided one of the few pathways to a job that was open to people with disabilities. That is, education was a pathway to their future career.

*Career is another concern. I am not sure what I will do for living in the future. But I know I need to study well first. (Participant 15, 14-year-old boy with a visual disability)*

In many cases, the desire for a high level of education was explicitly linked with securing an income and becoming financially independent of their families.

*If I had three wishes, the first wish would be study well to have a good job, so that I could be financially secure. (Participant 11, 14-year-old boy with a physical disability)*

*I will not have money until I have a job. (Participant 1, 16-year-old boy with a visual disability)*

Participants in late adolescence were acutely aware of the importance of gaining employment in the near future. Many participants expressed their concerns about how they would be able to make a living.

*I have no clear future. I do not know how I will live, what job I can do. I am so worried. (Participant 18, 19-year-old girl with a physical disability)*

*I do not know how to tell you and make you understand how deeply I need... that all I wish for is a stable job, a regular income to take care of myself, no need to live dependently to others. (Participant 16, 18-year-old girl with a physical disability)*

Concern about their future careers was not due to the absence of career goals. Many participants expressed an interest in a specific career. The most frequently mentioned aspirations were to be a musician, a therapeutic massage worker, a practitioner of traditional medicine, a traditional doctor, an information technology specialist and a teacher. However, many realized that extensive additional training would be required in order to pursue a career in these fields. Many noted that such training was not currently available.

*I would like to be an English teacher...I like learning English so it would be great if there were volunteers or English teachers here to teach us. (Participant 10, 10-year-old girl with a physical disability)*

Many participants recognized that their career choices would be limited by the narrow range of vocational training available to them. Five of the participants (1, 3, 9,14 and 19) expressed a personal interest in a career in music, but few believed that this was achievable.

*Regarding my career, I am pursuing traditional medicine. I love singing and playing guitar, but I do not think I am able to afford a guitar. I cannot pursue it as an official job. At school, there are teachers teaching us massage and traditional medicine so I will take these as my future career. (Participant 12, 15-year-old boy with a visual disability)*

For some participants, no vocational training was available. Some others were unable to afford the vocational training that was available for them.

*I would like to attend cooking, walking and singing class. These kinds of class are available, but my family is not able to afford them, so that I do not join them. (Participant 9, 12-year-old boy with a visual disability)*

Thus, there was often a wide difference between what adolescents with disabilities would like to do, and what they have to do, for their future employment.

Overall, challenges resulting from limitations in freedoms of movement, social relationships, and pathways to a career were prevalent among adolescents with visual and physical disabilities in Vietnamese.

**Other themes.** Other challenges raised by a minority of the participants included financial difficulties, lack of contact with family, harassment, low opportunity for marriage, and lack of medical provision. It is important to note that subsequent prompt questions revealed more challenges. For example, the challenges of maintaining contact with family members while in out-of-home care was never mentioned in response to the prompt question about challenges in

the previous month. However, many participants raised this issue in response to the question about the characteristics of an ideal service provider. They desired that family members would be allowed to visit, or ideally stay with them, when they attended a residential service. Currently, many families live at a distance that prevents regular contact with their child.

## **6.5.2 Topic 2 - Evaluation of current support services**

Two main themes were identified: demand for specific types of support and under-use of existing support services.

### **6.5.2.1 Support needed for well-being**

Many of the challenges that participants faced in daily life could not be overcome without the help of formal or informal provision of support. Several types of external support were mentioned by more than one participant. Most were directly relevant to the challenges they had identified in earlier responses.

**Support for travel.** Because freedom of movement was one of the biggest challenges faced by Vietnamese adolescents with visual and physical disabilities, it was not surprising that many participants reported that they needed and used support to overcome this challenge. Informal support providers, such as family and friends, were reported to provide most support for travel.

*There is a friend who takes me to class and I sit at my place until the class finishes and I go home with him. (Participant 1, 16-year-old boy with a visual disability)*

The absence of ‘disability accessible’ infrastructure, such as ramps or lifts, even in large cities makes it impossible for young people with disabilities to travel alone, even when they had mobility equipment.

*I need support from others in travelling. I cannot move around without other people’s help even though I have the walking cane. (Participant 18, 19-year-old girl with a visual disability)*

**Support for studying.** A lack of ‘disability accessible’ learning resources to support young people with a visual disability also limited their educational opportunities. Large print and Braille books are rarely available to students. In addition, most teachers have no access to specialist teaching aids. As a result, many adolescents with a visual disability reported a need for support in accessing information in textbooks, on the classroom blackboard and for completing assessable work. However, the availability of this support was often inconsistent.

*Regarding studying, there is lots of homework and it is hard to understand. Previously, some university students voluntarily came to tutor us at home from 7-8pm at night. But no one does that at the moment. (Participant 1, 16-year-old boy with a visual disability)*

**Vocational support.** Many participants expressed their need for support in the form of vocational orientation and training. This need was often repeated many times in a single interview.

*I wish I could receive the right vocational orientation so that I could have a good job in future...*

*...It would be great if there were a Psychological Counselling centre and Vocational Training Centre at every high school. (Participant 12, 15-year-old boy with a visual disability)*

School teachers were identified as a potential source of vocational training and support. However, few teachers currently had this as part of their role:

*I need all teachers in this centre to help me to study well and master a job that I want to do in future. (Participant 11, 14-year-old boy with a visual disability)*

**Psychosocial support.** Many adolescents expressed a need for someone they can trust to talk to, listen to, and seek advice from confidentially.

*I want to look for someone who can keep secrets so that I can share anything with them without any doubt. (Participant 1, 16-year-old boy with a visual disability)*

*I need to talk to others to seek their advice or just be listened to. (Participant 21, 15-year-old girl with a physical disability)*

Most participants sought this additional psychosocial support from their families and friends, especially when the main purpose in seeking support was to obtain acceptance or motivation to achieve their goals.

*I need support about emotion [sic], I mean I need people around me to encourage me, love me. Then it helps me to believe that I could have the power to do everything I like. (Participant 10, 10-year-old girl with a physical disability)*

However, a few participants explicitly indicated a need for support from a mental health professional.

*I am introverted so I really need someone to talk with. A psychological expert would be useful. (Participant 14, 17-year-old boy with a visual disability)*

Some participants revealed a level and type of psychological distress that might be best met by a combination of informal and professional psychosocial support.

*I usually sit. People think I just sit for rest, sit for fun. But actually I cry. Sometime I cry all night when I think about everything. (Participant 4, 16-year-old boy with a visual disability)*

**Financial support.** Several participants also shared their need for financial support.

*My family is poor, so that I cannot afford study equipment. My family is struggling to pay the tuition fee for my studies. I am always worried about the tuition fee I need to pay each month 1.050.000VND each month.<sup>3</sup> I wish I could have it paid so that I would not have to drop school. (Participant 14, 17-year-old boy with a visual disability)*

In summary, the participants expressed a need for a both material and psychological support for their well-being. The specific types of support they requested addressed challenges they had previously identified. Only a small number of participants indicated that they were able to access the support they needed.

### **6.5.2.2 Use and evaluation of current support services**

Two main sub-themes were identified: (1) a lack of diversity in the support service providers used by participants and (2) shortcomings of current support services.

**Lack of diversity in the support service providers used.** Most participants (17 out of 21) accessed support only from the single service provider from which the participants were recruited for this study. Most of these service providers offered a very narrow range of types of support, usually education and housing. Very few participants accessed any rehabilitation service or professional counselling. In some locations such services were not available.

*I would like to talk with a psychologist, but I rarely hear about psychological counselling services. I never see one. (Participant 6, 17-year-old girl with a visual disability)*

However, even in locations where services are available, young people with a disability were often unaware of them, and the means of accessing them.

*I even do not know that they are available so how can I use them. (Participant 15, 15-year-old girl with a physical disability)*

*I think they should actively advertise their services, introduce themselves to us so that I could hear their name. (Participant 15, 15-year-old girl with a physical disability)*

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<sup>3</sup> Equal around US\$50.

**Shortcomings of current support services.** Although one of the objectives of this study was to capture the evaluations of the advantages and disadvantages of existing support services, very little directly relevant data were provided, even when this was explicitly asked for. It seems likely that three factors contributed to this outcome. First, some participants had become attached to their current service provider and consequently see it in a very positive light, even though outside observers could see room for improvement. Second, in a context in which demand for services was greater than supply, participants were worried about the consequences of making negative evaluations of their main service provider if the confidentiality and their responses could not be maintained. Therefore, they avoided making any comment about the service provider. Third, participants lacked a point of comparison.

*I live in the Centre and it is like my family. I really treasure it. Nothing can compare to this place. (Participant 11, 14-year-old male with a visual disability)*

*Am I allowed to not answer this question? I would like to keep it for myself. (Participant 16, 18-year-old girl with a physical disability)*

*I never use other services other than this place so I do not know how to compare. (Participant 15, 15-year-old girl with a physical disability)*

However, when participants accessed additional support services, some evaluations of these services were made. In particular, participants made critical evaluations of one psychological support service and one vocational support service. The psychological service was perceived to be willing to address only a narrow range of psychosocial issues while the vocational support service seemed to focus more on theory than on practical training.

*It seems like the people there are very specialized in their profession. I mean they only answered one topic and did not know others. For example, I asked them about love issues and they helped me with that but refused to answer other things. (Participant 16, 18-year-old girl with a physical disability)*

*I am attending a vocational orientation class, which is held by the combination of [name of a service provider] and [a high school]... Yes, the current support service I am using has some certain disadvantages. It should follow the model of vocational training in Western countries that students should be allowed to do an internship and observe the job in person at the workplace. (Participant 12, 15-year-old boy with a visual disability)*

In summary, participants produced few evaluative statements about currently available services even though they were all in contact with at least one formal or informal provider of support. Those services that were evaluated were often perceived to be a poor 'fit' for the

participants' perceived needs. The finding that most participants received service from only one provider appeared to be due not only to the limited number and type of available services, but also the poor dissemination of information about available services for young people with disabilities.

### **6.5.3 Topic 3 - Characteristics of an ideal service provider**

Participants' descriptions of an ideal service provider related to two broad issues: the characteristics of its physical infrastructure and the services it provided.

#### **6.5.3.1 Physical characteristics**

The importance of the physical characteristics of the service provider was mentioned by about half of the participants. Given the challenges the participants had identified with freedom of movement, it is not surprising that they highlighted that having an accessible location was a key characteristic of an ideal service.

*This service should be close to me so that I can sometimes come to visit, especially when I feel sad. (Participant 1, 16-year-old boy with a visual disability)*

*A good service should open many branches, especially in remote areas, so that disabled people and their families can access them. (Participant 11, 14-year-old boy with a visual disability)*

Many service providers in Vietnam offer residential care together with education or vocational training services. Some specialist schools are boarding schools (Yoder & Office, 2004). Participants using the services of such providers considered that an ideal residential service would provide private space for personal use as well as public and accessible spaces for recreational activities.

*I also need private room for studying and relaxing.*

*... Studying is good but studying all the time is not good. It is also very important to participate in recreation activities. I play football every night with my friends. I have lived here long enough to remember every corner here. The centre has a small football ground in the front yard. We put a small bell in the ball and small stones in the coke cans which we tie on our legs. By that way, we can know the position of the ball and other players. Running is good. No run, no fun. (Participant 1, 16-year-old boy with a visual disability)*

In addition, the physical environment of an ideal service provider would be aesthetically pleasing. In keeping with the importance of aesthetics and the high value of flowers in

Vietnamese culture (Nguyen, 2007), flowers were often explicitly mentioned, even by participants who had a visual disability.

*This should be a beautiful centre... Yes, I mean this place would have plenty of room to play around and relax. It should have a football court and plant lots of beautiful flowers. (Participant 15, 15-year-old girl with a physical disability)*

*A beautiful place, it's clean and has lots of flowers. (Participant 8, 12-year-old girl with a visual disability)*

In summary, participants perceived that physical characteristics of the space occupied by a service provider were relevant to addressing their access, aesthetic, study and recreational needs.

### **6.5.3.2 Types of support**

Description of adolescents with a disability of the range of services offered by an ideal service provider confirmed their desire for holistic care. In particular, they perceived that an ideal service would meet needs in diverse domains of their lives by providing a source of vocational training, friendships, psychosocial support, recreation facilities, housing and health care.

*That would be the place I like the best. That place should provide me with the best services, taking care of me, and allowing me to have a job. Then I can take care of myself later. That place will allow me to make many friends, to see them and have fun. ...I also wish to have a bookshelf full of books. (Participant 4, 16-year-old boy with a visual disability)*

*That centre should be close to my family and be 'full' of people who could help young people with disabilities such as a psychological counsellor, a vocational adviser, a vocational trainer, etc. (Participant 16, 18-year-old girl with a physical disability)*

Among the services seen as desirable in an ideal service provider, vocational training and psychological support were emphasized by many participants.

*I think a good service should have functions to help disabled people who are looking for a job to find a stable job. (Participant 4, 16-year-old boy with a visual disability)*

*I also think that a good support service should have psychological experts to help people with a disability explain their confusing issues, help them solve troubles and overcome their difficulties. (Participant 14, 17-year-old boy with a visual disability)*

An ideal service provider would also be able to tailor the support it offered to the needs of young people with disabilities and to have the resources and expertise to allow this.

*Considering it is an ideal support service, it should be in good condition physically and spiritually. For example, if a student with visual disability wants to learn massage, then this place should have all necessary equipment and qualified teachers to help them study the best massage lessons. (Participant 14, 1 -year-old boy with a visual disability)*

Participants acknowledged that many of their support needs were different from the needs of members of the wider community. Therefore, several participants reported that specialist services were required. They felt more comfortable in specialist services because they would be among other people with disabilities.

*I would like all services for people with disabilities to be separated [from the services for all people], so that people with disability can feel comfortable to come and use them. (Participant 10, 14-year-old boy with a visual disability)*

However, the integration of multiple services for people with different types of disabilities into one ideal service provider was also a common desire among participants.

*...In addition, the centre should organize a variety of types of clubs to attract disabled people to participate and make contact with each other, because those people are disabled bodily, but can have diverse gifts. (Participant 14, 17-year-old boy with a visual disability)*

Participants' comments also highlighted that an ideal residential service would also facilitate ongoing close contact with families and friends. Currently, most residential service providers use a centralized model of service delivery that often requires young people with a disability to be separated from their families and friends.

*It would be good if my close friends and my family could live in there as well. (Participant 6, 16-year-old girl with a visual disability)*

*There should be friends of mine living there. (Participant 8, 12-year-old girl with a visual disability)*

### **6.5.3.3 Quality of support**

Participants also had expectations about the quality of support offered by an ideal service provider. They explicitly related this to the characteristics of the staff. It was expected that an ideal service provider would employ staff members who were friendly, competent and dedicated.

*I would like to have friendly teachers who I could greet and ask about their health. I can have a chat with them. That would be good. (Participant 4, 16-year-old boy with a visual disability)*

*It does not matter if they are men or women as long as they do their job well. (Participant 11, 14-year-old boy with a visual disability)*

*In my opinion, an ideal support service should be long-existing (sic) and sustainable. It means the staff in the service should love their jobs and overcome all challenges to maintain the operation of the service for a long time. (Participant 9, 12-year-old boy with a visual disability)*

Besides having good staff, an ideal service would also allow adolescents with disabilities to benefit from the expertise of its staff at an affordable price or at no cost.

*If it was an ideal place, it should not ask me pay. (Participant 2, 14-year-old boy with a visual disability)*

In the absence of information about the types of support that are available in other contexts (e.g., guide dogs, text-to-voice computer software), many participants' ideas about an ideal service provider were limited to variations on the support provider from which they were currently receiving support.

*I would like it to look like this Buddha temple, but more beautiful, cleaner and better. (Participant 10, 10-year-old girl with a physical disability)*

In summary, participants' perceptions of the characteristics of an ideal service provider largely reflected the challenges and needs for support that they had reported earlier in the interview. However, it also revealed for the first time their preference for a 'one-stop-shop' that provided holistic care, the importance of the characteristics of staff and the importance of aesthetic considerations. The features of an ideal service provider that were explicitly identified by participants were summarized into a model to guide the development of services for this population (Figure 6.2).

