Understanding Intellectual Disability in Vietnam: Perspectives of Parents and Healthcare and Education Professionals

by

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Abstract

Improving the quality of life for children and young people with intellectual and developmental disability has gained recognition among the key issues in the political agenda in Vietnam in recent years. This qualitative study seeks to contribute to this effort by exploring the understanding and response to intellectual disability within the healthcare and education system at two Vietnamese central provinces, Thua Thien Hue (TTH) and Quang Nam (QN). Findings from the study will inform the design and implementation of future programs and activities to support children with intellectual disability, their families and professionals at the two project sites, through a collaborative partnership with a local not-for-profit organisation.

A scoping review was also conducted to examine the existing literature on intellectual disability in Vietnam and identify research gaps. The study employed a qualitative study design and thematic analysis, guided by the ecological systems theory. Online, semi-structured interviews were conducted with 24 participants from three groups (nine parents of children with intellectual disability, seven healthcare professionals and seven education professionals) across two study sites. A scoping review was also conducted to examine the existing literature on intellectual disability in Vietnam and identify research gaps.

This study provides the first sets of data and findings pertaining to the understanding of and response to intellectual disability from the multiple perspectives of parents and professionals in Vietnam. Findings suggest that parents and professionals’ current understanding of intellectual disability align with the medical and deficit-based perspectives that had been documented in international research. The study also highlights conceptual inconsistency and ambiguity and the lack of reliable assessment tools and protocol, reflected through a plethora of terminology and diagnostic labels being used in professional contexts.

Response to intellectual disability and support needs within the family and the education and healthcare system were examined by invoking concepts from the ecological systems theory. Drawing from parents and professionals’ perspective, the study identifies and maps the characteristics, including both enabling factors and challenges, of the family, education and healthcare microsystems, the meso-systemic interaction between parents and professionals, as well as the social and cultural structures that influence the child’s development.

The study identifies the need for the consideration and adoption of broader perspectives, in line with current evidence-based approaches from international research, in understanding intellectual disability and in planning for services and supports. A range of recommendations are provided to foster these changes at multiple levels, including developing and enhancing the capacity of education and healthcare professionals and parents, improving access to information and peer support for parents, and raising community awareness.

Declaration

I 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.

Signed: Le Thi Huong Giang

Date: 30/07/2021

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> *A dream for my child? I hope she will have the chance to attend school. I hope she will be healthy and able to walk and run, to experience everything that the world has to offer just like all other children (A., Mother, Thua Thien Hue).*

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List of Abbreviations

AAIDD: The American Association on Intellectual and Developmental Disability

APA: American Psychiatric Association

CCIHP: Center for Creative Initiative in Health and Population

DSM: Diagnostic and Statistical Manual of Mental Disorders

GSO: General Statistics Office

ICD: International Classification of Diseases and Related Health Problems

ICF: International Classification of Functioning, Health and Disability

MOH: Ministry of Health

MOET: Ministry of Education and Training

MOLISA: Ministry of Labour, Invalids and Social Affairs

QN: Quang Nam Province

TTH: Thua-Thien Hue Province

VDS: Vietnamese Disability Survey

UNCRPD: United Nations Convention on the Rights of Persons with Disability

WHO: World Health Organisation

Preface

The researcher herself has a background in psychology and professional experience in the field of public health and disability. I worked for four years as a Project and Research Assistant at the Center for Creative Initiatives in Health and Population (CCIHP) on various programs to increase access to early identification and intervention for children with developmental disabilities in Vietnam, raise public awareness, and support policy advocacy, with a focus on autism spectrum disorder. The insights I have gained through this role about families and children with autism in Vietnam, parent-professional dynamics, the current practices in intervention/service delivery, public perception and how policies have changed over the year, had tantamount influences on my approaches to this study. As it turned out, three parent participants mentioned autism among the diagnoses given to their child, while self-identifying themselves as eligible for a study on intellectual disability. As will be discussed in detail in later chapters, my familiarity with the autism community and realities helped me understand this phenomenon in context and in relation with intellectual disability.

My professional and personal exposure to and understanding about the current situation regarding intellectual disability were much lower compared to autism. As I witnessed the surge in autism awareness in research, policy, services and community support, I wanted to find out why so little information was available relating to intellectual disability, despite the latter being formally recognised since much earlier. Have I not, I asked myself, looked hard enough? This following quote, by a participating health professional, captures the sentiment that motivated me to conduct this research:

> I was looking everywhere to find a professional whom I could work with to establish a support team, but I couldn’t find anyone. Perhaps I haven’t looked hard enough. But if we ourselves as professionals do not know where to look for support, how might parents? (O., Health professional 01, QN)

Chapter 1: Introduction

1.1 Background to the research

In 2016, it was estimated that 2.6 million people were identified as having cognitive disabilities in Vietnam and 14.7% of the population holds a state certification of intellectual disability (GSO, 2018). Despite significant progress in legislation and service provision in recent years, children with intellectual disability and their families in Vietnam continue to face significant disadvantages. Cultural beliefs about disability, for example, viewing disability as punishment for past wrongdoings, have led to negative views about having a family member with intellectual disability, stigmatisation, isolation and reduced social and familial support (Mestechkina, Nguyen, & Shin, 2014; Ngo, Shin, Nhan, & Yang, 2012). Even when families reach out for support, there are myriad barriers to access to services, including lack of trained professionals, especially in rural and remote areas, and financial constraints (D'Antonio & Shin, 2009). These accumulated disadvantages are likely to manifest more profoundly as the children grow up, with far-fetched implications on their life-long outcomes in employment, education, health, and overall well-being.

Intellectual disability has been referred to under various terms such as *chậm phát triển* (developmental delay) and *thiểu năng* (retardation/mental retardation); however, the conceptualisation, understanding and usage of the terms by professionals or laypeople in service provision, administrative, and daily life is not well-examined. There is a recognised lack of reliable and standardised assessment procedures and tools, as well as socio-cultural factors, including stigma and high expectations regarding academic performance, that affect the judgement of a child’s intellectual functioning (Vu, Whittaker, and Rodger, 2017). A critical gap exists in the understanding of the perception and construction of meaning regarding intellectual disability from the perspectives of families and professionals in Vietnam, where comprehensive and comprehensible diagnoses prove difficult to obtain.

Findings from cross-cultural studies suggested that the construction of meaning of intellectual disability, including causal attributions and beliefs about treatment, are linked to parents' quality of life, coping ability, and help-seeking behaviours (Jones, Bailey and Jones, 2017; Aldersey, 2012). Recent studies in Vietnam have started to explore the experiences of stigma and social isolation by parents/caregivers of children with intellectual disability, their needs for support, and application and evaluation of therapies or pilot models for implementing home-based intervention; however, much less is understood about the multifaceted nature of intellectual disability including its social, cultural and political dimensions. It is argued that various factors are involved in shaping the familial perceptions, attitudes and response to intellectual disability, yet have not been adequately investigated and captured in research conducted through biomedical lenses. Exploring parents' perspectives about intellectual disability in Vietnam not only complements the understanding of intellectual disability as a lived experience, but also aids the development and delivery of supports and services that are culturally appropriate, acceptable, and better meet the family's needs.

The workforce in disability-relevant fields has largely expanded in recent years in both public and private spheres. However, the extent to which increased resources, attention and expansion of workforce parallels improved quality and equitable access to services and support is open for investigation. Professionals' knowledge and perspectives are also important topics for research as they affect the quality of services not only for the children but also the entire family. Moreover, identifying the key factors that enable or impede service delivery from the professional's perspectives might provide insights about the political will and capacity of the state in response to childhood disability, as well as inform design and implementation of future policies and programs to improve outcomes of such effort.

Over the past decades, ensuring basic human rights for people with disability has increasingly become a recognised issue in the political agenda in Vietnam, demonstrated through key legislative milestones such as the establishment of the country's first Laws on People with Disability in 2010 and the ratification of the United Nation Convention on the Rights of Persons with Disability (UNCRPD) in 2015. This calls for research evidence that can serve as the basis for the organisation, delivery, coordination and integration of high-quality care and support for people with disability. The current project aims to contribute to this effort by examining the construction of and response to intellectual disability. This is a descriptive qualitative study that employs in-depth interviews with 23 parents of children with intellectual disability and professionals in two central provinces in Vietnam. Guided by the ecological systems theory of human development, the study seeks to understand families' response to having a child with intellectual disability as well as extra-familial conditions that influence the capacity for and experiences in managing the disability. Findings from this research will also inform future programs to better support children and young people with intellectual disability, their families, and professionals at the project sites, through partnership with the Center for Creative Initiatives in Health and Population (CCIHP), a local non-profit organisation in the field of public health.

1.2 Aims and objectives

The project aims to examine the construction of intellectual disability in Vietnam and how supports are provided for children and young people with intellectual disability and families within the healthcare and education systems. This is accomplished through the following objectives:

- To understand the construction of intellectual disability in Vietnam through parents and professionals' perspectives.

- To understand the current state of services and supports available for children and youths with intellectual disability, as well as barriers and enablers to accessing services and support.
- To understand the support needs of parents and professionals in caring for and providing services for children and youths with intellectual disability.

1.3 Research questions

To address these objectives, the following research questions framed the study:

- How is intellectual disability described and understood in Vietnam from the perspectives of parents/caregivers and education and healthcare professionals?
- What are the experiences of parents/caregivers in accessing supports and services for their children?
- What are the experiences of healthcare and education professionals in providing services and support children and young people with intellectual disability and their families?

1.4 Structure of the thesis

The structure of the thesis is as follows: Chapter 2 provides background information regarding the cultural and social construction of disability, healthcare and education policies for people with intellectual disability and their families in Vietnam, and an introduction to intellectual disability. Chapter 3 presents findings from a scoping review of the existing literature on the construction of intellectual disability and the country’s responses to intellectual disability within the education and healthcare system. Chapter 4 details the design, conceptual framework and methodology employed to address the three research questions. Chapter 5 presents the findings with themes and participant quotes. Chapter 6 discusses the findings in light of existing literature, limitations and implications of the study for future research and practice. Finally, Chapter 7 concludes the thesis with a summary of key findings and implications.

Chapter 2: Conceptualisation and Response to Disability in Vietnam

This chapter aims to provide the readers with an overall picture of the political, social and cultural context for understanding disability and response to disability in Vietnam. Following a brief overview of disability statistics, the chapter describes the various ways disability, and in particular intellectual disability, has been defined in legal documents as well as from cultural and social perspectives. An overview of current education and health policies and practices relating to disability, and intellectual disability specifically, is provided to set the background for exploring the experiences of families and professionals in providing care and services.

2.1 Disability statistics

The Vietnam Disability Survey (VDS) provides the largest national dataset to date on disability, with an aim to assess the disability status and related socio-economic conditions in order to provide evidence for policy making, monitoring and evaluation (General Statistics Office (GSO), 2018). Using the Washington Working Group (WWG) questionnaire to identify and classify disability types, the VDS reported disability prevalence at 7.06% among population aged 18 and older, and 2.83% among children aged 2-17. It was estimated that five million households had at least one member living with a disability. Psycho-social disability was the most common types of disability among children, followed by communication and cognition. The VDS also collected administrative data from disability-care centres/institutions and reported that people with psycho-social disability and intellectual disability [1] were the largest groups of people currently receiving institutional care (5.3% and 31%, respectively). Children and young people (aged under 30) accounted for nearly 40% of

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[1] Information regarding disability types were based on the Law on People with disability (2010), rather than the WWG questionnaire, as a person needed to obtain a disability certificate to be eligible to receiving services at these centers/institutions.

people with disability living in these institutions. Disability was unevenly distributed geographically and socio-economically, with higher concentration in North Central/Coastal provinces (which includes the two sites of this research), rural areas, and among households with lowest incomes (GSO, 2018). Due to compartmentalised information and inconsistency in methodology, particularly in definitions and categorisation of disability types, it is difficult to obtain accurate statistics, depiction of the current state of disability in Vietnam and how it is responded to in the policies as well as in practice (UNESCO, 2009).

2.2 Understanding Disability in Vietnam

This section focuses on the influences of political, social and cultural forces on the conceptualisations of disability in Vietnam. Changes in disability terminology and definition, as reflected in legal documents since 2010, have been proposed to better align with international policy and theoretical frameworks, such as the social model or human rights model of disability. Nevertheless, conceptualisation of disability in Vietnam remains heavily influenced by the medical model with a focus on individual impairments and associated disadvantages. Moreover, deeply entrenched cultural views and beliefs remain powerful forces in shaping the local understanding and response to disability.

2.2.1 Past and present terminology

A helpful approach to understanding disability conceptualisation is through how disability is defined in legal terms, including the laws and policies that provide the foundation for provision of disability services and support. The 2010 Law on Persons with Disability identifies six forms of disability as “physical disability, hearing disability, visual disability, mental and psychiatric disability, intellectual disability and other disabilities,” and provides the following definition of disability:

> *Person with disabilities (Người khuyết tật)* means a person who is impaired in one or more body parts or suffers functional decline manifested in the

> form of disability which causes difficulties of his/her work, daily life and study" (Socialist Republic of Vietnam, 2010)

Tran (2014) observed that between the years of 2006 – 2009, the period during which Vietnam became a signatory of the UNCRPD, there was a gradual shift from the use of *tàn tật* and *khiếm khuyết* to *khuyết tật* in Vietnamese legal documents, culminating to the above official definition in the 2010 Law. This change in terminology was seen as signalling positive changes in attitude and approach towards disability based on the social model of disability, better social awareness, and acceptance of disability (Tran, 2014). The new terminology *khuyết tật* has been widely endorsed in official laws, policies, program implementation, and by researchers as well as people with disability. For example, Vo Hoang Yen, a notable disability activist and scholar who uses a wheelchair, wrote about the perceived positive attitude associated with the terminology change, where *khuyết tật* is regarded as a less offensive and more "hopeful" term to describe one's disabling conditions (Vo, 2006) .

However, as shown in Table 1 below, even the newly proposed terminologies convey notions of impairment, illness, and bad virtues ("tật"), perishing, lacking and inadequacy ("khuyết"), while reference to social barriers is unclear. Stevens (2020) also pointed out how the 2010 Law draws from human-rights based concepts such as rights and inclusion, while in practice relying on deficit model for determining and categorising disabilities. For example, Article 3 defines three levels of disability (mild, serious, and exceptionally serious) based on the individuals' ability to complete daily self-care tasks: "Persons with exceptionally serious disabilities are those whose impairments render them unable to perform by themselves their personal daily-life activities " (Government of Vietnam, 2012). A Disability Degree Determination Council at each commune, comprised of primarily of local government/administrative representatives and a primary healthcare officer, is responsible for conducting a severity assessment through observation of people with disability carrying out daily life activities, using a set of medical and social criteria and other simple methods (Government of Vietnam, 2012; MOLISA, 2019) Such an assessment clearly does not consider the larger contextual factors in which the individual functions, besides lacking consistency and clarity regarding what constitutes "social and medical criteria."

Table 1. Vietnamese disability terminologies and English translations

Vietnamese terms	Translations
Người (n) (plural and singular)	(a) person
tật (n, adj)	illness; bad virtues
tàn (adj)	Withered, declined, fell into decay
khuyết (adj)	Impaired, weak, lacking

Another issue with this categorical approach is its focus on impairments and what the individuals cannot do, rather than their strengths and support needs to reach their full potential. As only people considered having a "serious" or "exceptionally serious" disability by the Committee are eligible for welfare and disability support, challenges faced by individuals whose disability are less visible or deemed light/moderate might be overlooked. This might contribute to their failures in education and healthcare settings, or in daily activities, because their needs are not recognised, and adequate support not provided. Thus, as reflected in the legal definition and in contrary to Tran (2014)'s argument, the recent terminological change does not seem grounded in substantive changes in terms of understanding about disability as a socially constructed phenomenon, as suggested by the UNCRPD. Instead, there is a continuing emphasis on individual impairments without acknowledgement of the role of social and environmental factors in creating the disability status.

2.2.2 Cultural and social understanding of disability

In Vietnamese culture, disability is attributed to fate and punishment of wrong-doings in the family line according to the karmic interpretations originated in Buddhist tradition, and often perceived in terms of burden (Gammeltoft, 2008; X. T. Nguyen, Stienstra, Gonick, Do, & Huynh, 2019). This results in a culture of blaming and shaming of the family members. As Rydstrom (2010) also noted during her fieldwork to study inclusive education in Vietnam,

> Disability in a person is not something which just happens. Rather strong, and sometimes frightening, forces are at play in the creation of disability. Disability is rendered meaningful, for example, as a consequence of bad 'morality' (dao duc) in a disabled person's ancestors (p. 88).

In an early, seminal ethnographic study on childhood disability in northern Vietnam, Gammeltoft (2008) observed that in the State's dominant construction of congenital disability, a person with disability was assumed incapable of either fulfilling their familial responsibility or contributing to the society. Thus, surrounded by a culture of blaming and shaming, parents defended their moral integrity and (re)gained recognition and acceptance from others by readily carrying upon themselves the responsibility of raising a child that "nobody wants," instead of seeking help from other people or relying on the State (p. 838). Thus, in both the local worlds and parents' construction, a child with disability was seen as bearing the marks of physical and moral flaws, inherently inferior and vulnerable, and incapable of attaining full personhood, and whose values as a person were constantly questioned, discredited and diminished by both the society and their family. Vietnamese culture also endorses many Confucian values, such as the ability to achieve academic success and to maintain harmony and order within the familial lineage (Ngo, Shin, Nguyen, & Yang, 2012). Taken together, the confluence of Confucian values and karma beliefs are compelling factors in the cultural backdrop in which childhood disability is perceived, understood and managed.