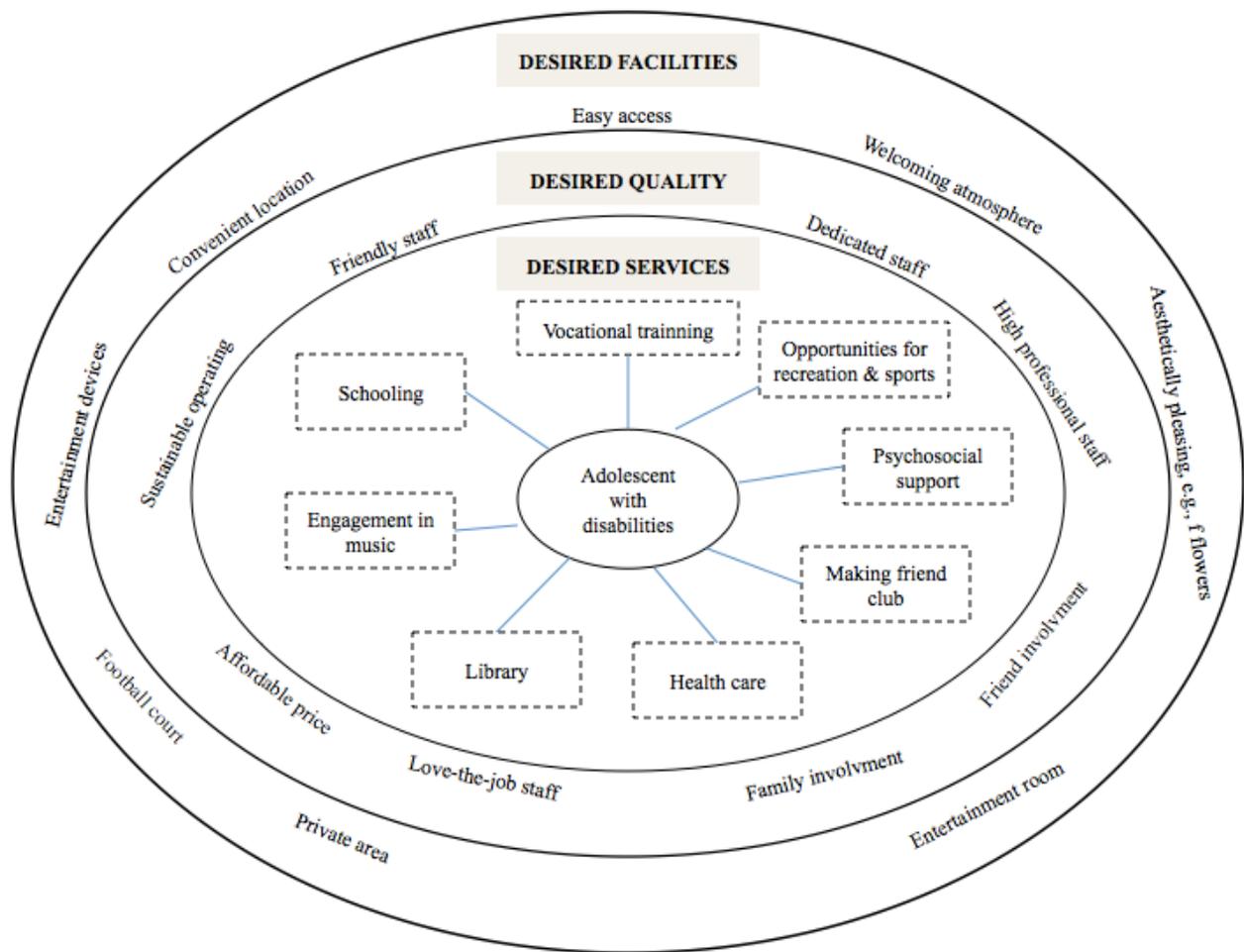


Figure 6.2: Model summarizing the characteristics of an ideal service provider from the perspective of Vietnamese adolescents with visual and physical disabilities

## 6.6 Conclusion and discussion

This study aimed to capture the views of adolescents with disabilities about the challenges to well-being that they faced and the type and quality of support they needed. Four different types of prompt questions (challenges, use of support, evaluation of support services and ideal service provider) were used to elicit this information. The results showed that many adolescents with visual and physical disabilities encountered challenges in both the physical and psychosocial domains of their lives. However, the majority of participants did not receive the support that was necessary to help them to address these challenges. Most participants had access to only a single service provider that provided a limited range of support. In contrast, an ideal service provider would help them to cope with their challenges by providing holistic care and meeting specific criteria about physical characteristics, staff characteristics and the types of service provided. A model that summarized and integrated participant's responses across the eight prompt questions was constructed to guide the design of new services and the reform of existing services for this population (Figure 6.1).

## **Challenges faced by Vietnamese adolescents with disabilities**

**Independent travel.** The challenges that Vietnamese adolescents with visual and physical disabilities encounter were consistent with those reported by people with disabilities worldwide. It was not surprising that adolescents with disabilities reported that their freedom of movement, education, employment and social relationships were severely limited. Similar findings have been reported by people with disabilities in many other countries (Groce, 2004; Stommen, Verbunt, Gorter, & Goossens, 2012; Watson, 2000). However, the level and nature of the challenges faced by Vietnamese adolescents with disabilities had unique characteristics and implications.

While adolescents with disabilities in a high-income country can often travel independently (Bureau of Transportation Statistics, 2003; Sacks & Wolfe, 1998), the majority of participants in the current study were unable to travel without support from others. The most common transportation vehicles in Vietnam are motorbikes, and road conditions are generally poor (Hays, 2014). In addition, public transport by bus is mainly restricted to urban centres and these are not equipped to be accessible for users with disabilities in either urban or rural areas (Figure 6.3). Therefore, it is rare to see people with disabilities using public transport (Ford, 2007). This situation is very different from that in many high-income countries. For instance, in the USA, 40 % of the passengers on public transport are people with disabilities (Bureau of Transportation Statistics, 2003).





Figure 6.3. Photographs of urban and rural settings in Vietnam showing obstacles to safe independent travel by adolescents with visual and physical disabilities (Sources: internet)

Limited freedom in mobility is particularly significant because it may lead to limitations in many other important domains of life. Without it, young people with disabilities find it difficult to gain the independence and autonomy, to develop self-confidence and a sense of social

inclusion (Porcelli, Ungar, Liebenberg, & Trépanier, 2014). In addition, the ability to exercise freedom of movement is a prerequisite for independent living and most forms of employment (Bouck & Satsangi, 2014). Thus, limited freedom of mobility is a barrier to material, psychological and social well-being.

Freedom of movement was a challenge shared by almost every participant in this study, despite marked individual differences in type and severity of disability. Importantly, the underlying reasons for restrictions on movement differed between adolescents with physical and visual disabilities. Adolescents with physical disabilities had limited access to mobility devices (e.g., wheelchairs, crutches), which contributed to restrictions on their movement. In addition, lack of investment in public infrastructure for disability access (e.g., ramps, elevators) was also a significant contributor. In contrast, adolescents with visual disabilities primarily faced restrictions on movement due to a lack of aids (e.g., white canes) and “unfriendly” traffic infrastructure (e.g., lack of textured pavements, traffic lights). It can be seen that the environment was a common factor in barriers to travel for both groups of adolescents with disabilities. Vietnam indeed has poor traffic infrastructure for people with disabilities (National Coordinating Council on Disability, 2010; UNICEF & MOLISA, 2010). This at least partly explains why independent movement was a challenge regardless of the severity or type of disability. In all cases, the functioning and participation of young people was restricted. This finding is consistent with the WHO perspective on disability that sees it as the joint outcome of impairment and a context that fails to support participation and functioning.

Most of the participants lived in a variety of out-of-home contexts. It seems likely that separation from family members contributed to the frequency with which the participants mentioned a desire to have greater contact with members of their families, and the fact that the site for provision of services (e.g., education) was also their residence is likely to have shaped some preferences (e.g., those reflecting the importance of the aesthetic characteristics of the site of service provision, or desiring more free space). This type of living might also contribute to their freedom of travelling.

In most high-income countries, there is wide acknowledgement that a physical environment that supports functioning for individuals with impairment requires the available supportive devices (e.g., wheelchairs, walking canes, prosthetic limb) and supportive infrastructure (e.g., buildings with ramps and lifts, streets with textured surface, walking lanes and acoustic traffic lights). However, relatively few of the participants in the current study mentioned these. As the study progressed, it became clear that most adolescents with disabilities in Vietnam were not familiar with the mobility aids that are commonly used in high-income

countries, such as guide dogs, electric wheelchairs, or electronic walking canes. There may be two underlying reasons for this. First, some of the devices may not be convenient to use in the Vietnamese environment. For example, electric wheelchairs are likely to be of limited use in many urban centres in Vietnam because of the presence of many obstacles on pavements, streets packed with motorbikes, and poor road and pavement infrastructure. Other commonly used mobility aids may simply be beyond the imagination of young people with disabilities living in poverty in Vietnam, and therefore they have no ability to request them. On the basis of similar findings in other LAMICs, it has been suggested that orientation and mobility training should be provided, especially for adolescents with a visual disability, to equip them with systematic knowledge about independent movement and to allow them to choose the most appropriate individualized method to navigate the world (Otero Fernandez, 2004). This type of training has been shown to be effective in Puerto Rico (Otero Fernandez, 2004). In addition, advocacy for traffic and architectural infrastructure that is “disability-friendly” needs to be a priority among stakeholders and publicized through popular media, social media, scientific presentations and in policies, because improvement on this issue is a commitment made in current Vietnamese law relating to disability (UNICEF & MOLISA, 2009).

Implementing laws about the rights of young people with disabilities in Vietnam has been a challenge (Rosenthal, 2009). It is noteworthy that no participant in this study mentioned that they had a right to specific services (e.g., education) that should be guaranteed under current laws. In addition, international commitments ratified by Vietnam specify that the state must provide care, assistance and information free of charge for person with disabilities to facilitate their development and achievement to the fullest possible extent (UNICEF & MOLISA, 2009). While state-of-the-art assistive devices and widespread renovation of public buildings may be beyond the resources of Vietnam and other LAMICs, many effective low-cost resources are available. In addition, establishing and maintaining a website/network that facilitates the flow of information and encourages referrals can also be achieved at low cost. There appears to be no defensible reasons why young adolescents with disabilities in Vietnam remain unaware of their rights and the resources of support that are currently available to them.

**Social relationships.** Isolation has been widely acknowledged to be one of the greatest impediments in the quality of life of young people with a disability (Groce, 2004). This is a very significant challenge for adolescents, for whom the development and maintenance of relationships with peers are key developmental tasks (Poulin & Chan, 2010). Social relationships with all generations are a particular priority for adolescents in collectivist countries such as Vietnam (Matsumoto & Juang, 2008). Findings from this study highlighted two issues. First,

very few of the participants had regular opportunities to interact with peers who did not have a disability, unless these were their siblings. This significantly constrains the number and nature of the social relationships they have the opportunities to form. Second, even participants who attended inclusive classes reported that they had very low levels of interaction with their classmates who did not have a disability. Marginalization within these classrooms appears to have been the outcome of both social withdrawal by adolescents with a disability and social exclusion and/or discrimination by other classmates. Clearly, inclusive education in Vietnam is currently failing to achieve its social goals for some adolescents with a disability. Both an improvement in the social skills of students with disabilities and efforts to overcome the stigma of disability among their classmates are necessary to overcome this challenge. In addition, in Vietnam, romantic relationships during adolescence are relatively rare (Teerawichitchainan, 2007). In this study, only two out of 21 participants reported that they had ever had a boyfriend/girlfriend.

The perpetuation of institutional care for children and adolescents with a disability in Vietnam is also a barrier to their quality of life. In Study 2, almost 50% of adolescents with a visual disability and almost 90% of adolescents with a physical disability were in out-of-home care. Because of the centralized nature of these institutions, many young people experience long separations from family and friends in order to achieve an education. Within the institutions, there is often little continuity in caregivers.

**Preparing for future career.** In many contexts, having a secure job is a prerequisite for an independent life for people with a disability (Chengguang Zhao et al., 2012; Roggero et al., 2005). It is therefore not surprising that Vietnamese adolescents with visual and physical disabilities expressed great concern about the adequacy of their education and vocational training as preparation for their future career. The very limited range of vocational choices available to the participants is also a cause for concern. Educators and employers in Vietnam do not appear to share the attitudes that have allowed people with a disability to enter almost every profession in most high-income countries. For example, despite being totally blind, Jacob Bolotin (USA) was fully licensed to practice medicine, Erik Weihenmayer is a successful mountaineer and Kelly Knot (UK) is fashion model with a physical disability. In this study, the participants showed their interest in diverse careers, but many of them were not able to follow their dreams. Although the participants may obtain a job, it seems unlikely that they will all reach their potential or have a happy career.

### **Evaluation of current support services**

Vietnam is a developing country with legacy of war and high prevalence of people with disabilities (Tatarski, 2013; UNICEF & MOLISA, 2010) and despite its commitment to improving life for people with a disability (Rosenthal, December, 2009; Tatarski, 2013), the support services are often not available or accessible to young people with disabilities (Groce, 2004; World Health Organization, 201b). The participants were recruited from diverse service providers including specialist state-funded schools, faith-based disability centres and orphanages funded by international charities and families. It was hoped that this would allow evaluations of a range of service delivery models. However, Vietnamese adolescents with visual and physical disabilities had very limited access to comparison support services and often did not wish to evaluate their current service provider, on whose goodwill they were dependent.

One of the reasons for the small number of services accessed by the participants was that they were unaware of the existence of nearby service providers even when these supplied the type of support they were seeking. It is unclear whether this is because service providers do not use effective techniques to advertise their existence to their target clients, or whether current support systems are already under strain and unable to support more clients. The later is often the case even in high-income countries such as Australia (Australian Government, 2016).

**Ideal service provider.** It is noteworthy that the unfriendly attitude of staff that adolescents encountered from staff in their current service providers was a feature that they wished to eliminate. In many high-income countries, work with people with disabilities has largely been professionalized and attracts staff who have a positive attitude toward young people with disabilities (De Laat, Freriksen, & Vervloed, 2013; Goreczny, Bender, Caruso, & Feinstein, 2011). In contrast, adolescents with disabilities in LAMICs like Vietnam may experience stigma and even negative attitudes from their caregivers in disability centres. The relationship between children with a disability and the staff who care for them in such centres is usually unequal; and the nature of this relationship is not between professional and client but between giver and receiver (Freidson, 1970). Additional research appears necessary to gain insights into the prevalence, type and impact of such attitudes and effective ways to address them in LAMICs (Finkelstein, 1980).

### **Framework to guide the development of support services for Vietnamese adolescents with visual and physical disabilities**

Participants' responses were integrated in to a model to guide development and reform of support services for adolescents with visual and physical disabilities (Figure 6.2). This framework is organized into three interconnected domains:

1. Main challenges faced by Vietnamese adolescents with disabilities;
2. Types of external support perceived to be necessary to overcome these challenges;
3. Qualitative characteristics of the service providers desired by Vietnamese adolescents with visual and physical disabilities.

There were five main challenges that Vietnamese adolescents with visual and physical disabilities faced in their daily lives. In addition to the three main challenges (mobility limitation, social relationship and pathway to a career), the participants also mentioned financial stress and limited opportunities for recreational activities. These factors all belong in the microsystem in Bronfenbrenner and Morris's bio-ecological framework (Bronfenbrenner & Morris, 1998, 2006).

It is noteworthy that each and every characteristic of an ideal support service was "responsible" for addressing one or more of the five challenges they identified. The types of services for which the participants perceived a need could be categorized into five groups according to the challenges to which they were most directly related (Figure 6.3). For example, schooling, vocational training, library and privacy were types of support directly relevant to preparing for their future career while psychosocial support, opportunities for friendships and contact with family were directly related to the need to develop and maintain social relationships. The close match observed between the challenges and support needs that the adolescents identified indicated the consistency and significance of these concerns among the participants.

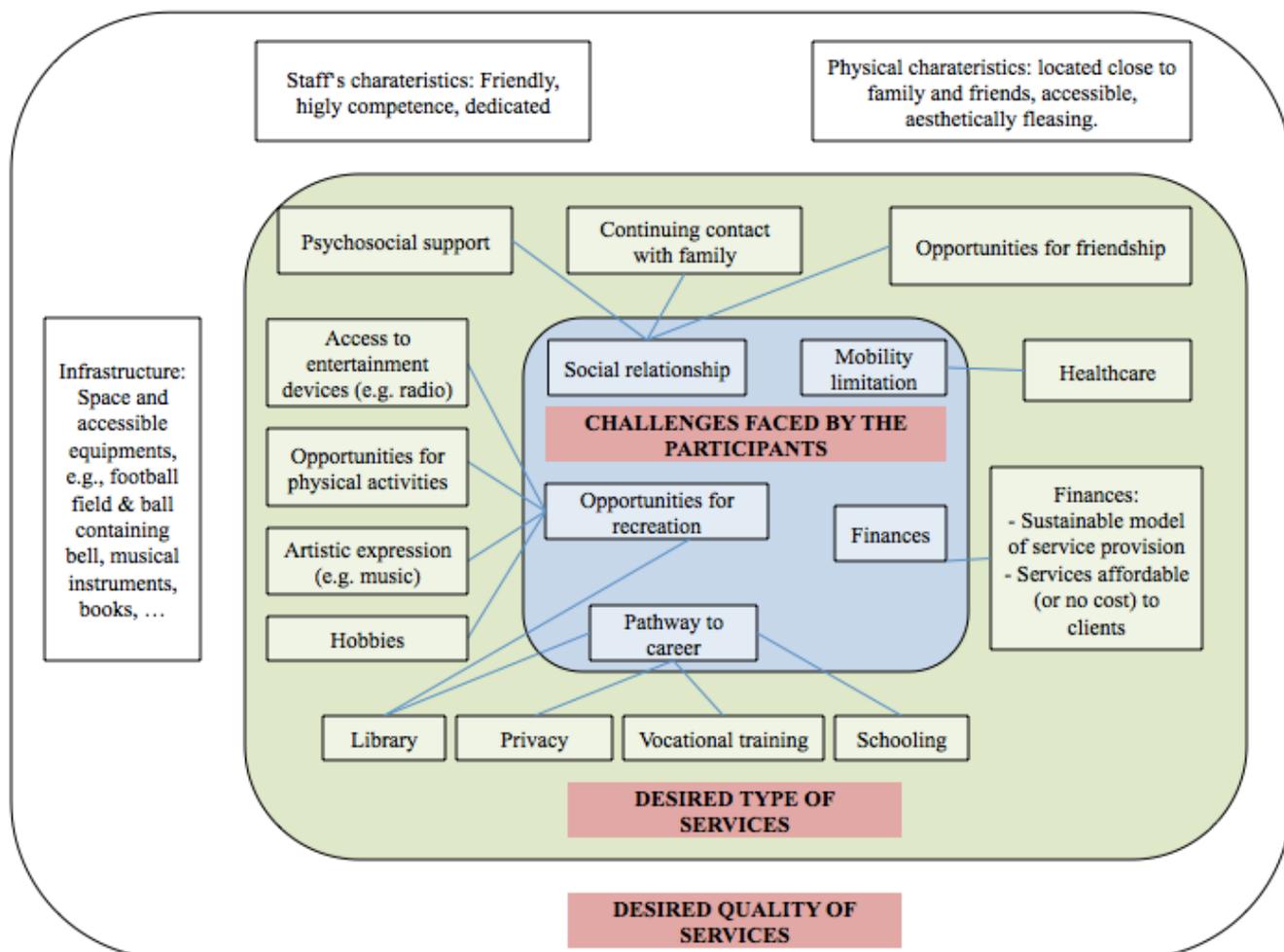


Figure 6.3 Model to guide the development and reform of support services for Vietnamese adolescents with visual and physical disabilities

In the model, the number of desired types of support varies across different types of challenges. The participants identified many specific types of support to address three challenges (opportunities for recreation, pathway to career and social relationships). In contrast, they identified very few specific types of support for mobility limitations and financial stress. One possible explanation for this disparity was that the participant’s understanding of support services was limited by their experience. Previous research suggests that the understanding of adolescents with a disability of relational and contextual resources depends on their experiences of the spaces and places they navigate (Porcelli et al., 2014). In the context of limited resources for orientation and mobility support in Vietnam (Only 4.62% of people with disabilities nationwide received rehabilitation treatment (UNICEF & MOLISA, 2010)), the participants were unaware of the range of potential types of support and were thus unable to give details about services they wished to have to increase their independent mobility. In particular, access to rehabilitation services was not mentioned by any participant.

Other important services were also not mentioned by the participants. In particular, no participants identified challenges relating to basic amenities such as water, food, and shelter. Accordingly, no perceived need for support to address these was expressed. However, this is inconsistent with the findings from Study 1 and other data indicating that the majority of young people with disabilities in Vietnam experience material deprivation (United Nations, 2012b). In such a context, Maslow's hierarchy of needs (Maslow, 1943) would suggest that challenges related to material deprivation would be given priority. It is possible that the findings of the current study are an artefact of the high prevalence of out-of-home care, in which the residential service provider takes responsibility for providing basic amenities.

The model was designed to guide service provision to meet the needs of young people with a disability. However, all the relationships between desired services could not be fully illustrated in a two-dimensional figure. Each type of support was relevant to several challenges. For example, the provision of a private space could be provided in the form of a women's room, a reading room, a TV area, or a small space in which adolescents could talk with their friends confidentially. Such private spaces, therefore, could serve to improve their social relationships in addition to providing a quiet space for study to facilitate education and vocational training as is indicated in the framework.

The diversity of the desired types of support captured in the model also reflects the participants' preference for a holistic support. This might be achieved by the involvement of multiple formal services, partnerships between formal and informal support sources or the availability of single holistic service providers. A first step would be to map and coordinate available services and to build a good network of staff from various service providers, young people with a disability and their families and friends (World Health Organization, 2011). Such an integration of services has been called for by the World Health Organization (World Health Organization, 2011).

The desired qualities of service providers and service delivery were also captured in the model. Vietnamese adolescents with disabilities focused on three main aspects of service quality: physical characteristics (convenient location, accessible, aesthetically pleasing), infrastructure (space, areas, useful equipment) and staff characteristics (friendly, dedicated and highly competent). Importantly the physical characteristics of an ideal support service were usually the first thing mentioned by the participants with a disability. Personal familiarity with many current service providers in Vietnam suggest that very few of these currently pay attention to aesthetic considerations when delivering support for young people with visual and physical disabilities.

Although many effective support services for young people with disabilities have been developed on other countries, services for Vietnamese adolescents with disabilities should be developed based on their unique needs and perspectives (UNICEF & MOLISA, 2010; Watson, 2000; World Health Organization, 2011). In addition to cultural appropriateness, policy makers and services provided must also take into account the unique challenges faced by, and the unique resources available to, the target population.

## **6.7 Limitations and future research**

In summary, this study bears all the limitations common to qualitative research and the face-to-face collection of self-reported data. The personality and relative status of the participants and the researcher may have affected the level of openness and honesty in communication. In addition, the quantity and quality of data are likely to have varied according to the conditions in the context in which the interview took place, and the extent to which a positive atmosphere was created between the interviewer and each participant.

This study used a sub-set of participants from Study 2, which was not representative of the population of young people with visual and physical disabilities in Vietnam. The purposeful sampling procedure is likely to have further reduced the representativeness of the sample. It is understood that bias is not inevitable. Therefore, caution should be exercised in any generalization of the findings.

The dominance of participants who live out-of-home in Study 3 might bias their opinions about challenges they faced and the number of opinions about the psychosocial support from family. For example, many adolescents expressed a need for additional psychosocial support from their families and friends, someone they can trust to talk to, listen to, and seek advice from confidentially. This kind of support is usually sought more from those living out-of-home. Most of the participants lived in a variety of out-of-home contexts. In study 3, only one participant lived at home answered the interview. It seems likely that separation from family members contributed to the frequency with which the participants mentioned a desire to have greater contact with members of their families, and the fact that the site for provision of services (e.g., education) was also their residence is likely to have shaped some preferences (e.g., those reflecting the importance of the aesthetic characteristics of the site of service provision, or desiring more free space).

Future research could be conducted to examine the suitability of the model proposed by this study (Figure 6.2). In addition, an exploration of differences in challenges to well-being and

need for support services between young people with congenital and acquired disabilities would be a useful direction for future research.

## CHAPTER 7 - CONCLUSION

### 7.1 Overview

The program of research reported in this dissertation consists of three interrelated studies investigating the life circumstances and well-being of young people with visual and physical disabilities in Vietnam. In doing so, it helps to fill a gap in the literature. As far as it can be determined, it is the first systematic study of the well-being of young people with a disability in Vietnam, and is one of the first studies of the well-being of young people with a visual or physical disability in any low- or middle-income country. This final chapter integrates the findings, identifies strengths and limitations of the program of research, and highlights the contributions it makes to our knowledge despite these limitations. In addition, recommendations for future research and the provision of support services are suggested.

### 7.2 Overview of the studies

The current program of research aimed to provide new insights by applying a developmental perspective on the living conditions and well-being of Vietnamese adolescents with visual and physical disabilities. The research plan included three studies. The first study was designed to make two contributions: (1) a description of the life circumstances of Vietnamese children with two types of disability (2) an examination of developmental outcomes in multiple domains. The results of this study provide background knowledge about children with disabilities in the period prior to adolescence. This aided the interpretation of findings from the subsequent studies, which focused on the period of adolescence. The choice of variables was informed by Bronfenbrenner and Morris's bio-ecological theory, and a longitudinal case study design was used to generate a deep description of the developmental context and trajectories of children with visual and physical disabilities in Vietnam. The second study applied the same theoretical framework to a detailed examination of the level of well-being in diverse domains, and the factors that influence this well-being, among adolescents with visual and physical disabilities. In order to allow this, Study 2 used a multi-site quantitative design and recruited a large number of adolescents with two types of disability. The results of Study 2 indicated that social support was an important predictor of both positive and negative well-being outcomes for this population. Study 3 a qualitative research design was used to capture the views that young people with a visual or physical disability held about challenges to their well-being, and their support needs, in order to gain an understanding of adolescents' views about current and ideal support services. A model that summarized these findings was created to guide the development

of support services that respond to the preferences and priorities of the people they are intended to serve.

In summary, the current program of research used Bronfenbrenner's bio-ecological model as a common framework across three studies that adopted different research designs in order to provide three distinct perspectives on the well-being of young people with a visual or a physical disability in Vietnam.

### **7.3 Overview of the findings**

Taken together, the results from the three studies showed that young people in Vietnam who have a visual or a physical disability face many disadvantages. During childhood, many children with these disabilities experience extreme material deprivation, show poor physical growth (shown by stunting) and poor cognitive development (shown by tests of academic achievement). During adolescence, many reported severe or very severe symptoms of anxiety and many also showed severe symptoms of depression. Their life satisfaction was either low or moderate. During adolescence they also encountered a wide range of challenges, including restricted independent mobility, communication, education, and career options, and had limited access to support.

Despite such disadvantages, young people with visual and physical disabilities had several notable achievements. Prior to adolescence, many children had a good vocabulary, reading and quantitative skills at 8 years of age. During adolescence, many adolescents reported moderate or good scores for flourishing and positive affect. These positive outcomes are evidence of resilience among Vietnamese children and adolescents with visual and physical disabilities.

The role that type of disability plays in the outcomes of young people with disabilities remains unclear. In Study 1, many features of children's life circumstances and developmental outcomes (e.g., stunting) appeared to be similar for children with visual and physical disabilities. In Study 2, adolescents with a visual disability showed higher levels of well-being than their peers with a physical disability, even when severity of disability was controlled. However, adolescents with a visual disability also had higher levels of two psychological assets (optimism and adaptive coping) and lower exposure to one risk factor (out-of-home care). Due to the high level of confounding between some of these variables and type of disability, it is currently unclear whether differences between the groups in levels of well-being should be attributed to the difference in their disability or differences in these predictors.

Despite the differences in level of well-being between adolescents with visual and physical disabilities, there were very few differences between these two groups in the relationship between the predictor variables and well-being outcomes. Indeed, one important finding from Study 2 was that the severity of disability was not an independent predictor for most well-being outcomes, and was not the most important predictor for any well-being outcome.

Three approaches were used to identify factors that influenced well-being outcomes during adolescence. First, Study 2 used a variable-focused approach to identify predictors that showed a statistical relationship with each of the well-being outcomes. One asset (optimism) and one resource (social support) were positively associated with three of the four positive domains of well-being and negatively associated with at least one negative domains of well-being. In addition, one risk factor (experience of discrimination) was positively associated with all four of the negative domains of well-being. In a very few cases, a predictor variable moderated the relationship between severity of disability and a well-being outcome. However, in the vast majority of cases, only direct effects were found.

Second, Study 2 sought to identify the factors that differentiated adolescents with different patterns of well-being outcomes through a person-focused analysis. This identified three clusters of participants. Membership of these clusters could be predicted on the basis of four predictor variables: optimism, adaptive coping, social support and discrimination. Thus, the predictors of well-being identified in the variable-focused and person-focused analyses showed almost complete overlap. The findings from these two approaches were constrained by the selection of measures.

The third approach overcame this limitation by asking adolescents to identify challenges to their well-being in their own words. This identified a range of factors that had not been identified in Study 2. In particular, worry about uncertainties about their future was identified as a significant source of anxiety. Many older participants perceived that they had limited or no available paths to a career that would allow them to be economically independent. They had no clear idea about what their lives would look like after they reached the age at which they were no longer eligible to remain in their school/training program. In addition, a lack of friends and confidants, and separation from family members were sources of sadness. In addition, an overarching challenge for all participants was the severe restrictions they faced on the independent movement they needed in order to make use of the few educational and social opportunities available to them. Study 3 also confirmed the negative effects of discrimination on the participants' well-being.

Finally, the research program explored the perspectives of Vietnamese adolescents with visual and physical disabilities on the challenges they faced, their support needs, and their preferences and priorities for support services. They perceived that they faced many significant challenges, but that they had very limited access to support. They also had very little knowledge of the general and disability-specific support services available to them. Despite this, adolescents with visual and physical disabilities had very well-developed ideas about the desirable characteristics of support services. These related to the physical characteristics of the facility in which services are delivered (e.g., spacious, aesthetically pleasing appearance, convenient location), the range of service they wished to access (e.g., psychological services, vocational training, opportunities for friendship formation) and the qualities of the staff providing the services (e.g., friendly, highly professional, consistent). These desirable characteristics were summarised in a schematic model that could be used to guide the development or refinement of services that reflect the priorities and preferences of these adolescents.

## **7.4 Study limitations**

Before considering the contributions that the current research program has made to knowledge in the field, it is important to acknowledge its limitations. The limitations of each individual study were discussed in the relevant chapters. This section will focus on the limitations of the program of research.

The most significant limitation of the program of research is that none of the studies used an experimental design, which would have allowed cause-effect relationships to be identified. The findings from all three studies establish only that there are statistical associations between particular variables and particular well-being outcomes, or that the participants perceive that there is a cause-effect relationship between particular circumstances and their well-being. This limitation could not be avoided, since the current program of research was the first of its kind in Vietnam. However, it limits the extent to which the findings can inform the development of interventions.

The second most significant limitation of the program of research was the failure to obtain a nationally representative sample of adolescents with visual and physical disabilities that would allow findings to be generalized from the research participants to the wider population with confidence. This limitation was unavoidable in the absence of national or provincial registers of all young people with a disability. However, it was compounded by two recruitment strategies. First, Study 1 drew on data collected for the *Young Lives* study which deliberately over-sampled children living in poverty, and in rural and remote locations, because these

children are rarely included in research and are likely to have an elevated attrition rate in longitudinal research. Second, even though Studies 2 and 3 included participants from four geographically distinctive sites, all of these were in the South or Central regions in Vietnam.

In addition, ideally the child participants in Study 1 would have been the contemporaries of, and from the same locations as, the adolescent participants in Studies 2 and 3. Although Studies 2 and 3 deliberately recruited participants from an overlapping set of locations, it was not feasible to access all locations included in the *Young Lives* study, on which Study 1 was based. Some of the older participants in Studies 2 and 3 were born up to 8 years earlier than the children in Study 1, while some of the younger children were born up to 3 years after the children in Study 1. The very rapid and inclusive recent social and economic changes in Vietnam (van Trotsenburg, 2014) make it likely that there were changes in the life circumstances of children with a disability during this period.

## **7.5 Implications and recommendations**

Despite the limitations acknowledged above and in previous chapters, the findings of the current program of research have important implications for future research, policy and practice for young people with a disability living in LAMICs. Although there are large numbers of young people with disability in LAMICs, they remain “*the invisible population*” in research (Groce, 2004 p. 16). Filling this gap is particularly important in such countries, which are characterized by a wide gap between legislation, in which the rights of people with a disability are proclaimed, and reality in which they continue to have little opportunity to exercise these rights (UNICEF, 1999; Rosenthal, December, 2009). The results from this program of research therefore provide a rare point of reference for theorists, service providers and other stakeholders whose decisions shape the opportunities, constraints and well-being of young people with a disability in LAMICs.

First, the findings from Study 1, which showed that children with visual and physical disabilities were often able to make substantial gains over time in physical, cognitive development and achieve moderate levels of life satisfaction are of particular importance for public education about disability in LAMICs. In many of those countries, the general population still holds traditional beliefs about disability, including a belief that that disability is a punishment from God and that children with a disability are incapable of learning (Ngo et al., 2012; Wang, 1992). Without wide exposure to examples of individuals who confound these beliefs, it seems unlikely that public attitudes will change to pave the way for people with disabilities to participate in society and fulfill their potential to live meaningful lives (International Labour Organization, 2013; UNICEF, 2013).

Second, a “deficit model” of disability informs the design of many services and government policies towards people with a disability in LAMICs. Young people with a disability in LAMICs are rightly considered to be a vulnerable population that is in need of tailored support to achieve positive development and well-being outcomes. However, the largest cluster of adolescents with disabilities identified in Study 2 can be characterized as showing ‘global resilience’ to the many challenges they faced. Thus, the findings from Study 2 showed that it is not appropriate to cast young people with a disability in LAMIC in the role of victims. Many possess the psychological strengths and resources necessary to thrive. Indeed, most of the factors that participants identified as central to their well-being were factors important to the well-being of all young people: positive social relationships, the opportunity for education, independent mobility, and the possibility of a positive future.

In addition, in the absence of any research that has identified cause-effect relationships between well-being and either life circumstances, or specific protective or risk factors for young people with visual and physical disabilities living in LAMICs, the associations found in the current program of research provide the best available guide for the development of interventions for this population.

Evidence from the current program of research highlighted the importance of ensuring that the rights of young people to access basic services are implemented. If this was done, it would clear many obstacles to their positive development and well-being. Three basic services appear to be important:

- a. **Education and opportunities for vocational training.** Results from Study 1 suggested that children with a disability who have the opportunity to attend school make progress in cognitive development over time. In some cases, their development can overtake that of peers who previously had a higher level of cognitive development but now do not attend school. Opportunities for education and vocational training were also reported as a priority for participants in Study 3. The current findings are therefore consistent with international initiatives to support children with disabilities to go to school as an essential contribution for their long-term social and economic contributions to their community, personal achievements and well-being. However, providing appropriate educational opportunities for young people with a disability will require a significant investment in professional development and resourcing in educational institutions. For example, one adolescent who was a talented pianist reported in Study 3 that she had contacted many

universities but none of them would admit her as a student even though she could pass the entrance exam, because no university had the staff or resources to meet her special needs.

- b. **Independent mobility.** Results from Study 3 show that both adolescents with visual and physical disabilities have difficulty travelling independently. Such travel is a prerequisite for participation and integration into society. Without investment in civil infrastructure and personal mobility aids, many young people with a disability living in LAMICs are unable to access social and educational opportunities or health services, or to exercise their civil rights (Rosenthal, December, 2009). This limitation also places a significant challenges on the family members and friends on whom the young person is dependent.
- c. **Emotional support.** Study 2 revealed the very high prevalence and severity of symptoms of anxiety and depression among the participants. Parallel findings have been reported among young people with disabilities in many previous studies conducted in other contexts (Silva et al., 2011b; Honey, et al., 2011). It seems likely that many of these mental health problems could be prevented if young people received the informal social support they crave, and that they could be effectively treated by the provision of the formal psychological support they also express a desire for (Ngo, Herrman, Chiu, & Singh, 2009; Patel et al., 2007).