2.3 Services and support in the healthcare and education systems

Vietnam has developed a fruitful legal framework and system in tandem with international accords and convention, which states that people with disability have equal access to health, education, employment and social participation (K. Tran, 2014). Despite such progress, people with disability continue to be among the most disadvantaged and marginalised groups in Vietnamese society (GSO, 2018). According to the VDS, there is a high incidence of poverty and poor living conditions among households living with disability. Large disparities have been documented with regards to employment opportunities and access to information, technology and social activities between people with and without disability. Discrimination and negative stereotypes remain serious barriers to the participation and inclusion of people with disability in the community (GSO, 2018). The state's response to disability has also been described to reflect the medical model, as well as charity- rather than right-based (X. T. Nguyen et al., 2019).

2.3.1 Healthcare Policies and Practices

The Law on People with Disability (2010), Law on Health Insurance (2008) and The National Program on the Development of Rehabilitation Services (2014 – 2020) are among the important legislations that regulate the diagnosis and assessment of disability, implementation of rehabilitation, early identification and early intervention of disability programs, and training of healthcare professionals in rehabilitation. According to the VDS, people with disability have comparable and even slightly higher access to general healthcare compared to people without disability, potentially thanks to healthcare benefits from the government (GSO, 2018). However, even with universal healthcare, there are extra costs associated with examination, treatment and rehabilitation causing economic burdens for households with member(s) having disability (GSO, 2018). Access to rehabilitation services is limited and varies vastly across regions, with only 57.3% of community health clinics providing rehabilitation services and only 16.9% meeting accessibility standards (GSO, 2018). Tran (2014) also noted that institutionalisation is the prominent approach underlying many educational, healthcare and social assistance policies, as evidenced by a slight increase in the number of special care institutions and centres in the past decades.

2.3.2 Education policies and practices

The rights to education for all children in Vietnam have been established in the Constitution (1992), the Laws on Education (2005, 2009), and international conventions and commitments such as the Universal Declaration of Human Rights, United Nation Convention on the Rights of Children, and the UNCRPD. The Law on Persons with Disability (2010) confirmed the state's responsibility in ensuring the rights to education for people with disabilities and was also the first binding law to mention the term 'inclusive education' (Stevens, 2020). Three educational models for students with disability were mentioned: inclusive, integrative/semi-inclusive, and special education, with inclusive education being seen as the primary and preferred model (H. X. Nguyen, Villa, Le, Thousand, & Pham, 2020). From as early as 1991, a number of pilot programs and models were implemented with substantial technical and financial support from international non-governmental organisations, helping to facilitate the introduction of inclusive education into the public education system in the early 2000s and subsequent policy changes. Between 2005 to 2019, a number of regulations were established mandating the staffing and training of human resources, curriculum, and organisation of schools and class based on the inclusive model (H. X. Nguyen et al., 2020).

Although inclusive education appears a key concept in many disability-related education policies, there is a lack of consistency in its definitions and clear strategies for its application, resulting in conflicting messages at policy level and confusion at implementation level (Stevens, 2020). For example, both the Laws for Disability and the updated Education Law mentioned inclusive education as the preferred method of education for children with disability while simultaneously endorsing segregated and specialist education on the basis of "suitability," seeming to suggest that specialist and exclusive centres might better serve the needs of some children with disabilities. In other words, the legal framework surrounding disability in general and inclusive education in particular is replete with what Stevens (2020) termed "blended discourses." Based on observational data at two schools with 20 years of experiences in implementing inclusive education, Stevens (2020) further contended that in practice, inclusive education is delivered mostly through individual measures such as developing Individualised Education Plans for students, reducing education content and reducing school fees, rather than efforts at systematic levels to ensure educational settings most conducive to students' learning needs and potential.

There is evidence that large discrepancies exist in access to education opportunities for students with disabilities compared to students without disability, which also widen as students get to higher education levels (GSO, 2018). The VDS shows that only 3% of schools surveyed met accessibility standards, while 75% did not have teachers who could support students with special needs and only 14.1% primary and secondary school teachers received adequate training to support students with disability. Only 42.7% of respondents in household survey believed that children with disability should receive education in inclusive settings (GSO, 2018). An overwhelming 45.5% of respondents believed that people with disability should receive care and treatment in institution, whereas only 15% said care should be family- and community-based.

According to B. Nguyen (2014), existing issues in the implementation of education policy for people with disability in Vietnam include: services being limited in both quantity and quality and not able to respond to the diverse learning needs of people with disability; poor infrastructures and facilities, and lack of strategic planning for resource mobilisation, monitoring and evaluation outcomes of programs; limited human resources capacity and lack of collaboration across sectors or at different levels. Major shortcomings in implementation of education policy for people with disability included inadequate support for people with disability from lower-income households and short-cycle funding affecting sustainability of inclusive education programs. People with disability also faced barriers such as transportation and accessibility issues at most offices and buildings in addition to financial constraints.

2.4 Intellectual disability

The current research focuses on the conceptualisation, meanings and response to intellectual disability situated within the local social and cultural context. The following section provides a brief introduction of intellectual disability, the history of its conceptualisation, and implication for the current research. This is followed by a discussion of terminologies used to describe intellectual disability through legal, social and cultural perspectives in Vietnam.

2.4.1 The evolving construction of intellectual disability

The conceptualisation and definition of intellectual disability has evolved as a result of changing knowledge and scientific evidence, as well as social and political forces (Wehmeyer, Shogren, Singh, & Uyanik, 2017). In the newest International Classification of Diseases and Related Health Problems, Revision 11th (ICD-11), developed by the World Health Organisation (WHO) (WHO, 2018), intellectual disability is coded within the group of neurodevelopmental disorders, specifically as a Disorder of Intellectual Development. “Mental retardation” was used in earlier versions of the ICD, as well as in first four editions of the Diagnostic and Statistical Manual of Mental Disorder (DSM) (APA, 2013), until it was changed to “Intellectual Disability (Intellectual developmental disorder)” in the current (fifth) edition (Bertelli, Munir, Harris, & Salvador-Carulla, 2016). The positioning of intellectual disability in the ICD-11 and DSM-V, two widely used international classification systems of diseases and disorders, was seen as implying “the conceptualisation of intellectual disability as a brain-based health condition and not as a disability” (Bertelli et al., 2016, p. 37).

Wehmeyer et al., (2017) further argued that the until the late 1970s, early conceptualisation of people with intellectual disability centred around “the dual characteristics of differentness and defect” (p. 14). Intellectual disability (then feeble-mindedness or mental retardation) was viewed as a defective condition residing within the person and manifested as a discrepancy between one’s chronological age and mental age. The focus of this pathology-based view was on mental slowness that was internal to the person and marked them as different and subnormal (Wehmeyer et al., 2017).

Over time, new theory and concepts emerged, such as the social model of disability and the International Classification of Functioning, Disability and Health (ICF), offering broader frameworks to understand human functioning and disability as multi-dimensional and a result of interactions among social, personal and environmental factors (Wehmeyer et al., 2017), and disability in general as a human-rights issues (Tomlinson et al., 2014). Moreover, the focus on person-environment interaction views disability as a lack of fit between personal capacity and demands of the environment in which they function (Thompson et al., 2009). It follows that response to disability means providing supports and services that address such gaps. Furthermore, the concept of contextualism, or the focus on context in evaluation of human functioning, inspires an approach to support and provision of services that view behaviours with regards to the circumstances in which they occur (Wehmeyer et al., 2008). This approach also acknowledges the role of the individual in their development, who actively contributes to the transformation of the surrounding environment as much as they are being transformed (Wehmeyer et al., 2008). Support and services provided to the person with intellectual disability need to integrate considerations of their impairments as well as environment. Finally, increased knowledge and investment in community-based intervention and management of disability, changes in disability policy and legislations, and the emergence of self-advocacy and parent advocacy effort, also contributed to changing how disability was understood and supports provided (Wehmeyer et al., 2017).

An example of how these conceptual shifts manifested could be observed in the changes in definitions of intellectual disability proposed by the American Association on Intellectual and Developmental Disability (AAIDD). The AAIDD defines intellectual disability as characterised by significant limitations in intellectual functioning and adaptive behaviours, with the age of onset before 18 (Wehmeyer et al., 2008). Intellectual functioning refers to the ability to understand complex ideas, learn from experience, engage in various form of reasoning and problem solving, whereas adaptive functioning is expressed in conceptual, social and practical adaptive skills that enable a person to function in various domains of everyday life (Wehmeyer et al., 2008). Difficulties in these areas are assessed in the context of a person's typical living environment, as well as the cultural and linguistical differences that influence their performance in daily activities**,** rather than considered as stemming only from the person (Wehmeyer et al., 2008). Additional assumptions underpinning this definition are that strengths often coexist with limitations within each individual, and that describing a disability aims at an important goal of developing a profile of support needs.

The historical examination of the evolving conceptualisation, definition and classification of intellectual disability illuminates its complicated nature, where intellectual disability has been concurrently understood as a health condition and a disability, indicating that deficit-based approaches remain influential on professionals' and public perception and attitudes. However, there has been effort and evidence to support the field of intellectual and developmental disabilities to transition towards strength-based approaches to disability. The nature of the disability is viewed as relational rather than fixed, being contingent on the fit between one's capacity and demands of the environments in which one functions (Wehmeyer et al., 2008). Therefore, concepts such as intelligence, intellectual functioning and intellectual disability must also be examined in the immediate environment surrounding the individual as well as the larger socio-cultural milieus (Emerson, Fujiura, & Hatton, 2007). This amplifies the importance of developing localised knowledge about conceptualisation(s) of intellectual disability across time and factors that contributed to changes, if any, in the way it is understood and managed, as this thesis hopes to achieve.

2.4.2 Intellectual disability in Vietnamese context

Having unpacked the intellectual disability constructs from major western perspectives, I will now discuss its conceptualisation relevant to the local context, and how they compare to international definitions. Conceptualisation of intellectual disability in Vietnam show both similarities and divergence to definitions developed in Western countries described earlier. *Intellectual disability* or *Khuyết tật trí tuệ* is a legally recognised category of disability, defined as a condition characterised by reduced or loss of cognitive and reasoning ability, manifested in slow process or inability to think, analyse and solve problem (Government of Vietnam, 2012). In practice, the use of terminology and understanding about intellectual and other developmental disability vary within as well as across disciplines and settings. For example, the Ministry of Education (MOET) and Ministry of Health (MOH) adopted the definition and diagnostic criteria in DSM-V (APA, 2013) and ICD-10 (2010)[2] and used terminologies such as *mental development delay/mental retardation* in their official guidelines and training documents for professionals. In daily conversation or in the media, various other terms have been used to refer to the phenomenon where an individual is seen as experiencing limitations in intellectual functioning and adaptive behaviours, such as *chậm*

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[2] ICD-10 is the official classification system used within the Vietnamese healthcare/medical system (C. V. Tran & Weiss, 2018)

phát triển (slow/delayed development), *thiểu năng (trí tuệ)*/(intellectual) retardation, and *chậm khôn* (delayed maturation). Table 2 lists some of the definitions and terminology used to refer to intellectual disability and the contexts in which they were used, and Table 3 provides the English translations of the elements that make up common terminology. Notably, the term *chậm,* which translates as *slow* or *delay*, is a common element in several of these terminologies.

Table 2. Intellectual disability terminology and definitions in various contexts

Terms	Context	Definition
Khuyết tật trí tuệ (Intellectual disability)	Vietnam Law on Persons with Disability, 2010	“A condition characterised by reduced or loss of cognitive and reasoning ability, manifested in slow process or inability to think, analyse and solve problem”
	Training Material: Assessment of learning outcomes and progress for students with intellectual, learning and language disability (Ministry of Education and Training, 2018).	Definition provided based on DSM-V (APA, 2013)
Chậm phát triển tinh thần (Mental development Delay/Mental Retardation)	Guiding Documents on Diagnosis and Rehabilitation (Ministry of Health, 2014)	“A group of disorders relating to mental development (affecting the ability to learn other skills compared to same-aged peers), due to pre- and post-natal reasons and during labour […]. Classification based on ICD-10: Mild: IQ score from 55 - 70%: inclusive education; Moderate: IQ score from 40 – 54%: is capable of attending inclusive education; Severe: IQ score from 20-39%: requires assistance; Very severe: IQ score under 20%: requires special assistance”

Chậm phát triển trí tuệ (Intellectual development delay)	Professional Training for Primary School Teachers Curriculum (Ministry of Education and Training).	“Children with intellectual development delay are children with impairments in intellectual functioning causing difficulties in learning and daily activities”
	Rehabilitation for children with intellectual development delay (Medical Publishing House, 2008).	“Children with below-average intelligence, slow reasoning capacity; learning capacity is slower compared to same-aged peers; delayed development of adaptive skills such as communication, self-care, daily activities, social skills, social participation, self-orientation, health and safety, learning, hobbies and employment.”
Developmental disability (Intellectual disability)	Supporting Inclusive Education (Action to Community Development Center, 2017).	“Intellectual disability, or mental developmental delay, might be congenital or acquired, characterised by limitations in cognitive ability.”

Table 3. Word/Elements that make up popular diagnostic labels

Vietnamese terms	Translations
trí tuệ (n)	Intelligence / intellectual
tinh thần, tâm thần (n)	Mental
chậm (adj)	slow/delayed
phát triển (n, v)	development
Rối loạn (n)	Disorder

Among healthcare professionals, lack of adequate understanding of intellectual and developmental disabilities results in diagnoses being hastily provided, and rarely explained in clear and fathomable terms to parents (Vu, Whittaker, & Rodger, 2017). For example, Cong and Huong's study (as cited in Vu, Whittaker, Whittaker, and Rodger (2014)) found that among 20 children who were given a diagnosis of autism, only two children showed stable characteristics of autism at a six-month follow-up, while six were "ambiguous cases" including mental retardation, autism and attention deficit – hyperactivity disorders, and the remaining children improved which meant an autism diagnosis would not apply. To be eligible for state support, children and parents need to attend an assessment process to determine disability form and degree, conducted by administrative officers without relevant and sufficient training, often based solely on how the disability is manifested in observable behavioural challenges (Vu, Whittaker & Rodger, 2017). This example illustrates not only the inadequate capacity for diagnosing, and potentially for responding to, intellectual disability in Vietnam but also difficulties in identifying and understanding intellectual disability solely through medical and legal terms.

Conceptual variations also contribute to the challenge in obtaining reliable and meaningful data concerning people with intellectual disability in Vietnam (GSO, 2018), as data collection inevitably changes depending on how intellectual disability is defined. As described in Section 2.1, the VDS utilised the WWG's questionnaire - a functional-based approach - that did not include intellectual disability as a separate category. Since the VDS is the only population-based report to date yet lacking data on intellectual disability as defined in the 2010 Law, it immediately raises the question of the extent to which statistics and reports regarding the outcomes and effectiveness of disability-related policies and programs accurately reflect the current state.

2.4.3 Addressing intellectual disability in the current study

For consistency and ease of reference, the English terms *intellectual disability* and its Vietnamese equivalence, *khuyết tật trí tuệ*[3] will be used primarily throughout this text. An exception is when other terms, such as “development delay,” are quoted directly from participants’ interviews or other studies’ findings. This is not to imply which terms are more accurate, appropriate or preferrable than the others, especially in the local context, but rather to provide a mutual starting point for further exploration and discussion of the nuanced understanding and interpretations surrounding intellectual disability.

The following chapter will provide a closer examination of understanding and current state of services pertaining to children and young people with intellectual disability in Vietnam through a scoping review of existing literature.

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[3] Because *Khuyết tật* means *disability* and *Trí tuệ* means *intelligence*, this legally official term *Khuyết tật trí tuệ* might be considered the closest literal translation of the term *Intellectual disability*.

Chapter 3: Scoping Review

This chapters presents finding from a scoping review of available literature on understanding and responding to intellectual and developmental disability in Vietnam, guided by the three research questions set out at the beginning. A search was conducted on ProQuest, PsycINFO, Scopus and two Vietnamese academic databases (Citation Gate and VNU-Repository databases) using keywords listed in Table 4. An informal search was also conducted using Google Scholar using Vietnamese search terms. Additional articles were identified through hand-searching the reference lists of selected studies. Due to time constraints and limited information available regarding intellectual disability in Vietnam, a systematic search on grey literature was not conducted; however, two reports commissioned by UNICEF Vietnam were brought to the researcher's attention by colleagues at CCIHP and included in the final review.

Table 4. Keywords for searching articles for scoping review

Construct	Keywords
Intellectual disability	**English:** (Intellectual Disab OR Intellectual Development Disorder* OR Cognitive Impairment* OR Cognitive Delay* OR Mental Retardation OR Developmental Disab*) **Vietnamese:** "Khuyết tật trí tuệ" OR "chậm phát triển" OR "chậm phát triển trí tuệ" OR "thiểu năng trí tuệ" OR "chậm phát triển tâm thần"
Parents/caregivers	Famil* OR Parent OR Mother* OR Father* OR caregiver* OR "care giver*"
Healthcare professionals	"healthcare provider*" OR "healthcare professional*" OR "healthcare staff" OR "health care provider*" OR "health care professional*" OR "health care staff" OR "medical staff" OR "medical professional" OR "health worker*"
Education professionals	Teacher* OR "special education teacher*" OR educator* OR "education professional*"

The researcher screened the titles and abstracts of all studies found, then read in full all publications in either English or Vietnamese that could be located to further assess their relevance to the research questions. During the review process, the researcher utilised broad inclusion criteria and did not apply additional exclusion criteria or appraise the study, as is the case with scoping reviews (Peters, Godfrey, Khalil, et al., 2015). This is to include the largest possible amount of information and knowledge currently available. Finally, some studies that included children with reportedly different diagnoses such as autism spectrum disorders or attention deficit – hyperactivity disorders were included in the review, due to the consideration that this was part of the authors' own conceptualisation of intellectual disability.

Seventeen articles were eligible for the final review[4]. Among these, six studies ([1]-[6]) came from the Family Needs Assessment Project - a collaborative research program between U.S experts and Vietnamese researchers (2003-2005) on intellectual disabilities/delays in Hue, one of the two research sites in this current project. This set of studies provides valuable information about the situation regarding families of children with intellectual disability in the early days, before the legislative changes in disability support were introduced. Eight studies (articles [8] to [15]) were published in Vietnamese, four of which were in national journals and four were Master's theses. Two UNICEF reports examined knowledge, attitudes and practice towards children with disability in Da Nang (Dexter et al., 2009), An Giang and Dong Nai (Trinh et al., 2011). These reports were significant not only because they provide more recent data, but also because the central provinces studied are in close proximity and bear some resemblances in terms of social – economic contexts with this current research's study sites.

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[4] See Appendix D for detailed characteristics of reviewed articles.

Data extraction was conducted on an excel file using the template suggested by Peters et al. (2015). Key findings from selected studies were analysed and synthesised into themes regarding 1) understanding about intellectual disability, 2) family experiences and support needs, and 3) professional experiences. The following section will present these key themes as well as gaps in the existing literature.

3.1 Understanding about Intellectual disability

3.1.1 Researcher's understanding and approaches to studying intellectual disability.

Recruitment of participants in some of the reviewed articles suggested the variations in the researchers' understanding and interpretations of intellectual disability in the local context. For example, Do and Cao (2010) and M. T. Nguyen (2015) included all children attending specialist centres as potential participants, while later specifying that the children had a range of diagnosis including autism, attention-deficit and hyperactivity disorders, and language delay. Thus, it is possible that the samples studied represented populations with distinctive disability yet mutually perceived as similar. This might also suggest that the authors already included these diagnoses into the umbrella term "intellectual delay*,"* therefore considering further steps to differentiate among students with other and/or multiple diagnosis as unnecessary.

One reviewed article reflected on the challenge in conducting research on intellectual disability in a setting where it was not possible to ascertain the children's diagnosis in any systematic manner (Rydstrom, 2010), as is the case in Vietnam. Even when similar terms are used, they might carry vastly different implications or underlying assumptions. This challenge is also present in this current research, where it was not feasible for the research team to re-assess the types of disability that participants reported their children as having. Nevertheless, it appears that other authors in this review neither questioned nor attempted to confirm the validity of the diagnoses given to children in their samples. This conceptual tension will in all likelihood remain a challenge for future research in intellectual disability in Vietnam, as well as a worthwhile topic for investigation.

3.1.2 Challenges in identifying and diagnosing intellectual disability

Shin, Nguyen, Crittenden, Valenti, and Hoang (2008) examined the agreement between parents and teachers' judgement on the nature and extent of disability among 120 children aged 3-7, who were identified by their kindergarten teachers as tentatively delayed or "học chậm" (studying slowly). The study found that, compared to teachers, parents generally rated their children at higher levels of functioning and most notably in three domains: intellectual functioning, communication and behavioural/social. For a child with genetically determined and physical conditions, parents and teachers were more likely to have congruent views on their functional level. The author attributed consistent discrepancies found between teachers' and parents' ratings in cross-cultural studies to the role of contextual determinants, such as social and cultural factors in judgement of children's intellectual disability. However, the fact that the study relied on ambiguous labels used by teachers such as *studying slowly* might have contributed in part to parents' confusion and led to disagreement.

In another study from Hue, Pham and Nguyen (2012) conducted a mixed-method study on identification and assessment for children with intellectual disability with a sample of 15 managers and teachers, 25 parents of children with intellectual disability from three specialist centres. Participants reported that healthcare professionals (doctors) played the most crucial role in the diagnosis and assessment procedure for their children/students. However, diagnosis was conducted simply through observation, and lacked standardisation and engagement from a multi-disciplinary team.

Intellectual functioning, communication and behaviour/social skills are crucial domains when considering an intellectual disability diagnosis. However, the reviewed study highlighted the lack of objective, standardised and culturally appropriate assessment tools and measures, which might further exacerbate the ambiguity of diagnosis outcomes, and result in either unnecessary labelling of some children as *intellectually delayed,* or underdiagnosis of others with less ‘obvious’ intellectual impairments.

3.1.3 Describing intellectual disability

D. Hoang (2017)’s dissertation examined the awareness about developmental disabilities in a sample of parents, teachers, and college students majoring in childcare and health-related fields from three major cities in Vietnam. There was a low level of self-reported knowledge about intellectual disability - with performance in intellectual functioning perceived as the most salient characteristic of intellectual disability, as well as specific aspects such as IQ score, onset of the disability, adaptive functioning and future pathways. Considering that the sample comprised of teachers and aspiring child/health-care professionals, the reported low level of awareness and knowledge raised concerns over the quality of care and support children with developmental disability might receive.

However, a potential issue in Hoang’s approach was to assess awareness and understanding of participants against a western-based, fixed set of knowledge (i.e., DSM-V criteria, APA, 2013) which participants might have been unfamiliar with, and without acknowledging the complicated nature of intellectual disability. In addition, the survey provided only three options regarding future prospect which were restricted and negative (“doing manual jobs” or “being dependent for the rest of their lives,”) or desirable but vague (“being integrated into the society”). Given the various terms used to refer to intellectual disability in local daily settings, an approach that allows participants to have more spontaneous input, such as open-ended answer regarding signs and symptoms and future pathways, might help to elicit richer, more meaningful data and nuanced view of participants’ levels of awareness and knowledge. In addition, conducting separate analyses for each cohort could have helped examine whether there were differences between parents and professionals’ perception and level of awareness and knowledge.

3.1.4 Intellectual disability and dependency

The reviewed studies show a tendency among participants (parents and professionals) to place children with intellectual, communication and behaviour challenges at high level of severity (Rydstrom, 2010; Trinh et al., 2011) compared to children with physical disability or mobility impairments whose “brains” are otherwise unaffected (Trinh et al., p. 48). There were reportedly differential treatments provided to each group of children, such that the former was perceived less favourably and received fewer and lower quality treatment (Trinh et al., 2011). Rydstrom (2010) observed that teachers at the mainstream schools often referred to their students as “disabled” or “normal” (p. 87), and that students with mild disability might be enrolled in inclusive schools, while students with more “severe cognitive disabilities (e.g., Down Syndrome)” (p. 91) might be placed in a special school or even kept out of school.

3.1.5 Intellectual disability as a stigmatised and devaluing condition

Ngo et al. (2012) provided important insights about the construction of intellectual disability through exploring its impact on social exclusion and stigmas experienced by the parents. The study found that culture-specific stigmas towards children with intellectual disability and their families caused both the individuals and the family to be labelled and discredited as well as imposing restrictions on family’s social life. Social exclusion was negatively related to parents' educational level which, the authors argued, might be because parents with higher educational levels were less susceptible to self-stigmas related to "karma" beliefs. This finding emphasises variations in perceptions and responses to intellectual disability at the interplay of culture and demographic factors.

Parents in Ngo et al. (2012) and Do and Cao (2010) expressed concerns about their children's employment and marriage prospects. While these concerns might not be unique to Vietnamese parents, they are particularly antithetical to the forceful Confucian values in the local culture which emphasises one's self-attainment and cultivation, harmony and the continuity of the family lineage through the practice of marriage and reproduction. Moreover, children with intellectual disability were overwhelmingly portrayed as burdens and described in terms of high dependency, e.g., unable to complete self-care tasks. Therefore, the presence of intellectual, communication and behavioural challenges and the assumed diminished capacity to achieve full adult status make intellectual disability a devaluing condition and stigmatised identity (Ngo et al., 2012).

In a culture with strong focus on academic achievement, an intellectual disability label is considered an unwelcoming remark within educational settings. As Rydstrom (2010) observed from an integrated classroom:

> Teachers prefer that students who have been labelled as having 'learning difficulties', are transferred to one of the segregated school classes for disabled students. Some parents, as well as their daughter or son, interpret such a transfer not only as a disqualification but also as a way of 'othering' a student who struggles to catch up in a mainstream school class (p. 94).

Thus, unlike in Ngo (2009)'s study where the intellectual disability identity is attached to and defines the individual, in this case it is the "transferrable" nature of the intellectual disability label that is stigmatising; that is, for as long as students strive to and are able meet academic standards, they can maintain their status among desirable group of "normal" students. As discussed in the first section, educational attainment is highly valued in Vietnamese culture and a strong determinant of social mobility. While extensive public and private household spending on education are often considered worthwhile investments (Bogenschutz, Im, Liang, & Luong, 2020), students with intellectual disability might be readily assumed incapable of learning, and persistently disadvantaged within the education system, despite efforts to implement so-called “education for all” initiatives. Rydstrom (2010) indicated the problematic lack of a reliable and systematic mechanism for identifying and responding to students with intellectual disability who attend inclusive education settings.

3.2. Access to services and support needs

3.2.1 Sources of support

Park, Glidden and Shin (2010) studied structural and functional aspects of social support among 106 mothers of children with cognitive delay and found that informal and social support was lower for mothers who had children with intellectual disability compared to mothers who did not, which indicated social isolation experienced by the former group. There was a significant lack of professional support and services as well as varied and generally low utilisation of these supports. An exception was support from teachers which ranked third among sources social support for mothers (after spouses and maternal grandmothers) and first among support from outside of the family circle. However, teachers' support was mostly provided by kindergarten teachers without prior training in special education. As many mothers from low-income households might not have access to private doctors or therapists for medical services, teachers appeared more accessible and valuable source of professional support such as assistance in teaching and training.

3.2.2 Accessing services

Children with intellectual disabilities in the reviewed studies faced many challenges to access education. Parents were not enthusiastic about inclusive education due to lack of other community services such as transportation, perceived lack of equipment and facilities appropriate to their child's need, perceived lack of attention from teachers, as well as perceived and experienced discrimination and stigma (Dexter et al., 2009). Parents also believed specialised provide more empathetic and non-discriminative environment for their children (Dexter et al., 2009). However, high educational cost at specialist schools was as a major hinderance for many families (Dexter et al., 2009).

In 2011, education access remained challenging for most families. Parents of children with intellectual disability in Dong Nai and An Giang, found it difficult to ensure that their children receive education, regardless of the educational settings (Dexter et al., 2009; Trinh et al., 2011). Parents reported concerns about severity of the child’s disability, the fear that they might be mistreated inside institution/boarding schools, and lack of belief in the child’s ability to benefit from academic pursuit. Environmental factors such as distance from house to school, poverty, and a lack of information among parents of available options and child rights also contributed to children being deprived of education opportunities.

No study has been located that focuses specifically on access to healthcare for families who have children with intellectual disability. As reported in the two reports on children with disability in general, access to medical and healthcare in the two project sites were generally low (Dexter et al., 2009; Trinh et al., 2011). In Da Nang, interviews with health professionals at managerial level revealed that “the prevention [of disability] is clearly a prioritised area for improvement” (Dexter et al., 2009). This seems to suggest a growing focus on screening, early identification, and early intervention of developmental disabilities, including intellectual disability and autism spectrum disorders. There remains an urgent need to examine access to healthcare for children with intellectual disability and families to ensure that they are not disadvantaged in accessing quality and equitable healthcare services and support.

3.2.3 Family support needs

Two studies, Nguyen (2015) and Trang (2014) reported findings on family support needs. Access to professional supports, including intervention services directly provided to the children and counselling services for parents was a prominent theme. Parents also reported the needs for financial support, access to information through participating in parents' groups, sharing experiences with other parents and training courses and workshops, and support with daily life activities (e.g., taking care of the children or other household responsibilities). As M. T. Nguyen (2015) and T. T. H. Tran (2014)'s studies were conducted in Ha Noi, where there are considerably larger networks and number of services (V. C. Tran, Pham, Mai, Le, & Nguyen, 2020), there is an urgent need to understand support needs specific to lower-resourced areas and families with additional socio-economic disadvantages. Against this backdrop, the current research seeks to contribute more current data regarding the situations of families living in Hue city, in light of the initial findings from the Family Needs Assessment project conducted nearly 15 years earlier. This study also examines the current situation in Quang Nam province, which to our best knowledge, has not been previously studied.

3.3 Experiences of educational professionals

3.3.1 Mainstreaming educational settings

Dinh (2015) studied the practices in communication skills training for primary students with intellectual disability among 78 classroom teachers in mainstream settings and found that communication skills were a common area of challenge that teachers noticed among their students with intellectual disability. Teachers also acknowledged that students encountered less challenges when not required to focus for a long period of time, or when given a system of questions. Classroom teachers' perception and attitude towards their students' strengths and support needs and knowledge about teaching strategies are critical elements to ensure appropriate support for students with intellectual disability inclusive setting. However, across the reviewed studies, low level of expertise was reported among both special and classroom teachers. H. X. Nguyen and Eda (2013) and Pham (2018) reported teachers' challenges in adapting and implementing academic curriculum, especially adaptive skills curriculum, and managing challenging behaviours.

There have been few attempts to research intellectual disability and update current knowledge and curriculums in training for general and special education teachers to improve their quality of teaching. Several resources have been identified to support teacher learning and development (H. X. Nguyen et al., 2020) and training materials provided by the Center for Inclusive Education in each province. However, there is a lack of evidence concerning the benefits of such training programs and materials, actual utilisation of these resources in practice, and the extent to which they resulted in improved outcomes for students with intellectual disability.

S. Nguyen (2014), Dexter et al., (2009) and Trinh et al., (2015) reported major structural barriers to inclusive education in Da Nang including lack of specialist schools, lack of specific guiding documents and knowledge in special education, and lack of support from the school administrators to provide resources, equipment, and motivation for classroom teachers. to take on additional tasks required for education of children with disability in the inclusive classrooms. These challenges intensified when students had intellectual disability compared to when they had mobility disability but otherwise "normal cognitive capacity" (Trinh et al., 2015):

> Having students with disability means we do not have time for the "good" students" and "the entire classroom will lose its "Excellence" status because teachers need to spend more time on students with disability."

These barriers almost exclusively concerned students with intellectual disability based on perceived inability to achieve successful academic outcomes. Even teachers at one of the earliest public schools to implement an inclusive education model held vastly different views on what inclusive education meant for students with intellectual disability and their teaching

(T. T. H. Tran, 2014). Such findings clearly suggest the persisting gaps in implementation of inclusive education policies even at schools with a history of providing inclusive education for students with disability.

3.3.2 Special education teachers

According to T. L. Q. Hoang (2014)'s study of graduates from Hanoi University of Education, about 70% of pre-service teachers received training in special education specialised in the intellectual disability track. Graduating students work predominantly in specialist settings as opposed to inclusive education, which seems congruent with findings from classroom teachers, where the collaboration between classroom special education teachers were reportedly limited, or hardly mentioned. This raises questions about the roles and experiences, if any, of special education teachers in the inclusive settings and the implementation of inclusive education, as well as any barriers to their participation and engagement in such processes.

Little is known about the understanding of special education teachers about intellectual disability, their experiences in service provisions as well as their support needs. Hoang (2014) found that while special education teachers might have received more targeted training compared to classroom teachers, many claimed that they relied primarily on experiences of their own or their colleagues, while lacking supervision or technical support from other professionals. Given that the study was conducted with graduates in Hanoi – a big city with where education services are more available than other places, there is an urgent need for further understanding of the experiences and needs of special education teachers in general as well as in areas with more limited resources, such as in Quang Nam province, as attempted in the current study.

3.4 Conclusion

The first section of this literature review showed the perplexing nature of intellectual disability in Vietnam, evidenced in the use of various terms and categorisation of disability and overlapping diagnosis. The reviewed evidence also suggests that various social and cultural factors are involved in shaping the familial perceptions, attitudes and response to intellectual disability. As these factors continue to change, future research needs to further its focus on exploring parents’ own perceptions, experiences and support needs. This study aims to contribute to the knowledge and understanding of intellectual disability as a lived experience from a family perspective, as well as to inform the planning and delivery of supports and services better meets the needs of children and young people with intellectual disability and their families.

As the number of children being given diagnosis and/or labels of intellectual and developmental disability increases rapidly, so does the demand for intervention services. The workforce in disability-relevant fields, such as early intervention, speech language therapy and special education, has largely expanded in recent years, as reflected in the increasing number of public and private service providers as well as training programs in intervention and special education (H. X. Nguyen et al., 2020). However, there has been relatively few attempts to critically examine the current state of disability support practices in healthcare and education contexts in general, and for children with intellectual disability in particular, as most previous studies do not distinguish between students with intellectual disability, autism or other developmental disabilities. Thus, in both public and private spheres, the extent to which increased resources, attention and expansion of workforce parallels improved quality and equitable access to services and support is open for investigation, if not urgently so.

In the existing literature, oft-cited challenges and barriers include the lack of facilities and human resources: trained professionals such as psychologist, child psychiatrists, therapists, and special education teachers who have adequate knowledge and skills to support children with various learning and support needs. Children and families living in rural and less-resourced settings might face additional barriers to services due to exacerbated difficulties in financial and living conditions. Other gaps and barriers included inconsistent diagnosis and implementation of intervention services, inadequate training and lower knowledge among general educators. While such barriers are commonly found in most countries and areas with low resources, no study to date has investigated the experiences of professionals in relevant fields in providing services and support for children and families with intellectual disability in Vietnam. Most notably, no study has been located focusing specifically to the provision of healthcare services for children with intellectual disability and their families. From the review of limited existing research, contextual and personal factors concomitantly influence the experiences of professionals who work and support individuals with intellectual disability and their families. In any case, professionals' knowledge, perspective and attitude are important topics for investigation as they affect the quality of services not only for the children but also the entire family.