However, the program of research also identified that lack of access to services was not solely due to the unavailability of these services. Access to services was also constrained by a lack of knowledge about existing services, and difficulties associated with travel to the locations at which services were offered. The existence of services will remain invisible to the people they are designed to serve without greater co-ordination and referrals between service providers, and without advertising that draws attention to these services among people with a disability who have no contact with any formal service provider. The development of a register and network of local support services for young people with a disability would be a low cost intervention that holds the potential to be highly effective. Such co-ordination has been found to enhance the effectiveness of service provision in many countries (World Health Organization, 2011). In addition, the feasibility of models of service delivery that overcome obstacles to mobility could be explored. These include models that support staff travel to clients (or to central locations that

can be easily accessed) and those in which services are delivered by telephone or internet. A variety of low-cost peer support services have been developed in other contexts. Adaptations of these to the context of young people with a disability in LAMICs could prove to be useful (e.g., Carter, Moss, Hoffman, Chung, & Sisco, 2011; Stewart, Barnfather, Magill-Evans, Ray, & Letourneau, 2011).

## **7.6 Study contributions**

This is the first study to provide comprehensive insights into the life circumstances and well-being of young people with visual and physical disabilities in a middle-income country. The lack of research about this population is particularly noteworthy given that 80% of the global population of people with a disability live in LAMICs and the majority of them are young people with a sensory or a physical disability (United Nations, 1990a). In this context, the current program of research significantly extends existing knowledge by (1) describing developmental trends over time during childhood; (2) interpreting these findings with reference to a large sample of non-children with a disability being raised in a similar context; (3) documenting outcomes in diverse positive and negative domains of well-being; (4) identifying a number of predictors associated with these domains of well-being; (5) providing data from the same measures from participants with two types of disability; and (6) developing a model to guide the development of support services that captured the voice of the young people with a disability that these are designed to serve.

### **Developmental trends over time during childhood**

Study 1 is the first research to report longitudinal data on the developmental context, developmental trajectories between infancy and preadolescence, and subjective well-being of children with a physical or visual disability in a LAMIC. Previous studies focused on the economic and social difficulties of families with children with a disability (Brinchann, 1999; Read, 2000), or on the ways in which specific aspects of children's developmental context (e.g., inclusive schooling) shapes their experiences (Davis & Watson, 2001) at a single point in time. In contrast, the current study had access to rich longitudinal data on many aspects of the living conditions and developmental outcomes of Vietnamese children with visual and physical disabilities. However, the developmental trends identified among the children with a disability in Study 1 should be interpreted with caution due to the case study design.

**Availability of a reference group of children without a disability.** Some earlier studies have collected data from a comparison sample of children without a disability to compare with the well-being of children with a disability (e.g., Abubakar et al., 2013; Wolman et al., 1994).

However, this is the first study have interpreted findings among children with a disability in LAMICs with reference to a large sample of children without a disability (n = 1753) at multiple ages (infancy, 5 years and 8 years).

**Positive and negative domains of well-being.** Historically, most research on the psychosocial well-being of people with a disability has focused on negative domains. Mental health problems, such as anxiety, depression, have been a particular focus (da Silva et al., 2011b; Kellerman et al., 1980). The dominance of research on negative domains of well-being is likely to perpetuate the unhelpful association between disability and deficit.

In the last decade, research on other groups with a high risk of poor psychosocial wellbeing have begun to broaden their focus to include positive domains of well-being (e.g., Gale et al., 2011; Sawatzky et al., 2010). It appears that no previous research on adolescents with visual and physical disabilities has attempted to assess multiple positive domains of psychosocial well-being. Study 2 appears to be the first study to attempt to document levels of psychosocial well-being across diverse positive and negative domains.

**Collection of data from participants with two types of disability.** Previous research has reported inconsistent results concerning differences in well-being across different types of disability. In addition, it is difficult to draw conclusions from past research because individual studies usually report data for young people with only one type of disability, or for a pooled sample of young people with diverse disabilities. In the Study 2, young people with a visual disability reported higher scores for three of the four positive domains of well-being outcomes (flourishing, prosocial behaviour and positive affect) than young people with a physical disability. However, there was no difference between the groups on the other positive domain of well-being (satisfaction with life) or on any of the four negative domains of well-being. Unfortunately, the high level of confounding between some predictor variables and type of disability in this study means that the resolution of whether this pattern of outcomes is due to disability type or differences in the predictor variables awaits further research. However, both groups of young people showed remarkably similar associations between predictor variables and well-being outcomes. This result has not been reported earlier.

**A model to guide the development of support services for young people with a disability.** It is good practice to consult with the prospective users of a service prior to its development, but this has rarely occurred in Vietnam (Maramis et al., 2011). As in other LAMICs, independent reviews have identified that Vietnam is in need of improved systems of support for people with a disability (UNICEF, 2010). The results from Study 3 describe the challenges to well-being, support needs, and support use of Vietnamese adolescents with

disabilities in their own words. These findings were summarized into a model that could guide the development of support services that address the preferences and priorities of young people with a visual or physical disability. It is hoped that this will be a useful reference for Vietnamese service providers, policy makers and other stakeholders who would like to improve well-being and quality of life for this population.

## **7.7 Future research**

Many advocates have called for an increase in both the quantity and quality of research in all areas relating to people with disabilities in LAMICs (Maulik & Darmstadt, 2007; United Nations, 1990a). The results of the current program of research, which show that the majority of young people with disabilities are raised in poor living conditions, have poor mental health and limited access to support, highlight the need for some of this new wave of research to have an applied focus. There is an immediate need to identify effective, feasible and culturally appropriate strategies to improve the achievement, participation and well-being of young people with disabilities in these countries.

In addition, several of the findings of the current program of research warrant follow-up. First, it is important to replicate the findings of the current research and to test the limits to which they can be generalized to young people with other disabilities and to those living in other LAMICs.

Second, although the predictors examined in Study 2 accounted for more than 25% of the variance in four domains of well-being (satisfaction with life, flourishing, prosocial behaviour, and symptoms of depression), they were less useful in predicting the three other domains of well-being that were assessed. In particular, the research model accounted for only 13% of the variance in symptoms of anxiety. Given the high prevalence of severe and very severe symptoms of depression among young people with visual and physical disabilities, it will be important for future research to identify more powerful predictors of this outcome.

Third, there is a need to explore underlying mechanisms that influence well-being outcomes through the use of experimental and longitudinal research designs. In particular, there is currently little understanding of the ways in which the well-being of young people is influenced by the types of discrimination towards people with a disability that are encountered in LAMICs and the distinctive contexts in which out-of-home care is provided in LAMICs.

Fourth, there appear to be few systematic evaluations of the effectiveness of particular types of support or particular models of service delivery to adolescents with disabilities in LAMICs, including Vietnam. The findings from such evaluations would provide a solid

foundation for decision-making about funding priorities, policy development and efforts to improve support services for this population (Hartley & Wirz, 2002; Stone, 2005).

## **7.8 Final thoughts**

In all LAMICs many interests compete for scarce resources. In this context, it is not surprising that other interests are often given higher priority than ensuring that infrastructure and support services are provided to ensure that young people with a disability can experience the rights they have been granted in law. However, such an approach is short-sighted. There is overwhelming evidence that people with a visual or physical disability can make important contributions to their community. Until LAMICs provide the necessary infrastructure and support for young people with these disabilities, a large pool of talent will remain untapped. In addition, without this infrastructure and support, many people with disabilities will continue to be dependent on the state and/or their families for economic support, and continue to live lives in which their well-being is unnecessarily diminished. The current program of research is a first step in pointing the way towards improvements that might be both feasible and effective in increasing the contributions and well-being of people with visual and physical disabilities living in LAMICs.



## APPENDICES

### *Appendix A: Distribution of continuous variables in Study 2*

Measure	M	SD	Skew	Kurtosis
Disability severity	37.62	5.91	-.12	0.63
Risk and protective factors				
Optimism	17.19	2.77	.24	.17
Social support	15.68	4.05	-.12	-.15
Adaptive coping	30.59	7.95	.56	1.14
Discrimination	23.35	7.94	.49	-.01
Positive well-being outcomes				
Satisfaction with life	20.31	6.38	-.26	-.73
Flourishing	38.06	7.93	-.23	-.33
Prosocial behaviour	5.83	1.95	-.20	-.13
Positive affect	28.45	5.60	.25	.02
Negative well-being outcomes				
Depression	12.94	6.40	.34	-.16
Anxiety	15.21	7.28	.51	-.09
Stress	16.20	6.20	.53	.05
Conduct problem	2.86	1.53	.29	-.73
Negative affect	23.29	6.92	-.84	-.65
Life satisfaction				
Current	4.99	1.60	.71	.54
Future	6.77	1.41	-.19	-.51

Note. M=Mean, SD=Standard deviation.

*Appendix B: Similarities in relationships between predictors and well-being outcomes for adolescents with visual and physical disabilities*

*Adolescents with a visual disability*

Predictor	Wellbeing outcome							
	Satisfaction with life	Flourishing	Prosocial behaviour	Positive affect	Depression	Anxiety	Conduct problems	Negative Affect
Disability severity	-.314**	-.387**	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.
Protective factors								
Optimism	n.s.	.268**	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.
Social support	.493**	.401**	.531**	n.s.	n.s.	n.s.	n.s.	n.s.
Adaptive coping	n.s.	.407**	.353**	n.s.	n.s.	n.s.	n.s.	n.s.
Risk factors								
Discrimination	n.s.	n.s.	n.s.	n.s.	.487**	.303**	.386**	.305**
Out-of-home care	n.s.	-.501**	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.

**Adolescents with a physical disability**

Wellbeing outcome

Predictor	Satisfaction with life	Flourishing	Prosocial behaviour	Positive affect	Depression	Anxiety	Conduct problems	Negative Affect
Disability severity	n.s.	n.s.	n.s.	n.s.	n.s.	.244**	n.s.	n.s.
Protective factors								
Optimism	.283**	.323**	.322**	n.s.	n.s.	-.245**	-.435**	-.243**
Social support	.584**	.473**	.475**	n.s.	n.s.	n.s.	n.s.	-.354**
Adaptive coping	n.s.	n.s.	n.s.	.392**	n.s.	n.s.	n.s.	n.s.
Risk factors								
Discrimination	.389**	n.s.	n.s.	.370**	.421**	n.s.	n.s.	.396**
Out-of-home care	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.

Similar pattern

*Appendix C: Questionnaire used to assess the perceived appropriateness of measures in the pilot test*

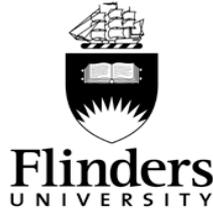
**QUESTIONNAIRE EVALUATION**

Now please give your opinions about the previous questionnaire that you have just completed by answering the following questions:

1. Do you understand the objective of the questionnaire?  
Yes                                      No                                      Not know
2. Do you think the answers in this questionnaire are able to convey its objectives?  
Yes                                      No                                      If no, which questions should be changed:
2. Do you feel comfortable answering the questions?  
Yes                                      No                                      If no, which questions:.....
3. Is the wording of the survey clear?  
Yes                                      No                                      If no, which questions: .....
4. Is the time reference clear to you?  
Yes                                      No                                      If no, which questions: .....
5. Are the answer choices compatible with your experience in the matter?  
Yes                                      No                                      If no, which questions: .....
6. Do any of the items require you to think too long or hard before responding?  
Yes                                      No                                      If yes, which ones:.....
7. Which items produce irritation, embarrassment, or confusion?  
Yes                                      No                                      If yes, which questions: .....
8. Do any of the questions generate response bias?  
Yes                                      No                                      If yes, which ones:.....
9. Is the survey too long?  
Yes                                      No                                      Not know
11. According to you, have any other important issues been overlooked?

*Thank you very much!*

*Appendix D: The final full questionnaire for Study 2 in Vietnamese*



**BẢN ĐỒNG Ý CỦA PHỤ HUYNH/ NGƯỜI BẢO TRỢ CHO TRẺ  
DƯỚI 18 TUỔI THAM GIA ĐỀ TÀI ĐỊNH LƯỢNG**

Sức Khỏe Tâm Lý Xã Hội của Trẻ Vị Thành Niên  
với Khiếm Khuyết Nhìn và Vận Động ở Việt Nam

Tôi .....  
là Phụ huynh/ Người bảo trợ của .....

Đang sinh sống/học tập/làm việc tại .....

đồng ý cho em tham gia vào một phần đề tài nghiên cứu “Sức khỏe tâm lý xã hội của trẻ vị thành niên với khiếm khuyết nhìn và vận động ở Việt Nam ” của cô Đinh Thị Thu Phương - nghiên cứu sinh ngành Tâm lý học tại trường Đại học Flinders, Úc.

1. Tôi đã đọc thông tin cung cấp, được giải thích về vấn đề nghiên cứu, và các thách thức liên quan đến người tham gia. Bản đồng ý này được đưa ra với sự đồng ý của con/em tôi.
2. Tôi đã hiểu các chi tiết cụ thể của tiến trình thực hiện đề tài và các khó khăn có thể có.
3. Tôi nhận thức rằng tôi nên giữ bản copy của thư giới thiệu và bản đồng ý này để tham khảo về sau.
4. Tôi hiểu rằng:
  - Con/em tôi không có lợi ích trực tiếp từ việc tham gia nghiên cứu này.
  - Việc phỏng vấn sẽ được ghi lại bằng thiết bị thu âm. (quantitative ko có cái này)
  - Con/em tôi hoàn toàn có thể ngừng tham gia đề tài này bất cứ lúc nào và có thể từ chối trả lời bất cứ câu hỏi nào.
  - Nếu thông tin trong đề tài này được xuất bản, thông tin cá nhân của con/em tôi sẽ không thể xác định và được giữ kín.
  - Dù cho con/em tôi có tham gia hay không, hoặc rút lui sau khi đã tham gia thì sẽ không có bất cứ sự tác động, ảnh hưởng nào từ các tổ chức, cá nhân hay dịch vụ đang sử dụng.
  - Dù cho con/em tôi có tham gia hay không, hoặc rút lui sau khi đã tham gia thì sẽ không có bất cứ sự tác động, ảnh hưởng nào tới tiến độ và kết quả học tập của em.
  - Con/em tôi có thể yêu cầu dừng tham gia bất cứ lúc nào, bất cứ giai đoạn nào của đề tài, mà không gặp phải một bất lợi nào cả..

Chữ ký ..... Ngày .....

Tôi xác nhận rằng tôi đã giải thích đề tài đến đối tượng tham gia nghiên cứu và đảm bảo rằng anh/cô/em ấy hiểu các thông tin liên quan và tự nguyện đồng ý tham gia.

Tên người nghiên cứu .....

Chữ ký ..... Ngày .....

*Dự án nghiên cứu này đã được cho phép và thông qua bởi Ủy ban đạo đức nghiên cứu hành vi và xã hội, trường Đại học Flinders (dự án số 6486). Để biết thêm thông tin, anh/chị có thể liên lạc Cán bộ quản trị của Ủy ban bằng điện thoại số 0061 8201 3116 hoặc bằng fax số 8201 2035 hoặc bằng email [human\\_researchethics@flinders.edu.au](mailto:human_researchethics@flinders.edu.au).*



**BẢN ĐỒNG Ý CỦA NGƯỜI THAM GIA TRÊN 18 TUỔI  
TRONG ĐỀ TÀI NGHIÊN CỨU ĐỊNH LƯỢNG**

Sức Khỏe Tâm Lý Xã Hội của Trẻ Vị Thành Niên  
với Khiếm Khuyết Nhìn và Vận Động ở Việt Nam

Tôi .....

Đang sinh sống/học tập/làm việc tại .....

trên 18 tuổi đồng ý tham gia, như đề nghị, vào một phần đề tài nghiên cứu “Sức khỏe tâm lý xã hội của của trẻ vị thành niên với khiếm khuyết nhìn và vận động ở Việt Nam ” của cô Đinh Thị Thu Phương - nghiên cứu sinh ngành Tâm lý học tại trường Đại học Flinders, Úc.

5. Tôi đã đọc thông tin cung cấp.
6. Tôi đã hiểu các chi tiết cụ thể của tiến trình thực hiện đề tài và các khó khăn có thể có.
7. Tôi nhận thức rằng tôi nên giữ bản copy của thư giới thiệu và bản đồng ý này để tham khảo về sau.
8. Tôi hiểu rằng:
  - o Tôi có thể không có lợi ích trực tiếp từ sự tham gia này.
  - o Việc phỏng vấn sẽ được ghi lại bằng thiết bị thu âm. (quantitative ko có cái này)
  - o Tôi hoàn toàn có thể ngừng tham gia đề tài này bất cứ lúc nào và có thể từ chối trả lời bất cứ câu hỏi nào.
  - o Nếu thông tin trong đề tài này được xuất bản, thông tin cá nhân của tôi, gia đình tôi hoặc con/em tôi sẽ không thể xác định và được giữ kín.
  - o Dù cho tôi có tham gia hay không, hoặc rút lui sau khi đã tham gia thì sẽ không có bất cứ sự tác động, ảnh hưởng nào từ các tổ chức, cá nhân hay dịch vụ đang sử dụng.
  - o Dù cho tôi có tham gia hay không, hoặc rút lui sau khi đã tham gia thì sẽ không có bất cứ sự tác động, ảnh hưởng nào tới tiến độ và kết quả học tập của tôi.
  - o Tôi có thể yêu cầu dừng tham gia bất cứ lúc nào, bất cứ giai đoạn nào của đề tài, mà không gặp phải một bất lợi nào cả..
9. Tôi đã có cơ hội để thảo luận về việc tham gia vào dự án này với gia đình hoặc bạn bè của tôi.

Chữ ký người tham gia .....Ngày .....