In conclusion, the literature reviewed thus far reflects an alarmingly low priority of intellectual disability on the research agenda in Vietnam in both quantity and the breadth of topics investigated. There remain critical gaps in the understanding of experiences of families and professionals and their support needs, which have not been substantially fulfilled even among the recent studies. Although there are lessons to be learned from the experiences of supporting people with intellectual disability from Western countries, there are cultural, political and social-economic conditions that shape both the perception of intellectual disability and the availability of services in ways that warrant careful generalisation of these insights into the local context. This therefore makes the case for localised knowledge about perceptions and responses to intellectual disability in Vietnam in order to inform future designs and implementation of policy and programs, as attempted in this proposed research.

Chapter 4: Methodology

4.1 Conceptual framework

The current research is guided by ecological systems theory to understand the family's response to having a child with intellectual disability as well as extra-familial conditions that influence the family's response capacity and experiences. Originally developed by Bronfenbrenner (1986), the theory focused on multi-level systems, their interdependence and impacts on individual development (Neal & Neal, 2013). Environmental influences are theorised as four inter-related systems: (1) the microsystem refers to the principal settings, such as home or school, that the person directly engages with through activities and interactions during a significant amount of time; (2) the mesosystem refers to interactions between any two microsystems in which development occurs, such as when events happening at home affects the child's educational experiences and vice-versa; (3) the exosystem is comprised of settings that indirectly influence development through their effects on the microsystems and (4) the macrosystem is defined as values and belief systems shared by members living the same community (Bronfenbrenner, 1986; Tudge, Mokrova, Hatfield, & Karnik, 2009).

Over the years, Bronfenbrenner's early ecological theory has undergone continual development by Bronfenbrenner himself and other scholars (Tudge et al., 2009). In later versions of the theory, Bronfenbrenner introduced the Person-Process-Context-Time (PPCT), which incorporated new concepts beyond the original four interconnected systems (Context) described above (Bronfenbrenner & Morris, 1998). The PPCT model acknowledges the role of the *person* and their characteristics that are brought into social interactions and situations, and *proximal process* or "enduring form of interactions" between the person and immediate environments (Bronfenbrenner & Morris, 1998, p.96). The last element, chromosphere, was a crucial addition to the theory, considering the ever-changing nature of the developing person of interest as well as the various systems that contain and influence the types of activities and interactions that take place (Tudge et al., 2009). This has important implications for this research for three reasons: firstly given the nature of child development and how assessment and identification of a disability changes as the child develops; secondly the changing needs of a child and the family, and thirdly the history of understanding, theories, policies and practices relating to intellectual disability documented internationally as well as in Vietnam (Chapter 2).

A widely known representation of the ecological systems is through a set of concentric circles with the child at the innermost circle, and micro-, meso-, exo- and macro-systems at the outer (Figure 1). Neal and Neal (2013) revisited the understanding of the ecological systems as nested and argued that this conceptualisation “obscured the relationships between them [the systems] (p. 723). The authors developed a networked model, or social network model, which progressed the traditional conceptualisation in two significant ways. Firstly, this approach conceptualises each system in terms of the social relationships centred around the focal person; secondly, it clearly illustrates the overlapping yet non-nested nature of the systems. For example, in Figure 2, the family and school micro-systems were juxtaposed and the school-family mesosystemic interactions were described as taking place outside, rather than within the education policy system as the nested model would suggest, while the child remained the focal point of social interactions based on which the systems were defined. This model provides a useful framework for examining the characteristics of the environment (i.e., multiple settings) surrounding a child with intellectual disability and their impacts on their development and therefore will be utilised as a guiding framework in this study.

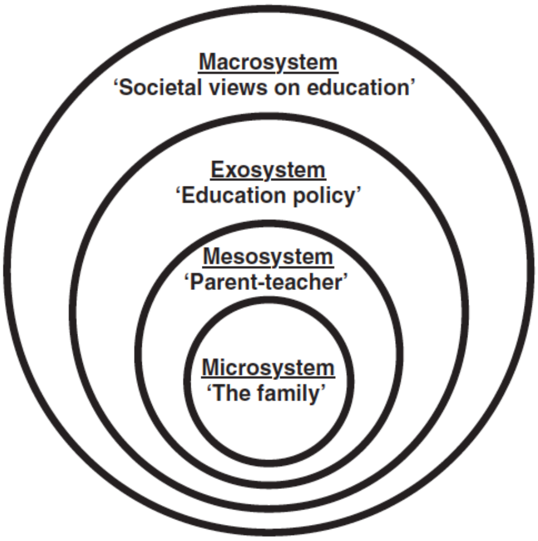

Figure 1. Nested model of ecological systems. Reprinted from "Nested or networked? Future directions for ecological systems theory," by J.W. Neal and Z.P. Neal, 2013, Social development, 22(4), p. 725. Copyright 2013 by the John Wiley & Sons Ltd. Reprinted with permission.

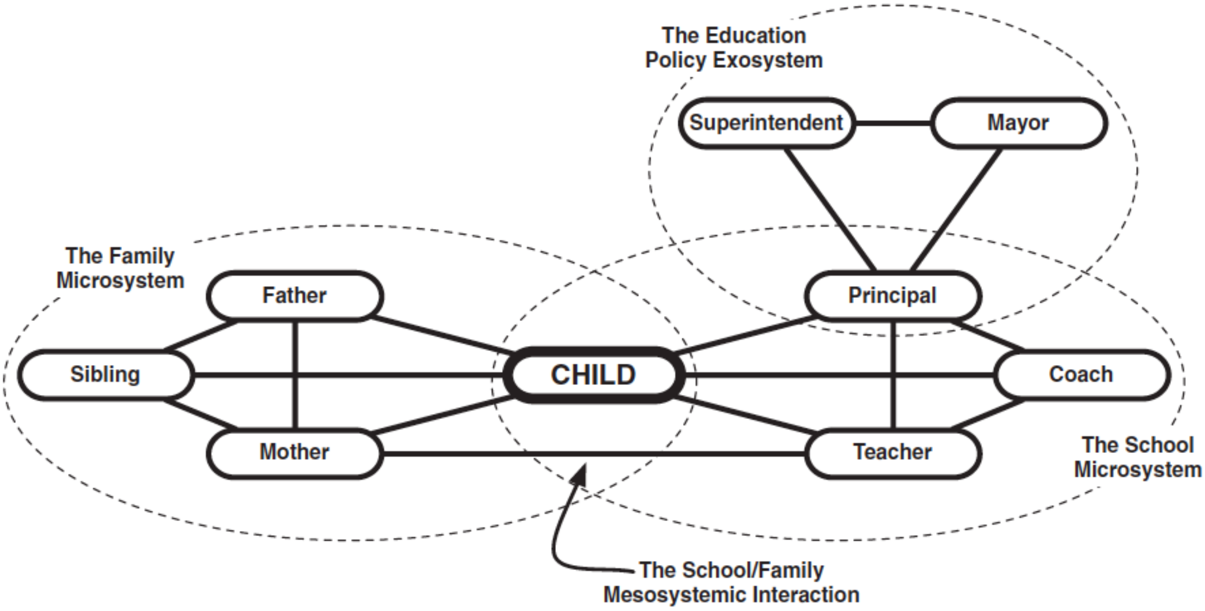

Figure 2. Networked model of ecological systems. Reprinted from "Nested or networked? Future directions for ecological systems theory," by J.W. Neal and Z.P. Neal, 2013, Social development, 22(4), p. 730. Copyright 2013 by the John Wiley & Sons Ltd. Reprinted with permission.

4.2 Research Design

The current research employs descriptive qualitative research methods to explore the constructions of meaning of intellectual disability from familial and professionals' perspectives, and how intellectual disability is responded to within education and healthcare systems. Qualitative research includes a range of methodologies and approaches to making sense of human experiences, reality, phenomenon through an exploration of "perceptions, interpretation, opinions, values and beliefs of research participants" (Schneider, Whitehead, & LoBiondo-Wood, 2016, p. 94). For qualitative researchers, the world is complex and multi-faceted, and one that is seen and constructed rather than objectively known (Walmsley & Johnson, 2003). As such, qualitative research is suitable to the aim of this research to generate understanding and meaning about experiences pertaining to intellectual disability in the local context of Vietnam (Schneider et al., 2016).

Understanding about intellectual disability in Vietnam as well as lived experiences of individuals with intellectual disability and their families are extremely understudied, and the existing literature as reviewed in Chapter 2 has shown large knowledge gaps and methodological limitations. The research questions as well as approaches to data collection and analysis in this research rest on the assumption that, rather than a problem situated within the individual that can be captured in fixed diagnostic terms, intellectual disability is a subjective and experienced phenomenon whose meanings are constructed and negotiated through culturally, socially, and politically unique processes. Families and professionals have inherent insight and knowledge of intellectual disability through their lived experience, while actively and constantly contribute to its conceptualisation and meanings. As such, the research employs semi-structured interviews with parents and professionals as the primary means of data collection to bring forward knowledge and insights about intellectual disability grounded in the experiences and views of the respondents.

4.3. Study site

The research was conducted in collaboration with the CCIHP and contributed to the organisation' efforts to design and implement projects to support individuals with intellectual disability, their families and professionals in related fields. As a result, the study sites for this research were initially selected from three central provinces where CCIHP were operating (Hue, Quang Nam and Quang Tri). The former two, Hue and Quang Nam provinces were selected as they were CCIHP's primary project sites and where broader network existed to connect the researcher with families and professionals. They were also more convenient in terms of time and travel arrangement for both the researcher and the RA.

4.4 Ethical considerations

The project was approved by Flinders University's Human Research Ethics Committee (Project Number 2031) and Internal Review Board at the Center for Creative Initiatives in Health and Population (CCIHP) (Project Number 1111). As the study involved participants with former relationships with CCIHP, measures were taken to mitigate any perceived coercion to participate. For example, participants were contacted with an introductory email and provided an information sheet which clearly stated that participation was entirely voluntary, and participants were free to withdraw at any time. Each interview began with the researcher providing a brief explanation of the research objectives and interview procedure and answering participants' questions. Participants were then asked to provide written consent in a form (See Appendix B and C) collected by the Research Assistant (RA) and received 150,000 VND (about AUD 10) as reimbursement[5]. All but one participant consented to video-recording of the interview, given the explanation that only the

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[5] As part of the collaboration, CCIHP allocated a staff (Research Assistant) to support the project and covered the cost for participants' reimbursement and travelling for the RA. The researcher herself did not receive financial support or payment from CCIHP to complete any part of this thesis.

audio extracted from the recording would be stored and used for the purpose of this study. For one participant who did not give consent to video-recording, we used a voice recorder instead.

4.5 Sample selection

4.5.1 Sources of participants

Participants for this study were recruited from CCIHP's existing pool of program beneficiaries and partners from past projects and activities. To address the research questions, three groups of participants were targeted:

1. Healthcare professionals (HP) who have experiences in providing healthcare services and/or supporting individuals with intellectual disability and their families.
2. Educational professionals (EP) who have experiences teaching and/or supporting students with intellectual disability and their families.
3. Parents/primary caregiver of individuals who have been diagnosed or identified as having an intellectual disability (or alternative terms in local language).

4.5.2 Identifying parents of individuals with intellectual disability

A data analyst from CCIHP generated a list of all potential participants based on location (two target sites) and information about their child's diagnoses; this information was provided by the parents prior to entry to CCIHP's programs and activities and entered into a database managed by CCIHP. From this list, 29 potential parent participants were identified. The list included diagnoses of intellectual disability and other common associations such as intellectual delay, developmental disorders, language delay, while excluding diagnosis of autism, attention deficit – hyperactivity disorder and specific language disorders if reported. Due to various issues with assessment and diagnosis of developmental disabilities in Vietnam, including a lack of standardised procedure for obtaining a diagnosis, it was not possible to ascertain how the reported diagnoses were made and their accuracy. Information regarding whether the child had a disability certificate, a formal diagnosis, or had undergone processes to obtain such documents, was collected during interview but not as part of the eligibility criterion.

After invitations were sent to potential participants, it was assumed that those who agreed to participate identified themselves as parents/primary caregivers of children with intellectual disability (or Vietnamese alternative terms) based on their own interpretation of the terms. This pragmatic approach has been used in previous research where formal diagnosis is lacking, inaccessible or not sought after by parents (Aldersey, 2012; Aldersey & Haines, 2018). Parents and professionals who, based on their lived experiences of living with and/or caring for a person with intellectual disability, might hold potentially diverse interpretations of the disability. These interpretations may or may not align with how intellectual disability is characterised in diagnostic terms developed from western contexts. It is hoped that such an approach will better capture the range of meanings constructed about intellectual disability.

4.5.3 Recruitment of participants

Following the approved procedure for recruitment, a designated Research Assistant (RA) from CCIHP contacted participants and arranged for interviews with the researcher. All participants, prior to the interview, received a copy of the Participants Information Sheet and Consent Forms[6] and Interview question (simplified version that did not contain follow-up prompts)[7] through email. A total number of 27 parents, 14 educators and 13 healthcare professionals were contacted, of whom nine parents, nine educators and seven healthcare professionals consented to participating in the interviews.

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[6] See Appendix B and C.

[7] See Appendix A for full version of the interview schedule.

As the study evolved, modifications to the recruitment procedure were made in response to cultural considerations, time and budget constraints, and restrictions to travel during COVID-19 pandemic. For example, some professionals were recruited during the RA's site visit to their workplace (under a different activity). These visits presented opportunity to establish trust with these potential participants, after it was explained to us that some professionals were, for cultural reasons, hesitant to be approached via phone or email. We found that in some cases, referrals through a trusted contact were perceived more favourably by the participants than our initial outreach through phone calls or emails. In these situations, careful considerations were made to ensure that recruitment aligned with ethical research conduct requirements.

4.5.4 Sample Characteristics

Parent participants. There were nine participants in the parent group, including six from QN province and three from TTH. Two parents were recruited through the CCIHP's database (P02, P04), while four parents (P01, P03, P05, P06) from QN were members of the local autism parent groups and recruited through referrals by local contacts. All three parents from TTH were recruited through referrals from the school their children were attending, where three professional participants were also working (E08, E09, H07).

Seven parents in this sample had young children between 4-7 years of age, and two parents had adolescent/young adult child (above 15). All parents were married and had obtained high-school diploma and above, five of whom having bachelor's degree. Although more mothers were represented in this sample, there was a balance of child's gender (five male and four female children). Detailed demographic information is provided in Table 5.

Table 5. Parent participant demographic characteristics

Participant Initials - ID (Province)	Age	Child's Age/Gender	Child's most recent diagnosis	Disability Certificate
Mother, H., 01 (QN)	36	7/M	Autism	Y
Father, H., 02 (QN)	37	4/F	Developmental delay	N
Mother, M., 03 (QN)	37	5/M	Autism	Y
Mother, M., 04 (QN)	39	7/F	Brain damage	N
Mother, H., 05 (QN)	35	4/M	Inconclusive	N
Mother, N., 06 (QN)	37	5/M	Developmental delay	N
Father, A., 07 (TTH)	56	21/F	Cerebral Palsy	Y
Mother, M., 08 (TTH)	51	15/M	Down Syndrome	Y
Mother, A., 09 (TTH)	33	5/F	Brain Damage (Pre-natal)	Y

Professionals Participants. The sample comprised of 15 professional participants (n=9 education; n=6 health) working in all major types of service providers in the two provinces (public, private, not-for-profit, self-employed) in both clinical and management roles. There was also a wide years of experience range between 2 – 40 (in disability services) and between 1 – 16 (intellectual disability specific). Most educational participants had background in psychology and education, and all health professionals received training in medical and health-related disciplines.

One participant, H., 04 who worked at local community clinic, was not included in the final sample for analysis, because her work role was primarily in providing health-related information for the families and not professional services. Detailed demographic information is provided in Table 6 (EPs) and Table 7 (HPs).

Table 6. Education professional participants demographic characteristics

Participant Initials - ID (Province)	Age/ Gender	Current professional role/position	Type of service provider	Level of Education	Years of experiences (in Intellectual disability)
D., 01 (QN)	31/F	Teacher	Not-for-profit	B.A (Educational Psychology)	8 (8)
V., 02 (QN)	29/F	Parent Coach, Teacher	Self-employed	Master (Psychology)	2 (2)
L., 03 (QN)	32/F	Social worker, Teacher	Public (Social Care Center)	B.A (Sociology)	6 (6)
D., 04 (QN)	40/F	Teacher,	Self-employed	N/A	3 (3)
T., 05 (QN)	33/F	Teacher	Private (Intervention Centre)	B.A, (Psychology)	6 (6)
H., 06 (TTH)	31/F	Teacher, Manager	Private (Intervention Centre)	Master, (Psychology)	9 (5)
Q., 07 (TTH)	32/M	Teacher, Job Coach	Private (Intervention Centre)	Master (Psychology)	5 (1)
T., 08 (TTH)	36/F	Teacher	Private (Semi-boarding centre)	B.A (Pre-K Education)	13 (13)
T., 09 (TTH)	39/F	Teacher	Private (Semi-boarding centre)	B.A (Accounting)	15 (15)

Table 7. Healthcare professional participants demographic characteristics

Participant Initials - ID (Province)	Age/ Gender	Current professional roles/position	Type of service provider	Level of Education	Years of experiences (in Intellectual disability)
O., 01 (QN)	30 /F	Speech and Language Therapist	Self-employed	B.A (Pharmacy)	4 (4)
L., 02 (QN)	30 /F	Primary Health Officer, Teacher	Private (Semi-boarding centre)	Nursing	8 (8)
L., 04 (TTH)	61 /M	Clinician, Manager	Public Hospital	M.D (Child Psychiatry, Rehabilitation)	40 (10)
D., 05 (TTH)	41 /M	Clinician	Public Hospital	M.D (Psychiatry)	16 (16)
S., 06 (TTH)	35 /M	Physical Therapist	Private	B.A., Rehabilitation	11 (11)
H., 07 (TTH)	28 /F	Clinician	Public Hospital	M.D (Rehabilitation)	3 (3)

4.6 Data collection

Individual interviews were conducted with each participant, based on an approved interview guideline. This interview schedule was semi-structured in format, including key questions and follow-up/probes that corresponded to the three research questions of interest. Following five pilot interviews with special education and classroom teachers (who were not part of the final sample), changes to the questions were made to improve clarity and appropriateness of the language use[8]. The final version of the interview schedule is included in Appendix A.

All but one interview was conducted via Zoom - an online video-conferencing platform with built-in recording function, with participants in Hue and Quang Nam while the researcher was based in Australia[9]. The research assistant arranged the interview time and location based on participants' preferences, including at home, at a quiet café, and at their workplace during weekend. The RA was present throughout each interview session to provide technical assistance as needed. also made considerable contribution to the interview process, by assisting the researcher with notetaking and reviewing the interview questions, during and at the end of each session, to make sure all questions had been covered for and followed up as necessary. For one participant who at the time of our interview was in France for a short-term residency, the researcher conducted the interview without the RA's attendance using Google Meet (another online platform). All interviews were conducted in Vietnamese and lasted between 50 minutes and 1 hour and 15 minutes.

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[8] The pilot interviews were conducted prior to the ethics approval process and thus these changes were approved.

[9] The researcher was not able to travel to Vietnam to conduct in-person interviews due to travel restrictions in both countries during the COVID-19 pandemic.

At the end of each interview, the researcher provided a verbal summary of the participants' responses; this was to give the participants opportunities to modify, add or retract, in parts or total, any responses they had given during the interview. Summarising participants' responses also proved tremendously helpful for me as a novice researcher. I was able to seek clarification and agreement from the participants regarding my summary, thus my understanding, of their responses. None of the participants decided to remove any parts of their response off record, while some provided additional information and made slight corrections to my paraphrasing. More importantly, having recorded my own summaries allowed me to later reflect on these initial interpretations and learn of my initial reactions, assumptions and potential bias while doing the interviews.

4.7 Researcher's positionality

My cultural, linguistic and educational background also shape my approaches to this research and throughout all stages, from collecting and analysing to making sense of the data. As a Vietnamese native who undertook under- and post-graduate training the U.S and Australia, I was familiar with western conceptualisation and understanding of intellectual disability, while also sharing the language, social and cultural heritage with the participants. My fluency in both languages allowed for a relatively smooth workflow, as I prepared interview schedules, conducted interviews, and reading transcripts in Vietnamese while coding, analysing and writing in English. This minimised the likelihood that cultural and linguistic nuances were lost in translation. This research presents more than a literal translation of data and findings including quotes, as I constantly and actively negotiated meanings and expressions based on my cultural knowledge and linguistic capabilities. Despite my best effort, this process inevitably adds another layer of interpretation to the presented findings.

When it comes to understanding about disability, however, my educational background, have rendered me distant from the participants and judgmental of my own culture. As the research progressed, I became increasingly aware that this background impacted my approaches in profound, unanticipated ways. For example, when designing the interview schedule, guided by the AAIDD's conceptualisation of intellectual disability and social model of disability, I purposefully added questions about the strengths of children labelled as intellectual disability, and positive changes brought to the families in raising and caring for these children. However, I found that so pervasive were negative attitudes associated with having a child with disability in Vietnam that it made these questions sound unusual and almost a challenge to ask. It took several interviews for me to find appropriate wordings of the concepts and questions. Bishop (2008) discussed this challenge as when the researcher, who was also a 'cultural insider,' became 'too close to the culture to ask the critical question.'

I also had to reflect on and work through my personal judgements where my own understanding of disability ran in contrary with participants' responses. Disability discourses produced in western countries are premised on the conceptual distinction between impairment and disability (X. T. Nguyen et al., 2019), and through the practice of keeping a research journal, I realised that I invariably used the term "intellectual disability" throughout the pilot and first few interviews, even when participants themselves did not. I reflected on this insistence as illustrative of my own presumptions, such that understanding about intellectual disability in Vietnam was lacking and its conceptualisation categorically problematic. Thus, to fully engage with participants and the topic of intellectual disability in my local context required the recognition of "cultural and historical conditions which shape such consciousness within the context of social change in the Global South" (X. T. Nguyen et al., p. 1056). It was only when I acknowledged that differences between western-based/English and locally relevant terminologies conveyed more meanings than just accuracy, that I started to ask participants: “Which terminology do you prefer to use?” and “Why?”.

4.8 Data Analysis

Audio-recording of the interviews were transcribed in-verbatim. The researcher listened to all recordings, checked again with each transcript for accuracy correcting as necessary, for example, mis-transcription due to difference in local dialects. This process of re-reading and listening also allowed the researcher to engage in the “data immersion phase” (Tracy, 2019, p. 213) and prompted instantaneous reflections and thoughts regarding preliminary themes.

The analysis process for this research is guided by the framework for conducting thematic analysis proposed by Braun and Clark (2006). The researcher also utilised an iterative approach, introduced by Tracy (2019) meaning that themes resulted from combining the emergent data with the researcher’s existing knowledge and research questions. This was described as a “reflexive process in which the researcher visits and revisits the data, connects empirical materials to emerging insights, and progressively refines his/her focus and understanding” (Tracy, 2019, p. 210). The decision to use the ecological systems theory, for example, was not made from the outset of the study but emerged after an initial cycle of coding revealed that mapping findings and potential themes and sub-themes into the intersecting systems well capture the relationships among them, such as family and professionals’ interactions and collaboration.

Two cycles of coding were conducted. In the primary cycle, primarily descriptive codes were generated concerning with “what” was present, such as actions, emotions, ideas and settings (Tracy, 2019). Little interpretation occurred during this process to retain as much as possible of the details and context, and keep the researcher open to multiple meanings behind the text. To manage coding at this level of detailed given time constraints, I adopted the recommendation by Tracy (2019) and completed highly thorough coding for six transcripts which represented the breadth of the data (one participant from each group - parent, education professional, health professional, and from each province). The next stage, secondary coding, focused on organising and synthesising the primary codes into interpretive themes and concepts (Tracy, 2019). During this stage, codes and themes were frequently revisited, contrasted with each other and revised to allow for new interpretations and perspectives to be considered.

Given the size of dataset, time and budget constraints, the researcher read Vietnamese transcripts and generated codes in English (without translating transcript into English or codes into Vietnamese). While I was not able to present the full dataset to my supervisors for cross-checking the codes, we reviewed and discussed lists of primary codes to identify potential directions and focus for coding the remaining data, as well as potential grouping frameworks. In addition, I discussed and cross-checked the emerging themes with the RA who, thanks to her involvement earlier, was also familiar with the dataset and contributed insights and new angles for my interpretation of the data. This also proved helpful in increasing reliability and reducing the researcher's potential bias reflected on earlier in the process of analysis and interpretation.

Chapter 5: Results

This chapter presents emerging themes from the data and structured as follow: (1) Understanding intellectual disability, (2) Access to and Provision of Health care and Educational services, and (3) Parents' and Professionals' support needs.

5.1 Understanding intellectual disability

5.1.1 Describing areas of challenges and difficulties

Across all participants, the most common areas of challenges and difficulties reported of children and young people with intellectual disability were in communication, daily and self-care activities, followed by limitations in learning and cognitive ability. Other areas of difficulties included attention, behavioural and emotional, interacting and playing with peers, social and community participation, motor skills, and awareness of safety.

There were some differences among parents and professional participant groups. Describing the areas their children have difficulties and/or need most support with, most parents mentioned communication, daily and selfcare activities, and language development, while difficulties in cognitive skills, in particular memory capacity, and learning were mentioned by only two parents. Many parents recalled having concerns over their child's language development, as the following quote illustrates:

> My concern is that she is not able to talk yet. She can walk now, which makes it a lot easier for me [to care for her], but because she does not speak, she is very hot-tempered. She will throw stuff if things do not go her way, she might bite or hit me. (M, P04, QN).

On the contrary, all education professionals listed difficulties in cognitive ability, such as poor memory capacity, perception and reasoning skills, and most mentioned difficulties in learning, communication and daily and selfcare activities. Low IQ was mentioned by five educators, but none from the other two groups. One educator noted in relation to learning and memory:

> I taught him to differentiate between the ox, the chicken, and the cat, just these three animals, but it took a very long time; for almost one year [the child] could not understand or remember which one was which. Each time I spoke a word he knew he needed to point to an image, but he did not know what I was talking about. (D., EP04, Quang Nam).

Similar to educators, the top three areas of challenges listed among health professionals were learning, cognitive ability and daily and selfcare activities, followed by behavioural and emotional, communication, and interacting and playing with peers.

5.1.2 Strengths of the children and young people

While most parents did not list specific cognitive abilities among areas of challenges for their children, many spoke of their child’s perception and ability to understand things. Among the skills mentioned were imitation, imagination, understanding and following instruction. Parents used such words and phrases that translated as “quick,” “intelligent,” “witty,” and “the older he is, the more he knows”, as illustrated in the following quote:

> She is very quick; sometimes when I ask her brother to bring me something, she gets it even before her brother. She cannot speak but she understands things and is very responsive (M., P04, QN)

Some participants mentioned strong emotional attachment, while one father listed “carefree” as his child’s only strength. Some professionals also described children with intellectual disability that they supported as being “nice and cooperative,” noting that this characteristic helped make supporting and providing therapy for these children easier and more effective, particularly in comparison with children with autism who were seen as more challenging to work with, as illustrated in the following quote:

> Autistic children are often more active and cannot sit still, or they might have defiant behaviours. Children with intellectual delay however are usually more compliant and they can sit at their place." (H., HP07, TTH).

5.1.3 A "normal" child

Throughout individual interviews as well as across participant groups, the reference to "normal children" was consistent in the way children with intellectual disability were compared to same-aged peers and children without the diagnosis. In a similar vein, mainstream schools were referred to by many participants as "normal schools" to differential with "specialised schools." While none of the participants explicitly described the children as "not normal," a sense of the children being seen as different and "lesser than normal" and the reference to lack of normalcy reverberated in this dataset; for example:

> Academic achievement is not important to us. The most important thing is that his understanding will improve. We do not need our child to become exceptional or anything. Just like a normal person would be enough. (N., P06, QN).

> Now she is able to walk and talk. If you just let her sit still, she looks like a normal person. (A., P07, THH).

5.1.4 Causes and risk factors

Most professionals mentioned genetic abnormality among the cause of intellectual disabilities. Many also mentioned factors affecting pregnancy, birthing complications, brain development, and other associated health conditions as resulting or contributing to the development of intellectual disability. Two educational and three health professionals listed lack of early intervention and learning opportunities and child-rearing practices among the risk factors.

5.1.5 Assessment and Formal Diagnosis

As indicated in Table 2, parents in this study had children who were diagnosed with a range of conditions, but none mentioned receiving a formal diagnosis of intellectual disability. Across the sample, a variety of terms were used in the children's diagnoses, including "language development disorders," "development delay," "autism," "attention deficit neither mild or severe," "brain development delay," and "motor development delay." Some parents mentioned that they had brought their children to multiple places for assessment, among whom some recalled that they got different diagnoses each time, and that their doctors either gave an unclear conclusion or said the assessment was "inconclusive" (H., P05, QN).

Similarly, three professionals recalled that diagnoses given to the children they worked with were "generic" and involved a range of different terminologies such as "at risk of developmental disorder," "language development delay," "motor development delay," "developmental delay." According to three doctors who listed providing assessment and diagnosis as part of their professional roles, assessments were based primarily on clinical observations, and more recently, developmental milestone test such as the Age and Stages Questionnaires (ASQ) after they received additional training provided by CCIHP.

> Assessments conducted [at my department] does not involve many professionals, and we assess the level of developmental delay in a quite subjective manner. I used some tools that I learned from training with foreign experts […] Other staff at the department were trained to use different tools […] The hospital does not require we use a particular tool. It depends." (D., HP05, TTH).

5.1.6 Making sense of the diagnosis

Use of Terminology by professionals. "Intellectual disability," and "Intellectual development delay" were the most common terminologies mentioned by professional participants. When communicating with parents about their child's diagnosis, four professionals said they used "intellectual disability," while eight professionals stated that "intellectual development delay" was the more common and preferred term among themselves or other professionals. Most professionals purposefully chose one term over another, or switched between the terms flexibly, to make it easier for parents to understand, as well as to avoid "hurting parents' feelings," regardless of which terms they actually used. One professional explained:

> The word "disabled" sounds too painful for parents, so I rarely use the term. I use "development delay." Parents will think that: "My child is delayed, I need to support my child, I will play with her, I will teach her, my child will get better, even if not comparable to other peers." (T., EP05, QN)

Two other professionals shared the above view that "development delay" appeared more hopeful and encouraging for parents as it signalled potential for progress. This was an obvious contradiction to another professional's choice:

> I think that "intellectual disability" is a "milder" term than "intellectual development delay". When I use this term, I think parents will find it easier to accept." (H., EP06, TTH).

Some professionals did not have strong preference as they believed the two terms were conceptually similar and equally understandable to parents. Still some professionals thought neither term was specific enough to help parents make sense of the diagnosis and added that they used other terms or tried to offer more detailed explanation to parents. The following excerpt captures how intellectual disability was variably referred to by professionals in the field:

> Researcher: What do you think is the more common terms used by teachers?

> Participant: We use intellectual development delay. We also use retardation, and we also use intellectual disability. It depends. There is not a rule that says what terms should be used within an institution (L., EP03, QN).

Perhaps not surprisingly, the diagnoses and conclusions provided by professionals left some parents confused and sceptical, as described in the following excerpts:

> They [parents] want to know why their children exhibit these symptoms, why this, why that; but most questions are left unanswered, because [the professionals] cannot classify the disability. (D., EP04, QN).

> To be honest, I brought my child to the doctor just for the sake of going somewhere…having an assessment. I did not get anything from them […] Even in Da Nang, there is no professional who has the expertise that I can trust to assess my child. (N, P06, QN).

Despite the confusion, most parents felt that the term “slow/delayed” accurately described their children’s intellectual development. This included the only two parents who spontaneously used the term “intellectual disability” in their responses, noting that it meant their child were slower compared to other children. This was also observed among parents who earlier described their children as having good understanding and cognitive skills, as illustrated below:

> She is still slower/more delayed… than normal children. She is better compared to other children with disability or those attending her [special] school, but compared to other 5-year-olds, she is slower. Other children might already know the letters and how to read, but she only knows little. (A., P09, TTH)

Similarly, many professionals referred to developmental milestones, indicating that children with intellectual disability’s development were equivalent to children at younger age and "delayed/slow" compared to same-aged peers. One health professional explained what he meant by "slow/delayed,"

> It means in comparison with their chronological age. For example, the child is two years old, but she is slow/delayed compared to other two-year old children. Or a child at five learning to do things that a three-year old can [already] do." (S., HP07, TTH).

5.1.7 Classification and severity level

Six professionals mentioned that severity of disability was used as a basis for determining the types of educational and healthcare interventions for children with intellectual disability, either by themselves or as reflected in the existing services. One professional based her judgement on IQ score, another on independent/selfcare skill level, and two others were not explicit in how they classified functioning level. According to these participants, "milder disabled" children were considered capable of learning and likely to attend mainstream schools or vocational training. On the contrary, educational services for more "severely disabled" focused more on teaching daily and selfcare skills, with an expectation that the children would require life-long support provided by the family or inside boarding institutions. Some participants indicated that social welfare institutions in both provinces typically served children of all ages who were considered as having "severe" disability, regardless of specific conditions.

5.1.8 Obtaining a certificate of disability

Five children in the current sample had a disability certificate. The other four parents cited different reasons for not applying for a certificate for their children, including feeling that it was not necessary at the moment, not having the time to go through the process, not knowing how to do it, or being told not to do it. Parents reported that having a disability certificate signified a "pitiful condition," as one mother of a 5-year-old boy recalled being told by people at the local administrative office that she should not try to get a disability certificate for the child but wait “for several years because he might know things better” (H., P06, QN). An educator spoke of similar observations among parents she had worked with, who “did not want to say that their child has a disability at the moment” and decided to “wait until the child is older to see if the condition persists” (H., EP06, TTH).

According to four professionals, three of who were directly involved in the process of assessment and diagnosis, having a diagnosis from the hospital was a necessary step in obtaining a disability certificate. Based on this diagnosis and other criteria, a local disability council regulated by the Ministry of Labour, Invalids and Social Affairs (MOLISA) determined whether the child and their family were eligible for this certificate and the benefits entitled to certificate holders. Professionals and parents provided mixed responses regarding the process, indicating that while it was easy and straightforward in some cases, many parents found it complicated and time consuming, and encountered difficulties in dealing with the council and the issuing offices. For families that managed to obtain a certificate, the outcome of the process appeared unconvincing and unfair, as the following quotes help to illustrate:

> Parents would compare their children with other children, and they complained to me: My child is more severely [disabled], why am I receiving less allowance than them? (L., HP02, QN).

One notable case was of a mother of a child with Down’s Syndrome who obtained a certificate of “mobility disability” because the child was unable to walk or stand at the time of assessment. Later on, the parent decided not to pursue another assessment, concerned that it might result in a reduction of the allowance they were currently receiving because the child had then learned to walk.