Tôi xác nhận rằng tôi đã giải thích đề tài đến đối tượng tham gia nghiên cứu và đảm bảo rằng anh/cô/em ấy hiểu các thông tin liên quan và tự nguyện đồng ý tham gia.

Tên nhà nghiên cứu .....

Chữ ký .....Ngày .....

*Dự án nghiên cứu này đã được cho phép và thông qua bởi Ủy ban đạo đức nghiên cứu hành vi và xã hội, trường Đại học Flinders (dự án số 6486). Để biết thêm thông tin, anh/chị có thể liên lạc Cán bộ quản trị của Ủy ban bằng điện thoại số 0061 8201 3116 hoặc bằng fax số 8201 2035 hoặc bằng email [human.researchethics@flinders.edu.au](mailto:human.researchethics@flinders.edu.au).*

<b>BẢNG ĐÁNH GIÁ KHUYẾT TẬT</b> (WHODAS 2.0)	Participant ID:			Ngày tháng:				

Bộ câu hỏi này hỏi về những khó khăn mà bạn gặp phải do tình trạng sức khỏe. Những tình trạng sức khỏe này bao gồm bệnh tật hoặc những vấn đề sức khỏe về cảm xúc, tinh thần, bị thương trong thời gian ngắn hoặc dài, hoặc có những vấn đề với rượu hay chất gây nghiện.

Hãy nghĩ về bạn trong thời gian 30 ngày qua và trả lời các câu hỏi sau, nhớ lại mức độ khó khăn mà bạn gặp phải khi thực hiện các hoạt động sau. Với mỗi câu hỏi, vui lòng chỉ khoanh tròn một câu trả lời.

Trong 30 ngày qua, bạn gặp khó khăn như thế nào trong việc:							CODING
S1	<u>Đứng trong khoảng thời gian dài (ví dụ trong 30 phút)?</u>	Không (1)	Nhẹ (2)	Vừa phải (3)	Rất khó (4)	Cực khó, không thể làm (5)	STAND
S2	<u>Làm các công việc nhà?</u>	1	2	3	4	5	WORK
S3	<u>Học một nhiệm vụ mới, ví dụ như học đi đến một nơi mới?</u>	1	2	3	4	5	LEARN
S4	<u>Bạn có gặp nhiều khó khăn trong việc tham gia các hoạt động cộng đồng (ví dụ các hoạt động tôn giáo, lễ hội hay các hoạt động khác)?</u>	1	2	3	4	5	COMM
S5	<u>Bạn hãy cho biết mức độ tác động của vấn đề sức khỏe đến cảm xúc của bạn?</u>	1	2	3	4	5	EMOTION
S6	<u>Tập trung làm gì đó trong 10 phút?</u>	1	2	3	4	5	FOCUS
S7	<u>Đi bộ một quãng đường dài chẳng hạn trong khoảng 1 km ( hoặc tương đương)?</u>	1	2	3	4	5	WALK
S8	<u>Tắm rửa toàn bộ cơ thể của bạn?</u>	1	2	3	4	5	BATH
S9	<u>Mặc quần áo?</u>	1	2	3	4	5	WEAR
S10	<u>Ứng phó với những người mà bạn không biết?</u>	1	2	3	4	5	COPE
S11	<u>Duy trì một tình bạn?</u>	1	2	3	4	5	MAINTAIN
S12	<u>Làm các công việc hằng ngày của bạn?</u>	1	2	3	4	5	DAILYJOB

		Số lượng ngày	
H1	<u>Tóm lại, trong 30 ngày qua, có bao nhiêu ngày là bạn gặp phải khó khăn?</u>	_____	SUMDIFFI
H2	<u>Trong 30 ngày qua, có bao nhiêu ngày bạn hoàn toàn không thể thực hiện sinh hoạt hoặc các công việc thường ngày do điều kiện sức khỏe của mình?</u>	_____	SUMCANT
H3	<u>Trong vòng 30 ngày qua, không tính những ngày bạn hoàn toàn không thể, có bao nhiêu ngày bạn đã <u>cắt giảm hoặc hạn chế</u> thực hiện các sinh hoạt hoặc công việc thường ngày do</u>	_____	SUMREDU

<b>THÔNG TIN CHUNG</b>	Participant ID:	Ngày tháng:
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1. Ngày sinh:										DATE OF BIRTH									
2. Giới tính:										GENDER									
3. Tôn giáo:										RELIGION									
4. Loại vấn đề của bạn:		Thị giác (1)				Vận động (2)				DISABILITY TYPE									
5. Nguyên nhân của vấn đề:		Bẩm sinh (1)		Bị thương (2)		Tai nạn giao thông (3)		Bom mìn (4)		REASON									
6. Bạn có đi học không?		Có				Không				GO TO SCHOOL									
Nếu có, bạn học lớp mấy?										CLASS									
7. Tên và địa chỉ Trường/Cơ sở:										LIVING									
8. Trường/Cơ sở thuộc sự quản lý:		Nhà nước				NGO/Cá nhân				SERVICE TYPE									
9. Bạn tự đánh giá thế nào về cuộc sống của bản thân? Thang đánh giá này gồm có 09 nấc. Giả sử nấc thang thứ 9 là nấc cao nhất, thể hiện cuộc sống tốt nhất có thể cho bạn và nấc thang thấp nhất là nấc thể hiện cuộc sống tệ nhất có thể cho bạn.																			
Hiện tại, bạn cảm thấy bạn đang đứng ở vị trí nào trên thang đánh giá này?		1	2	3	4	5	6	7	8	9	CURRENT SATISFACTION WITH LIFE								
Trong bốn năm tới, bạn cảm thấy bạn đứng ở đâu trên thang đánh giá này?		1	2	3	4	5	6	7	8	9	EXPECTED FUTURE SATISFACTION WITH LIFE								

<b>THANG ĐO SỰ THÀNH CÔNG</b> ( <i>Flourishing Scale</i> )	Participant ID:				Ngày tháng:			

Bảng đánh giá này tổng hợp 8-mục ngắn gọn về sự tự nhận thức thành công của bạn trong các lĩnh vực quan trọng như các mối quan hệ, mục đích, và sự lạc quan.

Dưới đây là 8 phát biểu mà bạn có thể đồng ý hoặc không. Hãy chỉ ra mức độ đồng ý bằng cách chọn từ 1-7 cho mỗi phát biểu tương ứng:

- 7 - Rất đồng ý
- 6 - Đồng ý
- 5 - Hơi đồng ý
- 4 - Trung lập
- 3 - Hơi không đồng ý
- 2 - Không đồng ý
- 1 - Rất không đồng ý

		Mức độ đồng ý							CODE
	Bạn hướng đến một cuộc sống có mục đích và ý nghĩa.	1	2	3	4	5	6	7	FLO1

Các mối quan hệ xã hội của bạn có ý nghĩa hỗ trợ và bổ ích.	1	2	3	4	5	6	7	FLO2
Bạn bận rộn và quan tâm đến các hoạt động hàng ngày của mình.	1	2	3	4	5	6	7	FLO3
Bạn chủ động góp phần mang lại hạnh phúc và sức khỏe cho người khác.	1	2	3	4	5	6	7	FLO4
Bạn thành thạo và có năng lực trong các hoạt động mà bạn cảm thấy quan trọng đối với bạn.	1	2	3	4	5	6	7	LO5
Bạn là một người tốt và sống một cuộc sống tốt.	1	2	3	4	5	6	7	LO6
Bạn lạc quan về tương lai.	1	2	3	4	5	6	7	LO7
Mọi người tôn trọng bạn.	1	2	3	4	5	6	7	FLO8

<b>THANG ĐO VỀ SỰ PHÂN BIỆT ĐỐI XỬ</b> ( <i>Discrimination scale</i> )	Participant ID:			Ngày tháng:				

Sử dụng thang mức độ từ 1-6 dưới đây, vui lòng đưa ra câu trả lời của bạn cho mỗi tình huống bằng cách khoanh tròn số thích hợp tương ứng với tình huống đó. Vui lòng trả lời thành thật.

- 6-Hầu như hàng ngày
- 5-Ít nhất một lần mỗi tuần
- 4-Vài lần một tháng
- 3-Vài lần một năm
- 2-Ít nhất một lần mỗi năm
- 1-Không bao giờ

**Trong cuộc sống hàng ngày, những tình huống sau đây xảy ra với bạn của bạn (người cũng có khuyết tật thị giác và vận động giống bạn) với tần suất như thế nào?**

	Mức độ						CODE
	Không bao giờ (1)	Ít nhất một lần/năm (2)	Vài lần/năm (3)	Vài lần/tháng (4)	Ít nhất một lần/tuần (5)	Hầu như hàng ngày (6)	
1. Họ bị đối xử ít nhã nhặn hơn so với người khác.	1	2	3	4	5	6	DIS1
2. Họ bị đối xử thiếu tôn trọng hơn so với người khác.	1	2	3	4	5	6	DIS2
3. Họ nhận các dịch vụ tệ hơn người khác tại các nhà hàng hay cửa hàng.	1	2	3	4	5	6	DIS3
4. Người ta hành động như thể người ta nghĩ họ không thông minh.	1	2	3	4	5	6	DIS4
5. Người ta hành động như thể người ta sợ bạn của bạn	1	2	3	4	5	6	DIS5
6. Người ta hành động như thể người ta nghĩ bạn của bạn thiếu trung thực	1	2	3	4	5	6	DIS6

7. Người ta hành động như thể người ta tốt hơn bạn của bạn.	1	2	3	4	5	6	DIS7
8. Bạn của bạn bị gọi tên hoặc bị trêu chọc.	1	2	3	4	5	6	DIS8
9. Bạn của bạn bị đe dọa hoặc bị quấy rầy.	1	2	3	4	5	6	DIS9

<b>THANG ĐO MỨC ĐỘ CĂNG THẲNG</b> (Symptoms of anxiety and depression: DASS-21)					Participant ID:			Ngày tháng:					
<p>Thang đo này tổng hợp 21 mục để đo mức độ căng thẳng và lo âu. Vui lòng khoanh tròn số 0, 1, 2, hay 3 để chỉ định xem câu nào thích hợp với những gì đã xảy ra cho bạn trong tuần lễ vừa qua. Không có câu trả lời nào đúng hay sai. Bạn không nên mất quá nhiều thời gian để lựa chọn.</p> <p><b>Cách phân loại như sau:</b></p> <p>0 - Điều này hoàn toàn không xảy ra với bạn.  1 - Xảy ra với bạn ở một mức độ nào đó, hoặc thỉnh thoảng.  2 - Thường xảy ra với bạn ở một mức độ đáng kể, hoặc nhiều lần.  3 - Rất thường xảy ra với bạn, hoặc hầu như lúc nào cũng có.</p>										<b>D</b>	<b>A</b>	<b>S</b>	<b>CODE</b>
1. Bạn thấy khó để mà nghỉ ngơi.	0	1	2	3			.....		DASS1				
2. Bạn thấy mình bị khô miệng.	0	1	2	3			.....		DASS2				
3. Bạn dường như không gặp bất kỳ một cảm giác tích cực nào cả.	0	1	2	3	.....				DASS3				
4. Bạn bị khó thở (ví dụ thở quá nhanh, khó thở trong trường hợp không gắng sức).	0	1	2	3			.....		DASS4				
5. Bạn thấy khó mà bắt tay vào công việc.	0	1	2	3	.....				DASS5				
6. Bạn có xu hướng phản ứng quá mức trong mọi hoàn cảnh	0	1	2	3			.....		DASS6				
7. Bạn thường bị run rẩy (ví dụ tay bạn bị run).	0	1	2	3			.....		DASS7				
8. Bạn thấy mình đã dùng quá nhiều năng lượng thần kinh.	0	1	2	3			.....		DASS8				
9. Bạn lo lắng về những tình huống trong đó bạn có thể hoảng sợ và làm cho bạn mất mặt.	0	1	2	3			.....		DASS9				
10. Bạn cảm thấy rằng bạn không có gì để mong muốn.	0	1	2	3	.....				DASS10				
11. Bạn cảm thấy bồn chồn.	0	1	2	3			.....		DASS11				
12. Bạn thấy khó mà thư giãn.	0	1	2	3			.....		DASS12				
13. Bạn thấy mình xuống tinh thần và buồn rầu.	0	1	2	3	.....				DASS13				
14. Bạn thấy thiếu kiên nhẫn với những điều cản trở việc bạn đang làm.	0	1	2	3			.....		DASS14				
15. Bạn thấy mình gần như bị hốt hoảng.	0	1	2	3			.....		DASS15				
16. Bạn không thấy hăng hái để làm bất cứ chuyện gì.	0	1	2	3	.....				DASS16				
17. Bạn thấy mình là người kém giá trị.	0	1	2	3	.....				DASS17				
18. Bạn thấy mình rất dễ nhạy cảm.	0	1	2	3			.....		DASS18				
19. Bạn thấy tim mình đập nhanh, đập hụt nhịp mà không do làm việc mệt.	0	1	2	3			.....		DASS19				
20. Bạn cảm thấy sợ vô cớ.	0	1	2	3			.....		DASS20				
21. Bạn cảm thấy cuộc sống mình không có ý nghĩa.	0	1	2	3	.....				DASS21				
Tổng cộng số điểm													
<b>Tổng cộng số điểm sau khi nhân cho 2</b>													

<b>THANG ĐO MỨC ĐỘ LẠC QUAN</b>	People ID:	Ngày tháng:
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(Optimism Measure: <i>Revised Life Orientation Test</i> )									
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Xin vui lòng trả lời thành thật và chính xác nhất có thể. Cố gắng không để câu trả lời của bạn về một ý kiến ảnh hưởng đến các câu trả lời về các ý kiến khác. Không có câu trả lời đúng hoặc sai. Hãy trả lời theo cảm nhận của riêng bạn hơn là nghĩ về ý kiến của số đông sẽ trả lời.

- 4 - Rất đồng ý
- 3 - Hơi đồng ý
- 2 - Trung lập
- 1 - Hơi không đồng ý
- 0 - Rất không đồng ý

	Mức độ đồng ý					CODE
	0	1	2	3	4	
1. Trong những lúc bất ổn, bạn thường mong đợi điều tốt nhất.	0	1	2	3	4	OPT1
2. Bạn thật dễ dàng thư giãn.	0	1	2	3	4	OPT2
3. Nếu có điều gì đó không hay xảy ra với bạn, nó sẽ xảy ra như một điều tất nhiên.	0	1	2	3	4	OPT3
4. Bạn luôn luôn lạc quan về tương lai.	0	1	2	3	4	OPT4
5. Bạn rất vui thích với bạn bè của mình.	0	1	2	3	4	OPT5
6. Điều quan trọng là bạn thích bận rộn trong công việc.	0	1	2	3	4	OPT6
7. Bạn hiếm khi mong đợi mọi thứ theo suy nghĩ của mình.	0	1	2	3	4	OPT7
8. Bạn không thất vọng dễ dàng.	0	1	2	3	4	OPT8
9. Bạn hiếm khi trông mong những điều tốt đẹp đến với mình.	0	1	2	3	4	OPT9
10. Nhìn chung, bạn mong đợi những điều tốt đẹp đến với bạn hơn là những điều xấu.	0	1	2	3	4	OPT10

<b>THANG ĐO SỰ ẢNH HƯỞNG TÍCH CỰC VÀ TIÊU CỰC</b> <i>(The Positive And Negative Affect Schedule)</i>	Participant ID:			Ngày tháng:				

Thang đo này bao gồm một số từ mô tả những cảm nhận và cảm xúc khác nhau. Hãy chọn mức độ đánh giá từ 1-5 cho cảm nhận/cảm xúc của bạn ở thời điểm hiện tại hoặc trong quá khứ.

- 5-Rất nhiều
- 4-Nhiều
- 3-Vừa phải
- 2-Một ít
- 1-Rất ít hoặc không

		Mức độ					CODE
		Rất ít hoặc không (1)	Một ít (2)	Vừa phải (3)	Nhiều (4)	Rất nhiều (5)	
(1)	Quan tâm	1	2	3	4	5	PAN1
(2)	Đau buồn	1	2	3	4	5	PAN2
(3)	Vui vẻ	1	2	3	4	5	PAN3
(4)	Thất vọng	1	2	3	4	5	PAN4
(5)	Mạnh mẽ	1	2	3	4	5	PAN5
(6)	Tội lỗi	1	2	3	4	5	PAN6
(7)	Hoảng sợ	1	2	3	4	5	PAN7
(8)	Căm ghét	1	2	3	4	5	PAN8
(9)	Nhiệt tình	1	2	3	4	5	PAN9
(10)	Tự hào	1	2	3	4	5	PAN10
(11)	Cáu kỉnh	1	2	3	4	5	PAN11
(12)	Tỉnh táo	1	2	3	4	5	PAN12
(13)	Xấu hổ	1	2	3	4	5	PAN13
(14)	Sáng tạo	1	2	3	4	5	PAN14
(15)	Lo sợ	1	2	3	4	5	PAN15
(16)	Kiên quyết	1	2	3	4	5	PAN16
(17)	Ân cần	1	2	3	4	5	PAN17
(18)	Dễ bị kích động	1	2	3	4	5	PAN18
(19)	Chủ động	1	2	3	4	5	PAN19
(20)	E ngại	1	2	3	4	5	PAN20

<b>THANG ĐO VỀ THỂ MẠNH VÀ KHỐ KHĂN</b> <i>(Conduct problems and prosocial behaviour:</i>	People ID:			Ngày tháng:				

Đối với mỗi câu dưới đây, bạn hãy đánh vào tình huống trả lời phù hợp: **Không đúng, Đúng một phần** hoặc **Đúng hoàn toàn**. Chúng tôi rất mong bạn trả lời tất cả các câu với khả năng cao nhất của mình, ngay cả khi bạn không tuyệt đối chắc chắn về câu trả lời đó. Bạn hãy cho biết cảm xúc của bạn **trong 6 tháng qua**.