Having a disability certificate also ensured that the children were entitled to admission to and additional support at mainstream schools, for example in the form of reduced or modified curriculum and assessment criteria. However, some parents and professionals were concerned that these supports were only tokenistic, resulting in the children's learning progress not being monitored or counted towards the school's achievement, and lowered quality of teaching.

> The schools cannot say no to us because T. had a disability certificate […] They [the school] told me that as long as my child behaves well and not interfere with the learning and teaching experience of the entire class, then he can attend the school. But how much he could learn depends on himself and the parents (H., P01, QN).

5.2 Access to and Provision of Healthcare and Education services

5.2.1 Disability policies and social welfare

Most participants were aware of the healthcare benefits, particularly health insurance, and monthly disability allowance available to children who were certificate bearers. Most parents and professionals spoke favourably of these sources of support, with some highlighting that the policy was "very good" and "a tremendous help for the family." Of five certificate holder families in this sample, all mentioned receiving health insurance, which covered most healthcare cost for their children, and four parents mentioned receiving monthly allowance. Three professionals working at major public hospitals in TTH, however, discussed how the current insurance scheme limited their ability to provide optimal care and services. For example, payment being capped at a very low level, which was insufficient to cover the cost for occupational therapy and interdisciplinary intervention, which they believed were essential for children with intellectual disability.

5.2.2 Education at mainstream school

Parents and educator participants believed that attending mainstream schools benefited children with intellectual disability by providing them with opportunities for social interaction and learning skills from other peers. However, many children were either denied access or admitted to school without receiving appropriate educational instructions; some subsequently dropped out or were later expelled. One participant described the inclusive education experiences of her student:

> There are 30 students in a class, so they leave behind the child who cannot catch up […] The teachers are not able to teach them, they receive bad marks, and drop out by grade 3 or 4. The school no longer accepted them, so they went back to us, or other specialised centres (L., HP02, QN).

Children with intellectual disability who attend public, mainstream school could be placed either at separate classroom with other students with special needs, or within a mainstream classroom with students without disability. While none of the educators in this study taught at mainstream class, some have had students attending these schools and were concerned about the low quality of teaching instructions provided.

> They create pressure or make it very hard for them to learn. Some students at my school have attended mainstream school. They have yet to get used to the school schedule and do not know where their classrooms are. But the teachers do not care if students don't show up. (D., EP01, QN).

All but one educator discussed the lack of special education teachers to provide additional support and instruction for the child as well as classroom teachers.

> Even if the parent can afford a support teacher, there would be no one to do it. We don't have the human resources. Then the school also would not accept the presence [of special education teachers] (T., EP05, QN)

Two parents and their children were rejected admission by local school, and one gave an account of her child's experience:

> "The teacher did not help, so my child just stood and watched other children dancing from the corner. She knew what they were doing but she could not do the same. [When I see this] I feel pity for my child." (M., P04, QN).

Three participants noted an encouraging change in the number of students attending mainstream schools and schools being more open to inclusive education. At the time of interview, three parents utilised a hybrid approach of mainstream day-care centre and private, individualised intervention afterschool, and two parents were hoping to transition their children into mainstream schools and later to transition to employment:

> I hope he could go to a mainstream school nearby. If not, he can stay at the special centre. I will teach him to read, then vocational training. I know that a school for my child is a difficult [task], lots of work…I do not know if my wish will come true. It is just my wish, just my dream. (M., P03, QN).

5.2.3 Professional disability services

Types of services. Most participants discussed some types of "can thiệp" (intervention) services for children with intellectual disability. Among the frequently listed specific types of intervention were language intervention, physical rehabilitation, occupational therapy, and early intervention. These interventions were typically provided on an individual (one-on-one) and hourly basis, either at home or at a specialised centre - commonly referred to as "trung tâm can thiệp" (intervention centre). One professional described her work at an early intervention centre:

> We provide individual intervention, either on an hourly basis or for full day. If the child only has language delay, they attend the centre for an hour and spend the rest of the day at the mainstream kindergarten. Within this one

> hour, we focus on skills such as fine motor, language, and cognition, attention, or imitation (T., EP05, QN)

According to participants, semi-boarding (day-care) services were also offered to children with intellectual disability and families in both provinces. Professionals mentioned institutional care as an option often reserved for children from poorer households, children with more “severe” disability, and within a wide range of age and disability types, where the focus was more on taking care of the children during the day rather than providing specific types of intervention/therapies, compared to the hourly services. According to a healthcare professional working at a social welfare centre that took care of 47 students with disability and victims of Agent Orange:

> In the past 8 years, we mostly provided day-care services. For example, we know their characteristics, and we teach them how to behave. Not specific about what they need to learn, or who learns to do what…nothing specific. (L., HP02, QN).

Eleven professionals and two parents from both provinces observed that many children with intellectual disability did not receive any types of professional support or services. Eight professionals discussed the views held by many parents of children with intellectual disability as hopeless, incapable of learning and efforts spent on interventions as futile, which explained why they did not pursue professional services and support for the children. Many children were kept at home alone, with grandparents, or left to their own device:

> I have met children who…I think that the children would fare much better had they received early intervention. But because of the home environment, especially if the family is poor, they just neglect the child. (L, HP06, TTH)

All children of parent participants in this study were, at the time of interview, having access to professional support and services, and none had ever attended boarding centres. Six parents mentioned that their children had been or were attending semi-boarding (day-care) services, and four parents utilised individual, hourly intervention services. Most parents also implemented some form of home-based interventions and teaching strategies for their children outside of intervention hours. For parents of younger children in particular, there was an overwhelming sense among these parents to invest in early interventions and try to hold on as much as possible, while a long-term vision for their child was either too uncertain or "not planned/thought of," as the following quotes demonstrates:

> We try to work to make enough money to pay for his tuition, month by month, so that he can develop better. We don't have a plan. (H., P05, QN).

Two parents who had adult children and professionals who worked with older students recognised the needs and aspirations of grown-up children with intellectual disability and regarded these as distinctive needs from those of younger children, particularly relating to puberty, relationships and sexuality. One mother was concerned about her young son's sexual behaviours, while one father spoke poignantly of his daughter's having limited socialisation with same-aged peers and an "invisible need" that she was not able to verbally express: frustration for not being able to verbally express her needs:

> Her interaction with peers, especially the boys, is very limited. Normal friends will not befriend her [because] they go to university and they have other things to do… Honestly, I could feel that she really wanted to be just like her peers, to be able to go to university, ride a bike, do this and that. but she cannot describe it (A., P07, TTH)

There was a general impression from both parents and professionals that services and support for older children were severely lacking. Limited options together with the family's inability to cope with the children's evolving needs resulted in many children dropping out from school, ended up inside institutions or being left at home as reported earlier. Against this backdrop, there was also ample discussion regarding vocational orientation and training for older children from both groups; while some models of vocational training and supported employment were listed, many parents and professionals saw this as a persisting gap in services and support.

Availability, quality and sustainability of professional disability services. There were positive changes in recent years observed by a small number of professionals from both provinces, including an over increase in the number of service providers serving children with intellectual disability and their families and improved knowledge among healthcare professionals. However, most professionals described current services available, either at their own institutions or other places, as inadequate or ineffective, and not meeting the needs of the children and the families. One clinician who also held a leadership position at a hospital in TTH expressed concern of the nascent stage and the lack of comprehensive intervention services provided at his department:

> Honestly the capacity of our department is at the very beginning stage, very limited […] Sometimes we want to provide occupational therapy, but we are limited in how much we can provide. Because it is not covered by the insurance, but we [professionals] find it extremely unreasonable to deny occupational therapy to children with intellectual disability (L., HP04, TTH).

This finding was confirmed by most parents, who believed their children were not receiving optimal care and services, including less than optimal hours of services and teaching strategies too demanding for the child, and because the centre was not accessible for children who also required mobility support. Parents utilised the current services because there was "no other option available" and because "professionals at the hospital said they could no longer offer any help, so I have to find a way myself.” Many participants in QN seemed particularly concerned about the extreme lack of services available in this province. Some professionals were also concerned about sustainability of services, citing the project-based, short-term nature of programs funded by charity foundations or not-for-profit organisations, and lack of reliable financial resources:

> We do not receive support from the government […] We do not have a long-term financial source, so we keep mobilising from different places…We’ll just have to see how it goes (L., HP 02, QN).

Some parents believed that the centres were not providing appropriate intervention tailored towards the specific needs of their child, even when they paid (supposedly higher fees) for individualised intervention. This was illustrated in the following quotes from two parents, both in reference to the same intervention centre:

> There are too many special needs kids at Morning Star.[10] They have very severe disability (H., P05, QN).

> Morning Star was the only option left. They take care of the children during the day so that parents can go to work. They do not provide any intervention services at all, but parents are paying the same fee as they would for intervention.” (H., P01, QN).

Geographical location and environmental factors. According to eight professionals, intervention services were primarily located in urban central areas or bigger cities such as Ho Chi Minh City, Ha Noi and Da Nang. Most parents and children in this sample had or were currently using services that were located far from their home or in other

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[10] Name of the center has been changed.

cities. One parent recalled the time her child was separated from the family to attend a special centre in the city:

> […] for three months, it was a very difficult time for us. His grandmother went with him, took him to the centre and picked him up every day. They stayed at one of our relative's house. My husband and I travelled to the city every other day and spent the evening with him. (N., P06, QN).

Both professionals and parent participants cited location of services a significant concern, particularly for most parents from rural and remote areas. Two professionals mentioned harsh weather conditions and poor road system further exacerbating the difficulties encountered by families. For many parents in this sample, geographical barriers limited their ability to choose a service provider for their children, especially as they consider professional services and support for their child a long-term necessity, as one mother recalled:

> They [the grandparents] urged me to try different places in Ha Noi or Da Nang. But I tell them: Where to go now? We need money and time; it is not a matter of a day or two that he could learn and get better (H., P05, QN).

Cost of services. The cost of private professional services reported by participants in this sample ranged from AUD 70-300 per month for day-care/semi-boarding centre and between AUD 8-15 per hour for individual intervention[11]. This cost range was much higher than what most families in these provinces could afford, as the following quotes illustrate:

> For an hour of therapy, the parent needs to pay [our centre] AUD 8. But that's what they make for a full day of living, so they cannot afford the intervention. There will be no food on the table (H., EP06, TTH)

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[11] To put into context, the highest reported amount of monthly allowance entitled to children with disability/carers included in this sample was AUD 39 – thus equivalent to just five hours of therapy.

According to one mother who paid for the most expensive types of interventions locally available, which amounted to nearly AUD 600 monthly:

> This was doubled my wage. Only one out of one hundred households would be able to afford this. Not many people could afford this much to accompany their child to access intervention (H., P01, QN)

Almost all participants considered financial resource a determining factor of whether the child had access to professional support. Some forms of services such as parent trainings, hourly intervention and personal support teacher at mainstream school were only available to families who had the "condition" – commonly referring to financial resources in Vietnamese culture. Except for free health services at public hospitals covered by insurance, all but one parents in this sample mentioned paying out-of-pocket fees, in part or full, for their children's private services which created a huge financial burden for their families.

From the professionals' perspectives, lack of investment in public services and the fact that families were not being able to pay any higher also created financial constraints limited their ability to provide higher quality services for their students/clients. According to an educator and manager at a private centre:

> It is difficult for the public schools because there are only two teachers for a class of 30 students. They can only look after students with disability but not teach them well, apparently. Perhaps ideally it would two teachers taking care of three children, but it means the family has to be in good financial situation to pay for [private] education. Otherwise, they have to go to public schools and it goes around in a circle (H., EP 06, TTH).

Another health professional shared the view that affordability was the major obstacle to comprehensive, interdisciplinary care:

> Interdisciplinary care is not covered by the insurance, so the cost would be multiplied many times. Working in the public sector, I feel sad because I want to do so much more, but the facilities are not available. What to do when patients are not able to afford the services? (D., HP05, TTH).

5.2.4 Human resources

Many professionals identified shortage of professionals working in the public service system (i.e., hospitals) as well as private intervention centres as a barrier to provision of intervention and services for the children and family. Participants were particularly concerned about the qualification and expertise of the current workforce, which they attributed to lack of formal training. According to seven professionals, attending short training courses and on-the-job training were the primary mode of training for the majority of staff working at hospitals and private centres. Healthcare professionals particularly find intervention/healthcare services for children with intellectual disability/delay an unfamiliar area of expertise in Vietnam and that the current emerging workforce lacked the training and experiences to support the children:

> There are many challenges, but first and foremost we lack a workforce with standardised and formal training. At my hospital, the last five to seven years we could not recruit any new doctor (L., HP04, TTH).

Some educators were also concerned about the current recruitment practice at some private centres that set the bar very low for who could enter the workforce, as demand for private services increased:

> They recruit anyone who were willing to work with the children and train them to become a supporter. They might attend short courses… I am not even sure if they do… Most of them do not understand that it was important

> for them to have more knowledge. They did not want to give up a working day and not getting paid (D., EP04, QN).

One educator described the training experiences of her colleagues and herself at the centre:

> We do not have expertise from special education or psychology or anything, we just learn from the courses, lasting for several days, and other skills to support the children (L., EP03, QN).

According to many professionals, shortcomings in skills and expertise of the workforce seriously undermined the quality of services that children with intellectual disability and their families were receiving, such as in diagnosis and assessment and working with parent. Another educator described the service her students and their parents received at a hospital:

> [The nurses] were working in a different role and position, so I think they did not have the understanding and empathy […] The child was crying or not cooperating, but they just let them be. Parents complained that they had come a long way to get to the hospital, and it was such long-term commitment, but the staff did not do anything to interact with the child and just let them cry (D., EP01, QN).

This was also true for children attending mainstream schools, as classroom teachers did not have the training and skills to support children with intellectual disability in a mainstream/inclusive environment.

> We worked hard to help a child attend mainstream school. We think that the child was ready for mainstream education, but they do not receive support there, so they returned to us. And once they were here, they were not going [to mainstream school] again. I think that wasted a lot of time.” (H., EP06, TTH).

5.2.5 Safeguarding the quality of services

There were challenges relating to disability policies raised by many professionals that affected the provision and quality of services provided for the children and their families. There was a recognised need among professionals for comprehensive disability policies that involved Ministry of Health (MOH), Ministry of Education and Training (MOET), and MOLISA. However, according to some professionals, there was no clear delineation of responsibilities and a mechanism for collaboration among ministries involved, resulting in confusion of roles and a lack of top-down, consistent regulation. In both health and education sectors, there was a lack of nation-wide and coherent approach to guiding, managing and ensuring the provision and quality services for children and their families. This included the lack of a common protocol for diagnosis, treatment and support; regulations and quality standards for service providers; and competency frameworks for professionals. Some professionals believed this was concerning as more centres were being establishing without being subjected to quality control. The following excerpts illustrate the numerous issues with current policies and legislations regarding provision and quality of disability services. Four professionals and one parent felt that services and support for children with disability was a "neglected" issue in the agenda that lacked adequate attention and investment from local governments. Some professionals also felt there was a lack of long-term vision and clear strategies in existing policies at national level.

> The policies are not clear, either at our provincial and national level. Children with intellectual disability are included in this program for people with mental illness. But [the policy is not very clear, and it ends this year (2021). We are currently drafting…a new program, to extend the previous program (L., EP03, QN)

The following excerpt was from an educator who was also a social worker actively involved in the works at the social welfare department:

> The centres are registered as social care institutions, not as education or healthcare providers. The education department does not know how to organise educational services so that the children can go to school; the social welfare department also has no idea how to support (D., EP04, QN).

As professionals themselves found confusion and ambiguities in the policies as well provision of services, parents also talked about being at a loss to know what to do and where to go to find support for their children and themselves.

> I do not know which services to go to that would be right and appropriate. Nobody shows me and I do not know any place. Even if I think about it [the types of support I need], what is there to think about? Where can I find people that can help me?" (M., P04, QN).

Some professionals also shared the same impressions about how the lack of coherently and nationally regulated treatments, protocols and policies left parents without any sense of direction as what steps to take upon finding out about their children's challenges:

> If I were a parent, I did not have knowledge like the professionals, so I would go to one place after another by myself. Autistic? Let's go an intervention centre. If they asked me where they should go first, I can't tell them. Everyone knows we need to go somewhere, but who is responsible for putting everything in place together? Nobody. (D., HP05, TTH)

5.2.6 Family and Professionals interactions and collaboration

Nine professionals mentioned collaboration with the family, mostly parents, as part of the services and support they provided. This included working with parents to set goals for intervention, exchanging information about lesson plans, and providing instructions for parents to implement intervention activities at home. Two parents similarly described their active and collaborative relationship with the professionals at special schools. Three parents considered working closely with classroom teachers as integral to their child's education at mainstream schools. One father recalled:

> When she first started school, lunch time would take almost an hour. Then her mother showed the teacher how to help her eat more quickly… how to do it better…Then there were obvious changes. Her eating has improved a lot since the last month (H, Parent 02, QN).

However, six professionals said that many parents did not work with them or were not actively involved in the child's education and intervention, which impacted the overall effectiveness of the therapy, particularly the opportunities for children to receive home-based intervention, as demonstrated below:

> Because of life [matters] not many mothers have the time to take care of the child. The treatment depends on the child having opportunities at home to practice and reinforce, in addition to time spent at the hospital, but this cannot be guaranteed (L., Health professional 04, TTH).