		Không đúng (0)	Đúng một phần (1)	Đúng hoàn toàn (2)	
1	Bạn cố gắng đối xử tốt với mọi người. Bạn quan tâm tới cảm xúc của người khác	[ ]	[ ]	[ ]	SDQ1
2	Bạn rất hiếu động, không ở yên một chỗ được lâu	[ ]	[ ]	[ ]	SDQ2
3	Bạn hay bị đau đầu, đau bụng hoặc mệt mỏi	[ ]	[ ]	[ ]	SDQ3
4	Bạn sẵn sàng chia sẻ với người khác (nhường quà, đồ chơi, bút chì, v...v...)	[ ]	[ ]	[ ]	SDQ4
5	Bạn hay nổi cáu hoặc tức giận	[ ]	[ ]	[ ]	SDQ5
6	Bạn thường lui thủ một mình hoặc hay chơi một mình	[ ]	[ ]	[ ]	SDQ6
7	Bạn luôn luôn vâng lời	[ ]	[ ]	[ ]	SDQ7
8	Bạn rất hay lo lắng	[ ]	[ ]	[ ]	SDQ8
9	Bạn thường giúp đỡ khi ai đó bị đau, buồn phiền hay bị ốm	[ ]	[ ]	[ ]	SDQ9
10	Bạn thường xuyên cảm thấy bồn chồn, bứt rứt	[ ]	[ ]	[ ]	SDQ10
11	Bạn có một người bạn tốt, hoặc nhiều hơn thế	[ ]	[ ]	[ ]	SDQ11
12	Bạn hay đánh nhau. Bạn có thể bắt các bạn làm theo ý mình.	[ ]	[ ]	[ ]	SDQ12
13	Bạn thường cảm thấy không vui, buồn bã hoặc mau nước mắt	[ ]	[ ]	[ ]	SDQ13
14	Bạn bè cùng lứa rất thích bạn.	[ ]	[ ]	[ ]	SDQ14
15	Bạn dễ bị sao nhãng, khó tập trung tư tưởng	[ ]	[ ]	[ ]	SDQ15
16	Bạn hay hồi hộp/sợ sệt khi gặp tình huống mới. Bạn hay mất tự tin	[ ]	[ ]	[ ]	SDQ16
17	Bạn đối xử tử tế với những bạn nhỏ tuổi hơn	[ ]	[ ]	[ ]	SDQ17
18	Bạn thường bị mọi người quy là hay nói dối/xạo hoặc gian lận	[ ]	[ ]	[ ]	SDQ18
19	Bạn hay bị những đứa trẻ khác chọc ghẹo hoặc ăn hiếp/bắt nạt	[ ]	[ ]	[ ]	SDQ19
20	Bạn hay tự nguyện giúp đỡ những người khác (bố mẹ, thầy cô giáo, bạn bè)	[ ]	[ ]	[ ]	SDQ20
21	Bạn suy nghĩ mọi việc trước khi làm	[ ]	[ ]	[ ]	SDQ21
22	Bạn lấy đồ mà không phải của mình từ nhà, trường học hoặc nơi khác	[ ]	[ ]	[ ]	SDQ22
23	Bạn dễ hoà đồng với người lớn hơn so với những bạn cùng tuổi	[ ]	[ ]	[ ]	SDQ23
24	Bạn sợ rất nhiều thứ. Bạn hay bị hoảng sợ	[ ]	[ ]	[ ]	SDQ24
25	Bạn thường hoàn thành công việc. Bạn tập trung tốt.	[ ]	[ ]	[ ]	SDQ25

<b>THANG ĐO MỨC ĐỘ HÀI LÒNG VỚI CUỘC SỐNG</b> <i>(The Satisfaction With Life Scales)</i>	People ID:			Ngày tháng:				

Dưới đây là năm ý kiến mà bạn có thể đồng ý hoặc không đồng ý. Hãy dùng thang mức độ đồng ý từ 1-7 bên dưới, và hãy chỉ ra mức độ đồng ý của bạn cho mỗi tình huống bằng cách khoanh tròn số phù hợp vào tình huống tương ứng. Vui lòng trả lời cởi mở và thành thật.

- 7 - Rất đồng ý
- 6 - Đồng ý
- 5 - Hơi đồng ý
- 4 - Trung lập
- 3 - Hơi không đồng ý
- 2 - Không đồng ý
- 1 - Rất không đồng ý

	Mức độ đồng ý							CODE
	Rất không đồng ý (1)	Không đồng ý (2)	Hơi không đồng ý (3)	Trung lập (4)	Hơi đồng ý (5)	Đồng ý (6)	Rất đồng ý (7)	
• Trong nhiều tình huống, cuộc sống của bạn gần như là lý tưởng đối với bạn.		2	3	4	5	6	7	SWL1
• Điều kiện sống của bạn là tuyệt vời.		2	3	4	5	6	7	SWL2
• Bạn hài lòng với cuộc sống của mình.		2	3	4	5	6	7	SWL3
• Cho đến nay bạn đã nhận được những điều quan trọng mà bạn muốn trong cuộc sống.		2	3	4	5	6	7	SWL4
• Nếu bạn có thể sống mãi với cuộc sống của bạn, bạn sẽ hầu như không thay đổi gì.		2	3	4	5	6	7	SWL5

<b>THANG ĐO MỨC ĐỘ HỖ TRỢ XÃ HỘI</b> (Social Support: self-reported <i>Expanded Vaux Social Support Record</i> )	Participant ID:			Ngày tháng:				

Vui lòng chỉ ra mức độ đồng ý và không đồng ý (từ 0-2) đối với mỗi ý kiến sau đây bằng cách khoanh tròn vào câu trả lời đúng nhất đối với bạn.

		 Không có (0)	 Một ít (1)	 Nhiều (2)	CODE
1	Ở trường, có những người lớn mà bạn có thể trò chuyện, lắng nghe suy nghĩ của bạn và quan tâm đến những gì xảy ra với bạn.	0	1	2	SO1
2	Ở trường, có những người lớn mà bạn có thể trò chuyện, chơi cùng và làm bạn hạnh phúc.	0	1	2	SO2
3	Ở trường, có những người lớn mà bạn có thể trò chuyện, cho bạn những gợi ý và lời khuyên cho vấn đề của bạn .	0	1	2	SO3
4	Ở trường, có những người lớn giúp đỡ bạn giải quyết các rắc rối như sửa đồ và làm đồ ăn.	0	1	2	SO4
5	Ở trường, có những người lớn khiến bạn thất vọng và giận giữ (ngay cả khi bạn không thể hiện điều đó).	0	1	2	SO5
6	Trong gia đình bạn, có người có thể trò chuyện với bạn, lắng nghe suy nghĩ của bạn và quan tâm đến những gì xảy ra với bạn.	0	1	2	SO6
7	Trong gia đình bạn, có người có thể trò chuyện với bạn, chơi cùng và làm bạn hạnh phúc.	0	1	2	SO7
8	Trong gia đình bạn, có người có thể trò chuyện với bạn, cho bạn những gợi ý và lời khuyên cho vấn đề của bạn.	0	1	2	SO8
9	Trong gia đình bạn, có người giúp đỡ bạn giải quyết các rắc rối như sửa đồ và làm đồ ăn.	0	1	2	SO9
10	Trong gia đình bạn, có người khiến bạn thất vọng và giận giữ (ngay cả khi bạn không thể hiện điều đó)	0	1	2	SO10
11	Bạn có những người bạn mà bạn có thể trò chuyện, lắng nghe suy nghĩ của bạn và quan tâm đến những gì xảy ra với bạn.	0	1	2	SO11
12	Bạn có những người bạn mà bạn có thể trò chuyện, chơi cùng và làm bạn hạnh phúc.	0	1	2	SO12
13	Bạn có những người bạn mà bạn có thể trò chuyện, cho bạn những gợi ý và lời khuyên cho vấn đề của bạn.	0	1	2	SO13
14	Bạn có những người bạn giúp đỡ bạn giải quyết các rắc rối như sửa đồ và làm đồ ăn.	0	1	2	SO14
15	Bạn có những người bạn khiến bạn thất vọng và	0	1	2	SO15

	giận giữ (ngay cả khi bạn không thể hiện điều đó).				
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<b>THANG ĐO ĐỐI PHÓ TÌNH HUỐNG</b> (Adaptive coping: <i>The Ways of Coping Checklist - Asian Version</i> )	Participant ID:			Ngày tháng:				

Để trả lời bộ câu hỏi này, bạn phải nghĩ đến một tình huống “căng thẳng” trong đầu. Hãy dừng lại trong vài phút và suy nghĩ về tình huống căng thẳng nhất mà bạn gặp phải trong **tuần vừa rồi**.

Tình huống “căng thẳng” được đề cập ở đây có nghĩa là một tình huống khó khăn hoặc gây rắc rối cho bạn. Bởi vì hoặc là bạn cảm thấy căng thẳng về những gì đã xảy ra, hoặc đòi hỏi bạn phải có một sự nỗ lực khá lớn để đối phó với nó. Tình huống này có thể liên quan đến gia đình, bạn bè, công việc hoặc những điều quan trọng đối với bạn. Trước khi phân hồi lại các phát biểu trong bộ câu hỏi này, hãy nghĩ về các chi tiết của tình huống căng thẳng, chẳng hạn như *nơi xảy ra, những người liên quan, cách bạn phản ứng và tại sao nó quan trọng với bạn*. Cho dù S

2 = Có sử dụng hơi nhiều

3 = Có sử dụng rất nhiều

	Mức độ				CODE
	0	1	2	3	
1. Thảo luận hoặc thỏa thuận để có được điều tích cực, có lợi từ tình huống.	0	1	2	3	COPE1
2. Chỉ tập trung vào điều tốt đẹp từ toàn bộ sự việc.	0	1	2	3	COPE2
3. Đưa ra một kế hoạch hành động và tuân thủ thực hiện nó.	0	1	2	3	COPE3
4. Bạn trở nên hiểu biết và cảm thấy tốt hơn khi trải qua sự việc đó.	0	1	2	3	COPE4
5. Thay đổi một số thứ để mọi việc trở nên tốt đẹp.	0	1	2	3	COPE5
6. Làm việc từng bước một ở mỗi thời điểm.	0	1	2	3	COPE6
7. Bạn biết điều gì cần làm, nên bạn nỗ lực gấp đôi và cố gắng nhiều hơn để làm mọi việc trở nên tốt đẹp hơn.	0	1	2	3	COPE7
8. Suy nghĩ và đưa ra nhiều giải pháp khác nhau cho một vấn đề.	0	1	2	3	COPE8
9. Thay đổi chính bản thân để có thể giải quyết tình huống tốt hơn.	0	1	2	3	COPE9
10. Giữ vững lập trường và chiến đấu cho điều bạn muốn.	0	1	2	3	COPE10
11. Chấp nhận điều tốt đẹp thứ hai nếu không đạt được điều tốt đẹp nhất mà bạn mong muốn.	0	1	2	3	COPE11
12. Cố gắng không hành động vội vàng theo cảm tính.	0	1	2	3	COPE12
13. Coi trọng cảm giác của bản thân, nhưng không để chúng chi phối quá nhiều đến những việc khác.	0	1	2	3	COPE13
14. Thay đổi bản thân như một người trưởng thành theo chiều hướng tốt.	0	1	2	3	COPE14
15. Nói chuyện với người khác để tìm ra giải pháp.	0	1	2	3	COPE15
16. Coi trọng sự đồng cảm và thấu hiểu từ người khác.	0	1	2	3	COPE16
17. Hỏi ý kiến của người mà bạn coi trọng về việc bạn đang cảm thấy như thế nào.	0	1	2	3	COPE17
18. Nói với ai đó bất kỳ về cảm giác của bạn.	0	1	2	3	COPE18
19. Tìm đến sự hỗ trợ chuyên nghiệp và làm theo hướng dẫn.	0	1	2	3	COPE19
20. Nói chuyện với người có thể giải quyết vấn đề đó.	0	1	2	3	COPE20
21. Đổ lỗi cho bản thân.	0	1	2	3	COPE21

22. Phân tích hoặc chỉ trích bản thân.	0	1	2	3	COPE22
23. Nhận ra chính mình đã tạo ra rắc rối cho mình.	0	1	2	3	COPE23
24. Hi vọng một phép màu sẽ đến.	0	1	2	3	COPE24
25. Ước bản thân là một người mạnh mẽ hơn, kiên quyết và lạc quan hơn.	0	1	2	3	COPE25
26. Bạn ước rằng có thể thay đổi điều đã xảy ra.	0	1	2	3	COPE26
27. Bạn ước rằng có thể thay đổi cách bạn đang cảm thấy.	0	1	2	3	COPE27
28. Bạn ước rằng những rắc rối sẽ đi chỗ khác và kết thúc bằng một cách nào đó.	0	1	2	3	COPE28
29. Bạn mơ mộng hoặc tưởng tượng về một nơi nào đó hay một thời gian nào đó tốt đẹp hơn hiện tại.	0	1	2	3	COPE29
30. Bạn tưởng tượng hoặc mơ ước về cách mà mọi việc sẽ diễn ra.	0	1	2	3	COPE30
31. Bạn để mọi thứ tiếp diễn như chưa có gì xảy ra.	0	1	2	3	COPE31
32. Ngủ nhiều hơn thường ngày.	0	1	2	3	COPE32
33. Tức giận với người hay đồ vật đã gây ra rắc rối.	0	1	2	3	COPE33
34. Cố gắng quên đi mọi chuyện.	0	1	2	3	COPE34
35. Cố gắng để bản thân thấy khá hơn bằng cách ăn uống, hút thuốc hoặc uống thuốc.	0	1	2	3	COPE35
36. Tránh gặp mặt mọi người.	0	1	2	3	COPE36
37. Từ chối không tin rằng việc đó đã xảy ra.	0	1	2	3	COPE37
38. Tránh không để người khác biết việc không tốt đã xảy ra.	0	1	2	3	COPE38

*Appendix E: Consent forms for participants over 18 years and for parents/guardians of participants under 18 years in Study 2 in English*



**CHILDREN OVER 18 YEAR OF AGE CONSENT FORM  
FOR PARTICIPATION IN THE QUANTITATIVE STUDY**

Psychosocial Wellbeing among Vietnamese Adolescents with Visual and/or Physical Disabilities

I .....  
being over the age of 18 years hereby consent to participate as requested in the study entitled "Psychosocial Wellbeing among Vietnamese Adolescents with Visual and/or Physical Disabilities" being conducted by Thu Phuong Dinh Thi as part of her postgraduate course at Flinders University.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
  - I may not directly benefit from taking part in this research.
  - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
  - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
  - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
  - Whether I participate or not, or withdraw after participating, will have no effect on my progress in my study, or results gained.
  - I may ask that the survey be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
6. I have had the opportunity to discuss taking part in this research with a family member or friend.

**Participant's signature.....Date.....**

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation

**Researcher's name.....**

**Researcher's signature.....Date.....**

*This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 6356). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email [human.researchethics@flinders.edu.au](mailto:human.researchethics@flinders.edu.au).*



**GUARDIAN/PARENT CONSENT FORM  
FOR ADOLESCENTS UNDER 18 YEARS OLD PARTICIPATION IN THE  
QUANTITATIVE STUDY**

Psychosocial Wellbeing among Vietnamese Adolescents with Visual and/or Physical Disabilities

I .....  
being parent/guardian hereby consent to my child .....  
participating, as requested, in the study entitled "Psychosocial Wellbeing among  
Vietnamese Adolescents with Visual and/or Physical Disabilities" being conducted by  
Thu Phuong Dinh Thi as part of her postgraduate course at Flinders University.

1. I have read the information provided and explained the study and other considerations for my child. This consent is also based on my child's will.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I am aware that I should retain a copy of the Introduction Letter and Consent Form for future reference.
4. I understand that:
  - My child may not directly benefit from taking part in this research.
  - My child is free to withdraw from the project at any time and is free to decline to answer particular questions.
  - While the information gained in this study will be published as explained, my child will not be identified, and individual information will remain confidential.
  - Whether my child participates or not, or withdraws after participating, will have no effect on any treatment or service that is being provided to him/her.
  - Whether my child participates or not, or withdraws after participating, will have no effect on his/her progress in his/her study, or results gained.
  - My child may ask that the survey be stopped at any time, and he/she may withdraw at any time from any parts of the research without disadvantage.

**Parent/guardian' signature.....Date.....**

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

**Researcher's name.....**

**Researcher's signature.....Date.....**

*This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 6356). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email [human.researchethics@flinders.edu.au](mailto:human.researchethics@flinders.edu.au).*

Appendix F: The full questionnaire used in Study 2 in English

Severity of disability



# WHODAS 2.0

WORLD HEALTH ORGANIZATION  
DISABILITY ASSESSMENT SCHEDULE 2.0

## 12-item version, self-administered

This questionnaire asks about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.

Think back over the past 30 days and answer these questions, thinking about how much difficulty you had doing the following activities. For each question, please circle only one response.

In the past 30 days, how much difficulty did you have in:						
S1	<u>Standing</u> for <u>long periods</u> such as <u>30 minutes</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
S2	Taking care of your <u>household responsibilities</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
S3	<u>Learning a new task</u> , for example, learning how to get to a new place?	None	Mild	Moderate	Severe	Extreme or cannot do
S4	How much of a problem did you have <u>joining in community activities</u> (for example, festivities, religious or other activities) in the same way as anyone else can?	None	Mild	Moderate	Severe	Extreme or cannot do
S5	How much have <u>you been emotionally affected</u> by your health problems?	None	Mild	Moderate	Severe	Extreme or cannot do

In the past 30 days, how much difficulty did you have in:						
S6	<u>Concentrating</u> on doing something for <u>ten minutes</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
S7	<u>Walking a long distance</u> such as a <u>kilometre</u> [or equivalent]?	None	Mild	Moderate	Severe	Extreme or cannot do
S8	<u>Washing your whole body</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
S9	Getting <u>dressed</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
S10	<u>Dealing</u> with people <u>you do not know</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
S11	<u>Maintaining a friendship</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do
S12	Your day-to-day <u>work</u> ?	None	Mild	Moderate	Severe	Extreme or cannot do

H1	Overall, in the past 30 days, <u>how many days</u> were these difficulties present?	<b>Record number of days</b> ____
H2	In the past 30 days, for how many days were you <u>totally unable</u> to carry out your usual activities or work because of any health condition?	<b>Record number of days</b> ____
H3	In the past 30 days, not counting the days that you were totally unable, for how many days did you <u>cut back</u> or <u>reduce</u> your usual activities or work because of any health condition?	<b>Record number of days</b> ____

<b>Flourishing Scale</b>	Participant ID::			Date:

Below are 8 statements with which you may agree or disagree. Using the 1–7 scale below, Indicate your agreement with each item by indicating that response for each statement.

- a. 7 - Strongly agree
- b. 6 - Agree
- c. 5 - Slightly agree
- d. 4 - Neither agree nor disagree
- e. 3 - Slightly disagree

- \_\_\_ I lead a purposeful and meaningful life
- \_\_\_ My social relationships are supportive and rewarding
- \_\_\_ I am engaged and interested in my daily activities
- \_\_\_ I actively contribute to the happiness and well-being of others
- \_\_\_ I am competent and capable in the activities that are important to me
- \_\_\_ I am a good person and live a good life
- \_\_\_ I am optimistic about my future
- \_\_\_ People respect me

<b>Discrimination Scale</b>	Participant ID:			Date:
<p>Using the 1 - 6 scale below, please indicate your answer with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.</p>				
<p>h. 6 - Almost everyday</p> <p>i. 5 - At least once a week</p> <p>j. 4 - A few times a month</p> <p>k. 3 - A few times a year</p> <p>l. 2 - Less than once a year</p>				
<p>In your day-to-day life, how often do any of the following things happen to <b>your friends who have visual or physical disabilities</b>?</p>				
<ul style="list-style-type: none"> <li>▪ They are treated with less courtesy than other people are.</li> <li>▪ They are treated with less respect than other people are.</li> <li>▪ They receive poorer service than other people at restaurants or stores.</li> <li>▪ People act as if they think they are not smart.</li> <li>▪ People act as if they are afraid of your friends.</li> <li>▪ People act as if they think your friends are dishonest.</li> <li>▪ People act as if they're better than your friends are.</li> </ul>				

# DASS<sub>21</sub>

Person ID:

Date:

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

*The rating scale is as follows:*

- 0 Did not apply to me at all
- 1 Applied to me to some degree, or some of the time
- 2 Applied to me to a considerable degree, or a good part of time
- 3 Applied to me very much, or most of the time

1	I found it hard to wind down	0	1	2	3
2	I was aware of dryness of my mouth	0	1	2	3
3	I couldn't seem to experience any positive feeling at all	0	1	2	3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5	I found it difficult to work up the initiative to do things	0	1	2	3
6	I tended to over-react to situations	0	1	2	3
7	I experienced trembling (eg, in the hands)	0	1	2	3
8	I felt that I was using a lot of nervous energy	0	1	2	3
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10	I felt that I had nothing to look forward to	0	1	2	3
11	I found myself getting agitated	0	1	2	3
12	I found it difficult to relax	0	1	2	3
13	I felt down-hearted and blue	0	1	2	3
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15	I felt I was close to panic	0	1	2	3
16	I was unable to become enthusiastic about anything	0	1	2	3
17	I felt I wasn't worth much as a person	0	1	2	3
18	I felt that I was rather touchy	0	1	2	3
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
20	I felt scared without any good reason	0	1	2	3
21	I felt that life was meaningless	0	1	2	3

REVISED LIFE ORIENTATION TEST - OPTIMISTIC MEASURE	People ID:			Date:
<p>Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements. There are no "correct" or "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer.</p>				
<p>n. 4 = I agree a lot</p> <p>o. 3 = I agree a little</p> <p>p. 2 = I neither agree nor disagree</p> <p>q. 1 = I Disagree a little</p> <p>r. 0 = I Disagree a lot</p>				
<p>___1. In uncertain times, I usually expect the best.</p> <p>___2. It's easy for me to relax.]</p> <p>___3. If something can go wrong for me, it will.</p> <p>___4. I'm always optimistic about my future.</p> <p>___5. I enjoy my friends a lot.]</p> <p>___6. It's important for me to keep busy.]</p> <p>___7. I hardly ever expect things to go my way.</p> <p>___8. I don't get upset too easily.]</p> <p>___9. I rarely count on good things happening to me.</p> <p>___10. Overall, I expect more good things to happen to me than bad.</p>				

<b>The Positive And Negative Affect Schedule</b>		Participant ID:			Date:
<p>This scale consists of a number of words that describe different feelings and emotions. Read each item and then list the number from the scale below next to each word. Indicate to what extent you feel this way right now, that is, at the present moment OR indicate the extent you have felt this way over the past week (circle the instructions you followed when taking this measure).</p>					
<p>s. 5 - Extremely</p> <p>t. 4 - Quite a Bit</p> <p>u. 3 - Moderately</p> <p>v. 2 - A Little</p>					
<p><b>Interested</b> _____</p> <p><b>Distressed</b> _____</p> <p><b>Excited</b> _____</p> <p><b>Upset</b> _____</p> <p><b>Strong</b> _____</p> <p><b>Guilty</b> _____</p> <p><b>Scared</b> _____</p> <p><b>Hostile</b> _____</p> <p><b>Enthusiastic</b> _____</p> <p><b>Proud</b> _____</p>			<p><b>Irritable</b> _____</p> <p><b>Alert</b> _____</p> <p><b>Ashamed</b> _____</p> <p><b>Inspired</b> _____</p> <p><b>Nervous</b> _____</p> <p><b>Determined</b> _____</p> <p><b>Attentive</b> _____</p> <p><b>Jittery</b> _____</p> <p><b>Active</b> _____</p> <p><b>Afraid</b> _____</p>		



<b>The Satisfaction With Life Scales</b>	People ID:			Date:
<p>Below are five statements that you may agree or disagree with. Using the 1 - 7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.</p>				
<p style="padding-left: 40px;">aa. 7 - Strongly agree</p> <p style="padding-left: 40px;">bb. 6 - Agree</p> <p style="padding-left: 40px;">cc. 5 - Slightly agree</p> <p style="padding-left: 40px;">dd. 4 - Neither agree nor disagree</p> <p style="padding-left: 40px;">ee. 3 - Slightly disagree</p> <p style="padding-left: 40px;">ff. 2 - Disagree</p>				
<p>___ In most ways my life is close to my ideal.</p> <p>___ The conditions of my life are excellent.</p> <p>___ I am satisfied with my life.</p> <p>___ So far I have gotten the important things I want in life.</p> <p>___ If I could live my life over, I would change almost nothing.</p>				

## Expanded Vaux Social Support Record

Please show how much you agree or disagree with each of these statements by ticking (✓) the answer which is most true for you.

		 Not At All	 Some	 A Lot
1.	At school, there are adults I can talk to, who care about my feelings and what happens to me.			
2.	At school, there are adults I can talk to, who I do fun things with and who make me feel happy.			
3.	At school, there are adults I can talk to, who give good suggestions and advice about my problems.			
4.	At school, there are adults who help me by doing something to help solve problems like fixing something or making food.			
5.	At school, there are adults I get upset with or angry at (even if I don't show it.)			
6.	There are people in my family I can talk to, who care about my feelings and what happens to me.			
7.	There are people in my family who I do fun things with and who make me feel happy.			
8.	There are people in my family I can talk to, who give good suggestions and advice about my problems.			
9.	There are people in my family who help me by doing something to help solve problems like fixing something or making food.			
10.	There are people in my family who I get upset with or angry at (even if I don't show it).			
11.	I have friends I can talk to, who care about my feelings and what happens to me.			
12.	I have friends I can talk to, who I do fun things with and who make me feel happy.			
13.	I have friends I can talk to, who give good suggestions and advice about my problems.			
14.	I have friends who help me by doing something to help solve problems like fixing something or making food.			
15.	I have friends who I get upset with or angry at (even if I don't show it).			

<b>The Ways Of Coping Checklist- Asian Version</b>	Participant ID:			Date:
<p>This is a four-point Likert scale (0 = does not apply and/or not used; 3 = used a great deal). The correct and official version would be replaced this attachment as soon as the bought version is delivered to the researcher.</p>				
<ol style="list-style-type: none"> <li>1. Bargained or compromised to get something positive from the situation</li> <li>2. Concentrated on something good that could come out of the whole thing</li> <li>3. Made a plan of action and followed it</li> <li>4. Came out of the experience better than when I went in</li> <li>5. Changed something so things would turn out all right</li> <li>6. Just took things one step at a time</li> <li>7. I know what had to be done, so I doubled my efforts and tried harder to make things work</li> <li>8. Came up with a couple of different solutions to the problem</li> <li>9. Changed something about myself so I could deal with the situation better</li> <li>10. Stood my ground and fought for what I want</li> </ol>				
<ol style="list-style-type: none"> <li>11. Accepted the next best thing to what I wanted</li> <li>12. Try not to act too hastily of follow my own hunch</li> <li>13. Accepted my strong feelings, but didn't let them interfere with other things too much</li> <li>14. Changed or grew as a person in a good way</li> <li>15. Talked to someone to find out about the situation</li> <li>16. Accepted sympathy and understanding from someone</li> <li>17. Asked someone I respected about how I was feeling</li> <li>18. Talked to someone about how I was feeling</li> <li>19. Got professional help and did what they recommended</li> <li>20. Talked to someone who could do something about the problem</li> </ol>				
<ol style="list-style-type: none"> <li>21. Blamed yourself</li> <li>22. Criticized or lectured yourself</li> <li>23. Realized you brought the problem yourself</li> <li>24. Hoped a miracle would happen</li> <li>25. Wished I was a stronger person--more optimistic and forceful</li> <li>26. Wished that I could change what had happened</li> <li>27. Wished I could change the way that I felt</li> <li>28. Wished that situation would go away or somehow be finished</li> </ol>				

29. Daydreamed or imagined a better time or place than the one
30. I was in Had fantasies or wishes about how things might turn out
31. Went on as if nothing had happened
32. Slept more than usual
33. Got mad at the people or things that caused the problem
34. Tried to forget the whole thing
35. Tried to make myself feel better by eating, inking, smoking, taking medications
36. Avoided being with people in genera
37. I Refused to believe it had happened
38. Kept others from knowing how bad things were

*Appendix G: Internal consistency of the measures included in the pilot test*

Measures	N	Cronbach's $\alpha$ coefficient
World Health Organization Disability Assessment Schedule 2.0	12	0.79
Flourishing Scale	8	0.84
The Everyday Discrimination Scale	9	0.78
The coping flexibility scale	10	0.51
Depression, Anxiety and Stress Scale	21	0.93
The Revised Life Orientation Test	7	0.60
Positive and Negative Affect Schedule	20	0.64
Strengths and Difficulties Questionnaire	25	0.78
Satisfaction with Life Scales	5	0.91
The Expanded Vaux Social Support Record	15	0.83

Note. N = Number of items.

## Appendix H: Introduction letters for Study 3



School of Psychology  
Faculty of Social Sciences

GPO Box 2100  
Adelaide SA 5001

Tel: +61 8201 2416

Fax: +61 8201 3877

Email: [psychology@flinders.edu.au](mailto:psychology@flinders.edu.au)

<http://www.ssn.flinders.edu.au/psyc>

CRICOS Provider No. 00114A

10 June 2014

### LETTER OF INTRODUCTION (Organizations - Quantitative and Qualitative study)

Dear \_\_\_\_\_,

I understand that this organization provides services for young people with disability.

This letter is to introduce Dinh Thi Thu Phuong, who is a postgraduate student in the School of Psychology, Faculty of Social and Behavioural Sciences, Flinders University, Australia and a lecturer at Hue University, Vietnam. She is completing a research study as part of her PhD studies.

Her project is entitled "*Psychosocial Wellbeing among Vietnamese Adolescents with Visual and/or Physical Disabilities*". The research study comprises of two parts: (1) investigating wellbeing of adolescents with visual and/or physical disabilities, and (2) exploring their challenges, perception of the current support services and expectation of a future support service. I am seeking your permission for young people who receive services from your organization to take part in the study.

I would be most grateful if you would volunteer to help by

- Allowing another person to come to your organization to explain the research study and to hand our Letters of Information and consent forms.
- Allowing Phuong place a drop box at a common place, so that young people or their guardians can return their consent forms indicating whether or not they are willing to participate.
- Allowing young people with a physical or visual disability who are in your care to answer the questions and give their opinion about them, if they have consent to participate in the study.
- If there is a quiet place is sometimes not needed for other activities, it would be helpful for Phuong to be able to use this space when she was conducting the study with the adolescents.

Phuong recognises that participation in the study may disrupt the activities of your organization. She will make every effort to minimize this. However, as a small token of our appreciation, she would provide you a small shopping token or gift or cash valued 50.000VND. This token will be provided at completion of all stages of the research.

If you agree to allow the adolescents in your care to take part in the study now, you are free to change your mind later. Your decision about whether to help with the study will not affect how Phuong or any other person treats you, or any other relationship you have with Hue University or Flinders University. Your decision will remain confidential.

Young people who choose to participate in this study will first be asked to complete a short questionnaire assessing their physical health. Those who are eligible to participate in the study will then be asked to complete a questionnaire. There are a large number of questions, so the questionnaire has been divided **into 3 parts, each part takes about 45 minutes** to complete. Young people can choose to complete none, one, two or all three parts.

There are questions about

- General information (such as participant's name, age, where they live etc.)
- Factors related to their wellbeing, such as about life satisfaction, how they feel at the moment, what difficulties they face in their life and about their relationships with other people.

inspiring  
achievement

Most questions can be answered quickly; young people just need to tell Phuong a number (0-7) for the best answer or which box to tick.

As a token of appreciation for their time, each young person who participates in answering the questionnaire will also be given a small shopping token or gift or cash **valued 15.000VND for each part of the three parts** of the study that they complete.

After completing the questionnaire, just a few adolescents (0-3 participants) might be invited to join the later qualitative study. Those who agree to participate will join a recorded interview asking about their current challenges, their perception about existing support service and their expectation from a future support service.

A thank you gift valued 30.000VND would be given to adolescents who join the interview in the interview. It will be provided at completion of all stages of the research.

Participants in the study will be encouraged to let Phuong, you or other staff members know if they experience any distress or discomfort during, or after, participation in this study. She will also provide each participant and the staff in this organization with an information sheet about how they can contact other sources of support.

All the information provided by the young people will remain confidential and they have the right to decline to answer particular questions, to withdraw from the study, and to withdraw information they have provided. Neither the young people, the organization, nor its staff members will be identified in the reports of the study.

Phuong will provide two copies of the information sheet about the study and a support services information sheet for staff for their records.

**Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.**

Yours sincerely



Julie Robinson, PhD, Senior Lecturer

*This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 6356). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on (+61) 8201 3116, by fax on 8201 2035 or by email [human.researchethics@flinders.edu.au](mailto:human.researchethics@flinders.edu.au).*



**CHILDREN OVER 18 YEAR OF AGE CONSENT FORM  
FOR PARTICIPATION IN THE QUALITATIVE STUDY**

Psychosocial Wellbeing among Vietnamese Adolescents with Visual and/or Physical Disabilities

I .....

being over the age of 18 years hereby consent to participate as requested in the study entitled "Psychosocial Wellbeing among Vietnamese Adolescents with Visual and/or Physical Disabilities" being conducted by Thu Phuong Dinh Thi as part of her postgraduate course at Flinders University.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
  - I may not directly benefit from taking part in this research.
  - My interview will be recorded by an audio recorder.
  - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
  - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
  - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
  - Whether I participate or not, or withdraw after participating, will have no effect on my progress in my study, or results gained.
  - I may ask that the survey be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
6. I have had the opportunity to discuss taking part in this research with a family member or friend.

**Participant's signature.....Date.....**

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation

**Researcher's name.....**

**Researcher's signature.....Date.....**

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**GUARDIAN/PARENT CONSENT FORM  
FOR ADOLESCENTS UNDER 18 YEARS OLD PARTICIPATION IN THE  
QUALITATIVE STUDY**

Psychosocial Wellbeing among Vietnamese Adolescents with Visual and/or Physical Disabilities

I .....  
being parent/guardian hereby consent to my child .....  
participating, as requested, in the study entitled "Psychosocial Wellbeing among  
Vietnamese Adolescents with Visual and/or Physical Disabilities" being conducted by  
Thu Phuong Dinh Thi as part of her postgraduate course at Flinders University.

1. I have read the information provided and explained the study and other considerations for my child. This consent is also based on my child's will.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I am aware that I should retain a copy of the Introduction Letter and Consent Form for future reference.
4. I understand that:
  - My child may not directly benefit from taking part in this research.
  - The interview will be recorded by an audio recorder.
  - My child is free to withdraw from the project at any time and is free to decline to answer particular questions.
  - While the information gained in this study will be published as explained, my child will not be identified, and individual information will remain confidential.
  - Whether my child participates or not, or withdraws after participating, will have no effect on any treatment or service that is being provided to him/her.
  - Whether my child participates or not, or withdraws after participating, will have no effect on his/her progress in his/her study, or results gained.
  - My child may ask that the survey be stopped at any time, and he/she may withdraw at any time from any parts of the research without disadvantage.