Parents' high expectation on the professionals and outcomes of intervention was cited by six professionals as a challenge for their work. Many parents might not fully understand their children' areas of challenges, and perceived the intervention as taking too long to achieve the goals that, from the professionals' perspectives, appeared unrealistic:

> Their [parents'] understanding of the child…is very far from ours [teachers]. I did not tell them that their child was too slow or anything, I just said the child had many difficulties. Still they wouldn't accept. They asked: "When will you teach my child to count to 100 or do addition to 100?" or "Give us a specific time after which my child can do this and that." They made such requests for a child with learning disability and poor memory (V., E02, QN)

5.2.7 Parents' skills and knowledge

A number of professionals felt that parents lacked understanding of their child's difficulties and support needs and the importance of intervention/professional intervention, and showed concerns of its impact on the types and quality of services their children could receive. This included seeking various treatment methods which were not supported by evidence or did not recognise their role in implementing some activities or interventional strategies at home. Most notably, professionals pointed to the views of parents and other family members that the child's challenges were not worthy of concern and attention, and that their child would improve naturally and gradually over time. One professional described:

> They do not think of the child as having a disability or a condition of some sort. They think that the child is slower, that the child will gradually change and get better. Then when the child is older, but they do not know what to do next (S., HP06, THH).

This finding was confirmed by five parents in this study who said they used to not understand the areas of challenges for their children and how to support them at home. One mother shared how she had to rely on the school to support her child who had brain injury:

> I thought I would bring her to the school for children with autism. I gave her to the teacher. I did not know where to look up on the internet, what to teach my child, how to teach her, so I just brought her to the school (M., P04, QN).

Just as lacking knowledge and skills was seen as interfering with parents' seeking and engaging in intervention services, activities such as training and coaching to improve parents' awareness, knowledge and skills were well received by parents and professionals. Parents who have attended parents training described feeling more confident in interaction with their child at home and contributing to their child's progress. One father described the changes in practical skills as well as mindset after his wife and himself attended parents' training:

> It was a big change. My child used to have many health issues, so we were reluctant about going out. But after the training course, we realised that … between the two concerns, we would need to choose to take her outside for social participation (H., P02, QN).

5.2.8 Working and Care-giving trade-off

Another prevalent theme raised by most participants concerned parents facing the choice between going to work and taking time off to care for the child with disability. The impacts of this trade-off on the children manifested in several ways. At the most direct level, parents simply left the child at home or chose a boarding/semi-boarding centre that would take care of their child while they were working. There was also a conflict between parents' working hours and when opening ours of the centres. Four parents or their spouses decided to leave their current employment to be able to care for and accompany their children to attend services. These families were then put under strenuous financial pressure to pay for the high cost of intervention, as described early, while also losing part of their income. A mother's elaboration on her decision-making process clearly showed how the difficult situation troubled her:

> I was both working and taking care of the family, so I did not have much time left to teach her and had to leave her to her father. I even planned to quit my job, but if my time is spent on just taking her to school and picking her up, how could I pay for her tuition fee? (M., P04, QN).

Some professionals expressed concerns that parents' work commitment interfered with their engagement in and collaboration with professionals, and affected parents' attendance at trainings that could help improve their knowledge and skill.

5.2.9 Parent group and support network

Most parents found peer group and support networks significant sources of information on a number of topics relevant to disability, including information and recommendations for where to access services, strategies to teach and take care of their children, parent training opportunities, and connecting with professionals. These groups varied in size and format, including an online parent forum (national), a local club of parents of children with autism, online group formed among parents attending a parent training, and among parents whose children attended the same intervention centre.

Besides informational opportunities, parents also mentioned psychological benefits from connecting with other parents and sharing experiences, such as celebrating their children's new achievements. One educator described how parent groups served as a focal contact point, through which she could pass on useful information to other parents who were more hesitant in their interaction with professionals. A few participants also mentioned that shame and stigmas associated with intellectual disability caused some parents to refuse to join the network, and smaller-sized groups was a more feasible format for the parents to join.

5.2.10 Stigmatisation and social isolation

Parents generally felt that their family was accepting of the child and received some form of support from their families and colleagues. Four parents proactively took the chance to disclose their child's diagnosis and challenges and sought support from other people while caring for their child. However, based on professionals' observations and parent participants' own accounts, many families tried to conceal their children's disability due to self-stigma, shame and fear of isolation. Some parents recalled situations when other parents feared that their child might imitate or be inflicted with the bad behaviours, thus prohibiting the children to play with each other. One adult child with Down Syndrome was often asked to leave social events because people "didn't like him there" (M., P08, TTH). Other people's staring and commenting at the child was a quite common experiences when the family were in public space. This caused hesitation among parents to take their children outside and participate in community/social activity to avoid the gazes on their child or themselves, as the following quote demonstrates:

> At first my wife and I were both having some psychological [issues]…having a child with a condition like that. We were hesitant. It's not that we were [ashamed]; we feel worried for her and it hurts when people would stare at her… so we rarely took her outside (H., P02, QN)

Some educators mentioned that parents of other children see students with intellectual disability as negative influences and objected to their admission to mainstream school. Some professionals also mentioned that intellectual disability was perceived by local people as resulting from moral wrongdoings committed by the family. Three professionals, however, also noted slight changes towards more positive attitudes and acceptance among local communities in recent years.

5.3 Support needs expressed by parents and professionals

5.3.1 Supporting the child at home

Many parents expressed the needs to enhance their own knowledge and skills in order to better support their children at home. Three parents suggested in-person training classes/courses where they could learn about intervention and teaching strategies to address their child's specific needs, possibly inspired by their positive experiences at the training provided by CCIHP. Two parents suggested information provided through other platforms and formats such as videos, phone consultation, and website. A father of a young girl with cerebral palsy discussed how an informative website could help increase access to support for children and parents:

> My child has cerebral palsy, other children might have Down's Syndrome or other conditions, so we will consult with the professionals and post the information there for everyone to read. It will be very useful. Many families

> are hesitant…or maybe due to family situation they do not go to the hospital… They can read and do [these rehabilitation exercises] at home for their children, that would be better. (A., Parent 07, TTH)

5.3.2 Professional support

Most participants expressed their wish to access more professional support and services in the forms of intervention and therapies. Regardless of the ages of their children, most parents envisaged a local specialised centre that would provide the services and intervention appropriate and tailored towards their needs. For some parents, such a centre would enable them to go to work while being assured that their children were properly taken care of. One working mother of a child with mobility support needs described her ideal place:

> [If my child can stay there] from the morning until the afternoon, they will take care of her daily needs, such as eating and hygiene, teach her new skills. That would be very nice (A., P09, TTH).

An educator shared her similar vision of a centralised service centres that provide comprehensive care and support for children with disability:

> […] where the children can learn; older children with autism or intellectual disability will learn independent skills, or receive employment support or vocational preparation of some sorts… There will also be other supporting services from the government available there (D., EP04, QN)

It was notable that the way participants described their ideal one-stop service centre did not suggest a sense of lack of engagement or reliance on professionals. Rather it was borne out of the hope that services would be available for children when they need it, as reality did not seem to offer many viable future pathways:

> A centre established by the government that will care about children who cannot attend primary school, to provide vocational training for older

> children. They might stand a chance to live independently…But if the situation remains like this, it is like there is no way out […] (H., P01, QN).

5.3.3 Social welfare and benefits

Four parents expressed the needs for financial support through increased allowances for their families as well as other families with a child living with disability. Four parents who did not mention a need for financial support were also families currently not receiving welfare benefits and whose children did not have a disability certificate. One father talked about increased funding for the school his child was attending, along with professional support, such as in helping teachers preparing better lesson plans, as the most practical ways for supporting his daughter. Finally, two parents talked about increasing health insurance coverage to account for the children's additional healthcare needs, along with other benefits such as priority room at the hospitals.

5.3.4 Communication to raise awareness

Three professionals talked about the importance of having communication strategies and campaigns to raise awareness and understanding about disability for the local community. The increased presence of children with disability in public space and familiarity of the community with disability, according to these professionals, could facilitate understanding and raise expectations of the child's capability, which in turn can influence parents' willingness to pursue support for their children

> When the parents are on their own, they might think that their child is different, that nobody else [is having the same condition]. But when they are exposed to information, they understand better and they think: This is okay, there are other children like my child. (S., HP06, TTH).

For two mothers, raising awareness and understanding was important so that the school and the community became an accepting and safer place for their children to join in.

> I fear of the dangers in the outside world for him… I hope…the society will have better support for children like my child. If he happens to break something in the public, they will know that my child is autistic, they will forgive him (M., P03, QN).

5.3.5 Professionals' support needs

The most pressing needs expressed among most professional participants was having more training opportunities to enhance professional expertise, knowledge and skills for themselves and other staff. Four professionals also mentioned having access to other experienced experts who could support them. For most participants, an important area for further training was in teaching and intervention strategies and approaches specific to the needs of children with intellectual disability. One clinician and lecturer suggested:

> I want to attend courses so that I can develop curriculum for my teaching that incorporates knowledge about intellectual disability. For example, most people know about interdisciplinary collaboration, but [we need to know] about the specific needs of children with intellectual disability (D., HP05, TTH).

> A course specifically about teaching strategies. I learned from a recent course that we need to make plan, from simple to more advance goals, we need to speak slowly and repeat ourselves. These are kinds of things I want to learn about (L., EP 02, QN).

Chapter 6: Discussion

This chapter discusses the reported findings and further examines their meaning and implications through theoretical lens. Firstly, it is argued that parents and professionals' conceptualisation of intellectual disability featured elements of the medical and psycho-educational perspectives of intellectual disability, as well as the medical and pathology-based model of intellectual disability that dominated the field of intellectual and developmental disabilities in the past (Wehmeyer et al., 2017). Next, ecological systems theory is utilised to examine response to intellectual disability, specifically the current state of services, and how factors at multiple-levels and their interactions contributed to enabling or creating barriers for families to access adequate and quality support. This is followed by discussion on family support needs and implications for future practice. Limitations of the current study and suggestions for future research will also be discussed.

6.1 Current perspectives on intellectual disability in Vietnam

Schalock, Luckasson, Tassé, and Verdugo (2018) described four current perspectives in understanding intellectual disability, namely the biomedical, the psycho-educational, the socio-cultural and the justice perspectives, with each perspective representing different worldviews and providing a basis for explaining intellectual disability, understanding associated factors, and making decisions regarding intervention and support provision. This study found that participants viewed intellectual disability as originated from a combination of genetic/physiological causes and psycho-educational risk factors, similar to the perceived cause of disability reported in Dexter et al., (2009), D. Hoang (2017) and Trinh et al., (2011). The biomedical and psycho-educational perspectives seemed to underpin participants' understanding of intellectual disability, particularly regarding the presumed locus of disability, identification of risks factors and types of classifications (Schalock et al., 2018). Challenges in communication were frequently noted, as in earlier research (Dinh, 2015), along with challenges in cognitive abilities and daily/self-help activities. Levels of adaptive functioning (*severe/very severe* versus *mild*) and IQ score range were often employed in the healthcare and educational systems as the basis for determining the services children received, with children seen as having more severe disability often ending up in day-care or boarding institutions (Rydstrom, 2010; Trinh et al., 2011). Also congruent with the psycho-educational perspective was the participants' emphasis on improving parenting skills and access to special education as primary forms of intervention and support.

Although this sample contained a small number of participants in each group, they were consistent in describing the children as developmentally delayed. Children were also compared with other "normal" same-aged peers in terms of what they could and could not do, suggesting that participants view the children as failing to achieve biological, intellectual, psychological/behaviour milestones as well as societal norms expected of them. Bogenschutz and Liang (2016) found that ascribing to normalcy was prevalent in the construct of a good life for people with disability by parents, professionals, and people with disabilities themselves. In this regard, understanding about intellectual disability in Vietnam also appears congruent with the earlier pathology-based perspective, described in Chapter 1, which views people with intellectual disability as defective and different (Wehmeyer et al., 2017).

This study further shows that description of intellectual disability by Vietnamese parents and professionals primarily centred around the limitations of the children in various domains, while understanding about their strengths were more limited to characteristics such as being carefree, compliant and cooperative. While several specific talents were listed, they did not seem to be tied into a holistic consideration of the child's development and support needs. In a similar vein, approaches to goal setting and intervention programming/planning for children were often based on professionals' assessments of capacity, such as measured against typical developmental milestones or what the child could and could not do. These findings are consistent with existing portrayals of children with intellectual disability in earlier research, particularly regarding the centrality of challenges and limitations in conceptualisation of intellectual disability (D. Hoang, 2017; Rydstrom, 2010; Trinh et al., 2011).

Deficit-driven and pathological-based perspective and a presumed internal locus of disability implies an approach to entry to community life that is based on "readiness" (Thompson, Wehmeyer, Shogren, & Seo, 2017). Within this approach, it is assumed that people with intellectual disability need "to be taught and to demonstrate prerequisite skills prior to having access to settings and activities in the community that others value" (Thompson et al., 2017, p. 28). The readiness approach for (re)entry into inclusive settings justifies services provided in segregated settings such as institutions and special classes and schools, puts the blame on the children and their parents, while exempting mainstream services from putting support in place that enable the children to be successful, as illustrated both in the reviewed literature in Chapter 2 and the findings of this study. Little support and instruction from the school or the teachers were provided to the students once inside the system, causing them to fall further behind until they dropped out. It has been argued that whilst in segregated settings, a person is rarely, if ever, seen as "ready" enough by normative standards (Thompson et al., 2017). To illustrate, one participant in this study recalled schools' response to parents of children with disability: "Why do you bring a child like this here? Take them to the special centre."

Findings from the study suggest that parents and professionals' current understanding of and responses to intellectual disability were consistent with some of the earlier dominant perspectives documented in international research. This might result from the dominant use of ICD-10 and DSM-V definition and diagnostic criteria for intellectual disability in Vietnam, as described in Chapter 2. However, in light of scientific evidence suggesting the impacts of environmental factors in shaping how intellectual disability is understood, managed and experienced, it is recognised that the pathological and deficit-based perspectives were restricting and limiting as an approach (Wehmeyer et al., 2017). New approaches to understanding intellectual disability have emerged “because of the way people with intellectual and developmental disabilities continued to be understood” (Thompson et al., 2017, p. 27). Schalock et al. (2018) proposed a synthesised, integrative theoretical framework that goes beyond the current perspectives (described above) to include elements from the social and justice perspectives. Applying such integrative framework to Vietnamese context has the advantage of enriching professionals and the general community’s understanding and response to intellectual disability, as well as better capturing the complexity of intellectual disability and inform future practice. Such broadened perspectives will also align with the country’s stated commitment and effort to improving the quality of life for people with disability guided by the social model and rights-based approach, implied by Vietnam ’s ratification of the UNCRPD.

The strength-based approach to intellectual disability (Wehmeyer et al., 2017) also provides perspectives that might encourage professionals to move past the medical and pathology-based model. This is an evidence-based approach that considers intellectual functioning based on the dynamics of the person and the surrounding environment (a person-context fit model). The approach has the potential to expand the field’s attention to such concepts as “self-determination, positive behaviour support, quality of life, and supported and customized employment,” which have been well established in international research (Wehmeyer et al., 2017, p. 18). Finally, the supports paradigm, also underpinned by the Person-Process-Context-Time (Bronfenbrenner & Morris, 1998) and the person-context fit model, might also have profound implications for Vietnamese researchers, practitioners, policymakers, and the wider community. Within a supports paradigm, the goal of professional support and practices - including assessment, classification and interventions planning, is to enable full participation by addressing the gaps between personal competency and environmental demands, not only by enhancing personal capacity but also by “modifying environment and activities” and “providing personalized support” (Thompson et al., 2017, p. 28) Most importantly, this approach offers new ways of thinking about services and support provision that stretch far beyond the readiness approach.

This study provides further evidence in a new cultural context that a plethora of terminology and diagnoses are being used in professional contexts, as described in Chapter 2. Parents in the current study noted that when seeking assessment and diagnosis for their child, they might receive different or generic conclusions that they did not always understand or find convincing. In Vietnam and other low-resource setting countries, there is a shortage of personnel with expertise in assessment and diagnosis of intellectual and developmental disabilities, and a lack of culturally appropriate, standardised tools, making it harder for professionals to provide consistent, accurate and reliable diagnoses (Shin et al., 2008; Thoresen, Fielding, Gillieatt, Blundell, & Nguyen, 2017; Vu et al., 2017). Participants in this study also reported issues in assessment practices, such as quick assessment based on subjective clinical observations. Thus, variations in terminology use might reflect poor capacity for conducting assessment and giving diagnosis.

Having a disability certificate in Vietnam enables access to governmental support and benefits such as health insurance and allowance, as well as access to public school. As described in Chapter 1, obtaining a disability certificate requires that a person be assessed by a local disability council, based on observations, as having functional impairments. If the council is unable to make a conclusion, a diagnosis from a medical institution would be required. However, findings from this study have suggested that both procedures were challenging and problematic. Social welfare officials often reportedly relied on observation as a means of assessing the child and family’s needs resulted in arbitrary and unfair conclusions, while getting a reliable and consistent diagnosis was itself a challenge. These challenges caused hesitance among some parents to apply and difficulties for many others in getting the actual certificate and their entitled allowances.

Therefore, findings from the study illuminate the need for a clear and consistent definition of intellectual disability that can be used across legal, administrative, and professional contexts, as well as shared understanding among stakeholders of terms that refer to different disabilities and conditions, to help children and families navigate through the social welfare, education and healthcare systems and ensure equitable access. The current evidence-based approaches described earlier (e.g., the supports paradigm) can prove useful as a starting point for the field moving forward. For example, promoting these changes might begin with incorporating these broadened perspectives into training programs to enhance the capacity of education and healthcare professionals and parents, and campaign to raise community awareness. The partnership with CCIHP in this project may as well enable these changes at grassroot levels.