**Parent/guardian' signature.....Date.....**

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

**Researcher's name.....**

**Researcher's signature.....Date.....**

*This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 6356). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email [human.researchethics@flinders.edu.au](mailto:human.researchethics@flinders.edu.au).*

## CODE BOOK

### Research questions for study 3

1. To identify:
  - Common challenges facing Vietnamese adolescents with visual and physical disabilities
  - The challenges for which participants believed that they needed support from external sources
2. To capture the evaluations of current support services by Vietnamese adolescents with visual and physical disabilities
3. To explore perceptions and expectations concerning an ideal support service for Vietnamese adolescents with visual and physical disabilities

### Interview questions

The ultimate aim of this research is to improve the services provided to young people with a disability which would help them overcome their challenges/difficulties. In order to do that, I am, first of all, very interested in understanding your challenges/ problems in your lives.

**Question 1.** *Could you share with me the kinds of challenges that you have encountered in the last month?*

#### Coding:

- Unawareness: used for “I don’t know”, “I am still small, I do not think about it” Filters/I don't know
- Challenges/ require external support
- Challenges/ Individual autonomy/cooking
- Challenges/Emotion/positive feelings
- Challenges/ Leisure and recreation/difficulty learning basketball
- Freedom of movement: Challenges/Freedom of movement/Need friend's assistance
  - Challenges/ Freedom of movement
  - Challenges/Freedom of movement/limited
  - Challenge/Freedom of movement/difficulties
  - Challenges/Freedom of movement/Need friend's assistance
  - Challenges/Freedom of movement/Require technical assistance
  - Challenges/Freedom of movement/Adapting
  - Challenges/ Freedom of movement/ challenges compared to others
  - Challenges/ Freedom of movement / Accidents
  - Challenges / Freedom of Movement / Recreational Activities
  - Challenges/Freedom of movement/ Only able to walk
  - Challenges/Freedom of movement/ Dangers
- Freedom of movement/ Access (to washing machine, study space, study equipment, computer, electricity...)
- Finance: Financial management, getting-by, no worries,
- Education:
  - Challenges/Education
  - Challenges/Education/Large homework
  - Challenges/Education/Difficulty understanding
  - Challenge/Education/Able to cope with
  - Challenges/Education/ Require external support
  - Challenge/ Education/ Distance from school
- Learning/Developing skills
  - Challenges / Disability/ Reading and handwriting
  - Challenges / Disability/ Writing

- Leisure activities
- Preparing for the future
  - Challenges/Finance
  - Challenges/financial management
  - Challenges/ Finance/ Require external support
- Career
  - Challenges/Career
  - Challenges/Career/lack of money
  - Challenges/Career/future concern
  - Challenges/career/job readiness
- *Social relationship problem*: require cooperation, neutral, Social relationship/passive responds
  - Challenges/Social relationship/passive attitude
  - Challenges/Social relationship/Few classmates
  - Challenges/Social relationship/Anxiety
  - Challenges/ Social relationship/No problems
  - Challenges Social relationship/ Questions by friends
  - Challenges /Social relationship/ Identifying individuals
  - Social relationship/ Not many friends
  - Challenges/ Social relationship/ Making new friends
  - Challenges/Social relationship/ Problems communicating with friends
  - Challenges/Social relationship/ Hard talking to strangers
  - Challenges/Social relationship/Difficulties
  - Challenges/Social relationship/Lack of confidence
  - Challenges/Social relationship/ Language issues
  - Challenges/Social relationship/ Idea expresion
  - Challenges/Social relationship/ Communication barriers
- *Relationship problem*: require cooperation, harmony living, friendship, family, love, etc...
- *Practical problem*: health, transport, finance, career, etc...
- *Emotions*: anxiety, fear, depression, frustration, joy, optimism, able to be stable.
  - Emotions/Negative/Worry over situation
  - Emotions/Negative
  - Emotions/Negative/Worry over situation
  - Emotions/ negative/ disability
  - Emotions/ negative/ unable to assist family
  - Emotions/ negative/ individual capacity
  - Emotions/ Homesickness
- *Support seeking*: low utilisation of formal services, lack of information and knowledge about services, and isolation.
- *Stigma and discrimination*: being hated, disturbed or teased...
  - Discrimination/hated
  - Discrimination/disturbed
  - Discrimination/ teased
  - Discrimination / Teased by friends
- *Individual capacity*: limited vision,
  - Individual capacity/ Communication/neutral
  - Individual capacity/ Communication/ Positive
  - Individual capacity/Communication/ Adapting to challenges

- Individual capacity/ disability/ poor vision since birth
  - Individual capacity/ disability/ limited vision
  - Individual capacity/Freedom of movement / autonomy
  - Individual capacity/ Finance/ Unable to manage
  - Individual capacity/Communication/ not open personality
  - Individual capacity/ disability/ limited vision
- 5 Individual interest/ Career/ uncertain
- External support access:/Education/private tutors
  - External support access/Education/lacking
  - External support/ Positive communities
  - External support /Education/ Lack access
  - Career/exploring individual inter

**Question 2.** *Now, I would like to ask you about an imaginary situation. Imagine that you had a magic wand that could help you change three things. You could not change your disability, but you could change anything else, what would you change? And why?*

Coding: Similar coding concepts in the Question 1: Health, transportation, finance, career, harmony living, friendship, family, love, stigma, discrimination, communication, support services etc...

- The most concerned: disability/eyesight,
- Individual capacity/Freedom of movement/mobility
- Wishes and Desire /disability/the most concerned
- Wishes and Desire/Many
- Wish and need/ Not many
- Wish and need
  - Wish and need/ Vague
  - Wish and need/ friends
  - Wish and need/ health
  - Wish and need/ leisure and recreation
  - Wish and need/ Finances
  - Wish and need/ Finances/ able to support family
  - Wish and need/ Quality of life/good
  - Wish and need/ family
  - Wish and need/ Family welfare
  - Wish and need/ Family welfare/ health
  - Wish and need/ Family welfare / less workload
  - Wish and need/Freedom of movement/easier access
  - Wish and need/Freedom of movement/ access to mobility equipment assistance
  - Wish and need/Leisure or Recreation/ access to facilities
  - Wish and need/Leisure or Recreation/ access to facilities (TV or Radio)
  - Wish and need/Freedom of movement/autonomy
  - Wish and need/Career/uncertain about interest
  - Wish and need/Career/future job
  - Wish and need/Career/job preparation awareness
  - Wish and need/ career/ success
  - Wish and need/ Career/ Autonomy
  - Wish and need/ career/ a good voice to become a singer
  - Wish and need/ success in vocational training
  - Wish and need/ education/ success
  - Wish and need/Education/ Literacy
  - Wish and need/ Education/ Numeracy and finance

- Wish and need/ Education / Writing
- Wish and need/ Education / ability to feel with both hands for learning braille
- Wish and need/ Education/ good
- Wish and need/ Positive communication
- Wish and need/Communication/more opportunities
- Wish and need/ Communication and language skills
- Wish and need/Communication/longer friendships
- Wish and need/Communication/ Many friends
- Challenges/Communication/few opportunities
- Challenges/Communication/potential problems
- Challenges/Education/lack of support from classmates
- Challenges/ Unawareness
- Challenges/Freedom of movement/mobility
- Challenges/Freedom of movement/require external help
- Individual capacity/Freedom of movement/mobility
- Individual capacity/ Finances/ Awareness of job importance
- Individual capacity/ disability/ unable to feel with right hand
- Individual capacity/side-effect of being confident
- Challenges/Stigma
- Discrimination/isolation
- Discrimination / Fear
- Emotion/negative
- Filter/Repeating the question

**Question 3.** *Now I would like you to think about the real world. I am interested in gaining a better understanding of your perceptions of what would help them to overcome the challenges they face. What are challenges that you think you can solve yourself?*

Coding:

- I don't know
- Freedom of movement
- Individual capacity/ Freedom of movement/learning to walk alone
- Individual capacity/ Freedom of movement/learning and practising new routes
- Finance
- Individual capacity/ Finances/positive outlook on supporting family
- Leisure activities
- Preparing for the future
- Career
- Individual ability/Career/good skills
- Individual capacity/ job proficiency
- Individual interest/Career/exploring of interests
- Individual interest/Career/ future career
- Individual capacity/ Career/ positive outlook
- Wish and need
- Wish and need/
  - Wish and need/Career/optimistic and opportunity
  - Wish and need/Career/exploring of interests
  - Wish and need/Career/importance of enjoyable job
  - Wish and need/ Communication/ Many friends
  - Individual capacity/learning to cook
  - Individual capacity/ Education /positive motivation
  - Individual capacity/Education / positive outlook
  - Individual capacity/ Education/ writing

- Individual capacity/ adapting to daily living/ recognizing objects by touch
- Individual capacity/ quality of life/positive outlook
- Individual characteristics/ intrapersonal/confidence
- Individual Capacity/ Communication/ Require more effort
- Challenges/individual capacity/building confidence
- Challenges/Education/Math and English
- Challenges/Education/ Require external support
- Access to washing machine, study space, study equipment, computer, electricity...
- *Communication problem*: language issues, idea expression, communication barriers, Communication/Friendships/require cooperation
- *Relationship problem*: harmony living, friendship, family, love, etc...
- *Practical problem*: health, transport, finance, career, etc...
- *Emotions*: anxiety, fear, depression, frustration, joy, optimistic...
- *Support seeking*: low utilisation of formal services, lack of information and knowledge about services, and isolation.
- External support/communication/teacher's support in friendships
- Stigma and discrimination: being hate, distured or teased...

**Follow-up question:** How do you resolve it yourself?

Coding: Interviewees may mention some coping strategies:

*Self care, distraction, denial, humor, seeking support, problem-solving, relaxation, physical recreation, adjusting expectations, self-blame, venting...*

#### **Problem-focused strategies**

- Self care
- Analyze the situation: identifying source situation and generating possible solutions.
- Increase effort: working harder
- Increase knowledge: searching and reading material about individual's problems
- Increase application of knowledge: Applying what you have already learned to daily life.
- Seek support searching support service online
- Talk to a person that has a direct impact on the situation

#### **Emotion-focused strategies**

- Brooding: e.g. going over and over the same hurt or disappointment
- Venting: e.g. complaining as a way to release the negative emotion to avoid the explotion
- Magical thinking: e.g. winning a lottery, finding money on the street...
- Imagining better future
- Avoid/Deny: Avoiding everything that is related to the situations or taking drugs and/or alcohol to escape from this situation.
- Blame: Blaming yourself or others for the situation.
- Social support: talking to your best friend or seek professional support services

**Question 4.** *What other challenges that you think you need external support?*

Coding:

- Communication problem: language issues, idea expression, communication barriers...
- Relationship problem: harmony living, friendship, family, love, stigma and discrimination, etc...
- Practical problem: Health, transport, finance, career, etc...
- Challenges/Education/individual motivation

- Challenges/Education
- Challenges/Education/pessimistic about individual capacity
- Challenges/Education/pessimistic about learning process
- Challenges/Career/ challenge from self-taught
- Freedom of movement/ require external support
- Emotional problem: love, sexuality and all other problems that affect their feeling/emotion as a result.
- Support seeking: low utilisation of formal services, lack of information and knowledge about services, and isolation.
- External support
  - External Support/Lack of knowledge
  - External Support/Technological support
  - External support/ Have not used
  - External support/Awareness of services
  - External support/ Awareness of services/information from friend
  - External support/Awareness of services/friend making
  - External Support/Vocational support
  - External support/ Vocational training/ Access
  - External support/Awareness for career preparation
  - External support/ Career/ awareness they require external support
  - External Support/Communication/ Making friends
  - External Support/Benefits for others
  - External Support/ Access support barrier
  - External Support/ Technology access
  - External Support/ Language barrier
  - External support/Access/barrier due to disability
  - External support/ Must haves/ vocational, friend making and psychological services.
  - External support/Finances/subsidized tuition fees
  - External support/ Education/Require teacher's support
  - External support/ Education/Require external support
  - External support/friend making service/accessible
- Wish and need
  - Wish and need/Career/external support
  - Wish and need/Relationship/confidentiality
  - Wish and need/Relationship/confidentiality
  - Wish and need/Education/English
  - Wish and need/Education/application
  - Access to technology/ available to others
  - Access to technology/ available to others
  - Access to technology/benefits
  - Model/ Online services
- Individual: Individual interest/ career/ massage career
- Follow-up question: Seeking external coping strategies: companionship, sympathy, emotional support, practical support... from others). If the participant mentions only informal support (e.g., family and friends), they will be explicitly asked about the existence, accessibility and effectiveness of formal support (e.g., counselling services, employment agencies, non-government agencies etc):

Suggested themes

- Type of support: Informal or formal support. Informal support includes friends, family members, close teachers. Formal support includes commonwealth government, State government, private sector and community sector (Vocational support centers, counselling center, radio-counselling service, making-friend network etc...)
- Type of services: Psychological, Vocational, Residential, emotional support etc.,

**Follow-up question.** Could any of the problems you mentioned be **solved by the existing support services** in your area? What are they?

Coding:

Type of support services used: Vocational support centers, counselling center, radio-counselling service, making-friend network, social support networks etc... which belongs to one of the following sections:

- Commonwealth government,
- State government,
- private sector and
- community sector
- I Don't know/I've never thought about it
- External Support/ Lack of knowledge
- External support/accessibility/financial barriers
- Model/finances/less cost

**Question 5:** *Is there anything about currently available support services that you think is not effective and unhelpful for you, and why?*

Coding:

- Lack of reputation
- Location
- Poor infrastructure
- High fees
- Lack of vocational training experts
- Lack of psychological experts
- Long waiting time is long
- Lack of service
- Staff problems
- Poor quality of support

**Question 6.** What kinds of services do you **want to be available but do not exist** at the moment?

Coding:

1. Navigation-skill class for people with disabilities
2. Consultation and Information Centers for people with disabilities: where to learn Braille, where to buy braille books or wheelchairs etc...
- 5 Vocational support centers
- 6 Counselling centers
- 7 Radio-counselling service
- 8 Making-friend network
- 9 Blind-dating service...
- 10 I Don't know/ I've never thought about it
- 11 External Support/ Lack of knowledge
- 12 External Support/ not consider
- 13 External support/ have not used

- 14 External support/ psychological counselling/ available
- 15 External support/ lacking psychological counselling
- 16 Wish and need/Finances/Able to afford school
- 17 Model/ Raising awareness on support services
- 18 Model/ Finance/ affordable

**Question 7.** Is there anything that those supports **should be changed or improved** in order to be more effective?

Coding:

- 19 Infrastructure changes for easier access: ramps, lift, not too far from where they live,  
...
- 20 Offer service to the child, not passively waiting for the child to come
- 21 Friendly, welcoming atmosphere
- 22 Diverse range of services provided
- 23 Low charge or free basic services
- 24 Access to technology/need
- 25 Access to technology/technological barrier
- 26 Access not technology/language barrier
- 27 Services/ Vocational training/ need
- 28 Services/ Not needing friend making support
- 29 Model/ Must have/ cooking, walking and singing classes
- 30 External support/ desired classes/available
- 31 Services/ Friend Making services/need
- 32 Services/ Psychological counselling/Need  
Services/ Vocational Training/Need

**Question 8.** *What characteristics do you think that a support service would have?*

Coding:

- (1) Physical characteristics: big, clean, nice...
  - Model/Physical characteristics/ Facilities
    - Model/Physical characteristics/ Distance and location
    - Model/ Physical characteristics/ Beautiful place
    - Model/ Physical characteristics/ Have plants
    - Model/ Location/ Close to family
    - Model/ Location/ Close by
    - Model/Freedom of movement /Easy access
    - Model/Physical characteristics/Private areas
    - Model/ Physical characteristics/ Daily living facilities
    - Model/Technical support/ Availability
    - Model/Technical support/Full of support
    - Individual ability/Leisure and Recreation/ Access to recreation facilities
    - Current support system/Leisure and Recreation/ Creative
    - Model/Freedom of movement /easier access)
    - Model/ Available support/ specialized for individuals with disability
    - Distance: near their families, or located in downtown...
- (2) Types of available services:
  - Sports training,
  - Vocational training,
  - Musical training,
  - Recreation,
  - Psychological counselling,
  - Library,
  - Private room,

- Friend-making services
- Model/more opportunities for friendships
- Model/Psychological support/ availability
- Model/Vocational support/ availability
- Model/ Education/ additional support
- Model/ Education/ vocational training
- Model/Leisure and Recreation/ importance
- Model/ Positive communities
- Model/ positive communities/ have friends
- Model/ available support/ teachers and mentors
- Model/Good teachers
- Model/ available support/ communication opportunities teachers and mentors
- Model/finances(cost)/willingness to pay
- Model/finances(cost)/cheap
- Model/ Finances/ affordable
- Model/ Finances/ Free
- Quality of services
  - Model/ Services/ long lasting
  - Model/Services/dedicated and committed staff
  - Model/ Good quality services available
  - Model/Friendly staffs
  - Model/highly-qualified staffs
  - Model/Competent staffs
  - Model/Family member involvement
  - Model/Friends visited
  - Model/ Finances/ affordable
- Other issues
  - Model/finances(cost)/willingness to pay
  - Model/finances(cost)/cheap
  - Model/ Finances/ affordable
  - Model/ Finances/ Free
  - Individual interest/Leisure and Recreation/ Frequency
  - Individual interest/Leisure and Recreation/ Importance
  - Individual capacity/ Finances / unable to manage
  - External support/ Raising awareness and accessibility
  - The balance between education and recreation

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