6.2 An ecological approach to understanding response to intellectual disability

As introduced in the method chapter of this thesis, response to intellectual disability within the family and the education and healthcare system can be examined by invoking concepts from ecological systems theory (Bronfenbrenner & Morris, 1998; Neal & Neal, 2013). As the research drew from parents and professionals’ perspectives, the study identified characteristics - including both enabling factors and challenges - of the family, education and healthcare microsystems, the meso-systemic interaction between parents, and professionals and social and cultural structures that influence the child’s development. These findings are visually illustrated in Figure 3, which has been adapted from Neal and Neal (2013) and will be discussed in the following sections.

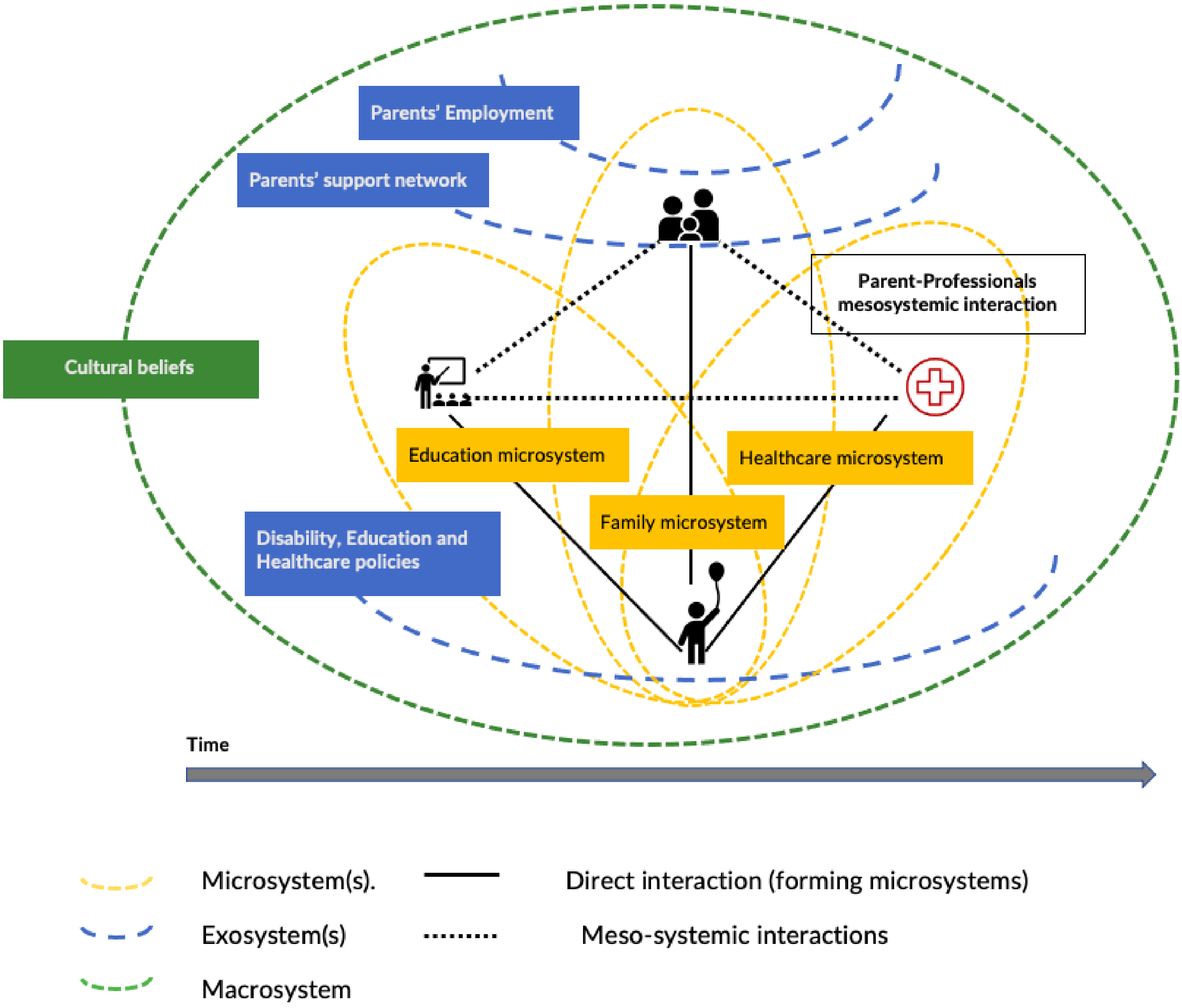

Figure 3 A networked model of ecological system and influences on responses to intellectual disability and support needs

6.2.1 Family responses and needs

Family microsystems. The study found that the costs associated with services and facilities (schools, specialist centres, and hospitals) being located far from home limited the range of service options available to the family and the child. Thus, socio-economic conditions affected the parents' and child's access or, in some cases, meant no access to supports and services. The study also found that parental skills and knowledge was a salient factor contributing care-taking practices among parents, as well as patterns of service utilisation. Perceived benefits of parents training included improved parents' knowledge and skills, child's progress, and increased parents' engagement in child's intervention. By contrast, participants also reported many children in the two provinces being left at home or not receiving proper care and interventions, attributing this to parents' lack of knowledge and understanding about child development and intellectual disability.

Information, education, and training is a fundamental area of family support needs (Hewitt, Agosta, Heller, Williams, & Reinke, 2013). The benefits of information and training opportunities were voiced by most parents, as was the need to have access to such resources and opportunities, consistent with findings from the scoping review (Nguyen, 2015; Tran, 2014). Access to informational and educational opportunities in the early years enables parents to have "high expectations" of their children through exposure to possibilities and potential (Koegel, Symon, & Kern Koegel, 2002). Thus, the dearth of quality educational services and intervention, as described earlier, combined with low level of awareness and knowledge might lead to some parents' having low expectations, as they were unable to envisage many future pathways for their child. In addition, while home-based interventions have been suggested to address the lack of professional services in low-resource settings (Shin et al., 2009), the feasibility and potential of this solution needs to be considered in the context of the socio-economic situation of the family, such as parents' time, mobility, financial resources and ability to pay. Likewise, support or services provided in the forms of training and education needs to take into consideration these socio-economic barriers. Future studies will be needed to evaluate different approaches, including their structure, content, and delivery format, and identify best practices in information and education support practices for the families.

Parents' support network exosystem. It has been observed in previous research that in some low-resource countries where formal and structural support for children with disability are lacking, parents often take the lead to counter or redresses the inadequacies and poor quality of existing services (Thoresen et al., 2017). Research has pointed to the perceived and actual benefits of peer family support and networks in terms of emotional and informational support for parents of children with intellectual disability (Reynolds, Gotto, Agosta, Arnold, & Fay, 2016). In Vietnam, the significance of parent-led response to autism and their impacts have been documented (Vu, 2014). In this study, the outcomes from the advocacy efforts of parents of children with autism and the establishment of a parent support group in QN seemed to have created a ripple effect on parents of children with other developmental disability, with four parents and one educational professional participant being members of this group. Most parent participants in this study reported benefiting from joining parents support group (both autism and other conditions) - and connecting with other families through shared experiences, including emotional support and additional access to informational and educational opportunities. The finding that support group and network serving as a major source of information for families was even more noteworthy given the paucity of professional services and formal support, low level of awareness about intellectual disability in the community. Parent networks might also be the among the few only source of information for families who were less willing to disclose their child's disability status due to fear of shame and stigmas, suggesting that this could be a viable, culturally safe channel for professionals and services providers to reach out to more children and families in need. Joining a parent support group (exosystem) might also address the need for exchanging information among parents with shared experiences and concerns, as described earlier.

Parent employment exosystem. The pressure to secure financial resources to pay for services and maintain other family functioning led to disruptions and changes in parents' employment arrangement, which in turn might interfere with their ability to take care of their children, attend parents' training, and involve in home-based intervention (microsystem level). This provides an example of the bidirectional influences among factors at multiple levels (Small, Raghavan, & Pawson, 2013). The government's one-size-fits-all approach to provide a limited, fixed amount of monthly allowance for the families was clearly not sufficient to alleviate the financial burdens for them to manage the cost of disability care among other priorities. This is consistent with existing evidence about the impact of caring for a child with a disability on family's economic well-being due to additional cost of professional services and loss of income opportunities for family members (Anderson, Dumont, Jacobs, & Azzaria, 2007; van der Mark, Conradie, Dedding, & Broerse, 2017). The salience of economic hardship affecting family's response in this study also suggests that future research is needed to further understand the impacts of poverty on accessing services and caring a child with intellectual disability in Vietnam.

Cultural influences in the macrosystem. Negative perceptions and attitudes towards disability discouraged families from seeking support and services and resulted in experiences of discrimination and social isolation for many children and their family. Participants also mentioned local parenting practices, such as little attention being given to the child meeting developmental milestones, as contributing to delay in seeking professional supports. These findings fit with existing evidence regarding the impacts of cultural beliefs (macro-system level factors) on children and family's access to services (Dexter et al., 2009; Shin & McDonaugh, 2008; Thoresen et al., 2017; Vu et al., 2014). Although social inclusion of children and family was not a focus of this study, the findings might indicate that few opportunities for participation in community and social activities and spaces exist beyond the sphere of immediate microsystems (school and family) for children across ages, as suggested in the literature (Small et al., 2013). Notably, a gradual shift toward understanding and positive attitudes towards intellectual disability was observed by some participants, attributable to some reported efforts in raising community awareness and understanding through communication campaigns and training for professionals at public educational and healthcare facilities. These findings are clear examples of a chronosystem effect where changes taking place around the child over time have impacts on the microsystems that they interact with. Potential areas for future research include examining factors and conditions that foster political and social positive changes and support for children and families across the lifespan.

6.2.2 Disability services and professionals' support needs

Education and healthcare microsystems. Many children with disability have early and enduring direct interactions with educational and healthcare professionals, making institutions such as specialised centres, mainstream schools and hospitals major settings, or micro-systems, as illustrated in Figure 3. The limited evidence from existing literature suggests that professional disability support and services for children with intellectual disability in Vietnam are severely lacking (Nguyen, 2015; Park, Glidden, & Shin, 2010; Tran, 2014). This study provides new evidence of the scarcity of professional services provided at these critical microsystems that can meet the diverse needs of children with intellectual disability. Parents in the current study reported that day-care and boarding centres were popular types of educational services available and offered to the children. While these institutions could provide some forms of educational experiences, they served mainly as a place to keep the children while parents were away working. Moreover, long-term and across the lifespan support for children with intellectual disability was particularly lacking, with no structured form of services that catered towards the need of older children, in congruent with an earlier finding regarding the absence of formal support in key areas such as transitioning, vocational training and accommodation (Kwok & Chui, 2008). This finding illuminates the intersecting effect of chronosystem, professional microsystems and exosystem where the education and healthcare systems are not able to meet the evolving needs of children with intellectual disability as they grow up, a situation poignantly described by a young mother as “there’s no way out” (H., Parent 01, QN).

While there has been an increase in the number of private specialised intervention centres to fill in the demand for professional services in QN and TTH, as is the case nationwide for children with autism (Vu et al., 2014), parents and professionals consistently rated these services as inadequate, inappropriate, and ineffective, despite being offered at very high cost. Congruent with earlier findings, access and participation of the children with intellectual disability at mainstream schools were also found to be restricted, with many children being excluded or provided with subpar instructional quality compared to other students in segregated settings (Dexter et al., 2009; GSO, 2018; Rydstrom, 2010, Trinh et al., 2011). Given that seeking and utilising professional disability services incurred high economic burden to the family, the finding about quality of services at both public and private facilities and lack of regulation was alarming, besides apparent impacts on the children who were missing out on opportunities for appropriate care and interventions.

Disability, education and healthcare policies exosystem. Poor existing services were attributed to factors in the exosystem, including lack of financial and human resources, lack of centralised legislation, policy and guidelines from relevant ministerial offices to regulate and safeguard the quality of service provided across facilities, as reported earlier (B. Nguyen, 2014; Vu et al., 2014). Professional participants highlighted the lack of formal training and national guidelines, such as treatment protocols and professional competency frameworks, to guide their practices and professional development. While public hospitals were major service providers, particularly through disability healthcare insurance scheme, their ability to provide interventions and therapies tailored to individual needs of the children and improve the quality of services were significantly constrained by lack of financial and human resources. This indicates the need for structural and systemic solutions such as increasing government's commitment to building competent workforce and allocating resources for development of disability services and support. Human resource shortage and low level of expertise were significant factors that participants linked to the low quantity and quality of professional services, in line with previous findings about disability workforce in Vietnam (Shin et al., 2009; Vu et al., 2017). Many professionals also acknowledged their limited experiences and expertise in the emerging field of intellectual and developmental disability in Vietnam and expressed willingness and needs to attend further training to enhance their professional knowledge and skills. This study provides the first sets of preliminary evidence regarding the needs of professionals who support children with intellectual disability in TTH and QN. Increased research will be needed to the explore the experiences and support needs specific to professionals in each discipline and best practices in professional development to enhance the quality of disability workforce, taking into consideration systemic and structural constraints.

Parents-Professionals mesosystemic interactions. The current research provides insights into the mesosystemic interactions between parents and professionals, as represented in Figure 3, manifested through patterns of their communication and collaboration. It has been noted that many factors might contribute to the patterns of terminology use in professional settings and parent-professional interactions. Vu et al. (2017) study on assessment of diagnosis of autism in a major city in Vietnam raised concerns over diagnosis practices among professionals who provided an affirmative diagnosis even in borderline cases to prompt parents to seek autism intervention, which they believed to be good for any children with developmental delay. As Lenne and Waldby (2011) discussed, giving diagnosis and recommendations of a developmental disability was a negotiation process based on scientific knowledge, clinical experiences, and family factors such as emotional coping ability, financial capacity and parents' agency. In this current study, educational and health professionals' choice of which terms to use when communicating with parents was based on their concerns over the terms' cultural appropriateness and potential motivational effect on parents for seeking treatment, rather than over conceptual differences among the term. Professionals also used different terms based on their judgement of parents' ability to understand the diagnosis indicated by parents' socio-educational levels. Thus, parent-professionals interaction is influenced by factors in the family microsystems, the professional settings/microsystems, as well as the socio-cultural milieus in which the interaction is situated. Future studies might examine how professionals' communication patterns - for example describing the child as "delayed" rather than "disabled" to make parents feel more hopeful and encouraged - might affect parents' understanding of the child's disability, strengths, challenges, and support needs. Such insights could help professionals make better decisions in communicating with parents in a way that is culturally safe, consistent and enables parents to make informed decision regarding their child's intervention and support.

From an ecological perspective, changes and support occurring at this mesosystem level can contribute to meeting the need for education and training for parents. Many professionals in this study reportedly worked closely with parents and provided training and instructions for parents to teach their children at home, illuminating a meso-systemic interaction at play. However, low level of expertise among professionals themselves might limit their ability to support parents in this aspect, as many professional also noted. Thus, capacity building for the professionals (exosystem factor) to support parents might also contribute to improving parents' knowledge and skills.

6.3 Beyond a one-stop service centre: Bridging the past, present and future

The wish for a local, centralised service centre that offers a broad array of services and support, from intervention to education and vocational training for their children, was popular among parents. In the earlier section, I have argued for service provision in the future to move beyond the “readiness approach” which assumes children and adults with intellectual disability are best served in segregated settings. From this perspective, a one-stop service centre, no matter how large in size or comprehensive in their scope of service, is not likely to provide supports and services that will enable children with intellectual disability to maximise their strengths and potential and enable authentic inclusion into the community. However, as the analysis thus far demonstrated, extrafamilial factors at multiple levels, such as family’s financial situation and the inadequacies of existing services and support, constrain realities of pathways that are available to children and adults with intellectual disability, shape parents’ support needs, and perception of what supports work best for their children and the family in long and short terms. In the current case, a one-stop centre run by trained professionals was not only an expected response to intellectual disability that corresponds to the pathological-based perspective underpinning current conceptualisation of intellectual disability in Vietnam. Indeed, it was perceived by participants in the current study as an ideal setting and a pragmatic solution to parents’ needs for information and professional services, while reducing the needs for transportation and navigation through different services in the context of time and financial constraints. However, the current recommendation is for Vietnamese policy and national plans to consider development strategies with community-based approaches.

Therefore, genuine paradigm shifts beyond the medical-institutional or pathological-based approach to the community-based or strength-based models of support required simultaneous efforts to address barriers at “not simply one level of the ecological system, but integrated aspects of living” (Bogenschutz, Im, & Liang, 2016, p. 252), such as those identified through this research. Indeed, the supports paradigm might encourage us to do just that. In the meantime, rather than following a one-size-fit-all pathway or solution, a better place to start is to identify the gaps between what currently is, and what can be based on the experiences and evidence available from more developed countries (Thompson et al., 2009; Thompson et al., 2017). This further highlights the importance of translational research to identify how existing knowledge generated from western countries have relevance for lower-resourced settings (Tomlinson et al., 2014). Understanding parents' and professionals' views and conceptualisation, as well as their experiences in responding to intellectual disability provides evidence and foundational understanding of what is, inspire our visions of what can be, and enable our collective actions to create changes.

6.4 Limitations

Despite its contribution, there are several limitations in the current study. Firstly, the sample contains a small number of participants in each project sites, many of whom have been recruited through the existing database and network of beneficiaries from CCIHP's capacity building programs. Most parents in this sample completed at least two years of college, while most professional participants had background in education and health-related fields. Thus, their knowledge, understanding and attitudes might be influenced by their educational level and through attendance in such training and not generalisable to the values and beliefs held by the local community and in Vietnam. The findings, however, enable focused efforts and actions to improve the status quo by informing future design and implementation of activities that could directly benefit children with intellectual disability and their families at the project sites.

Secondly, while the research was conducted in Vietnamese by a native speaker researcher, the broad array of terminology and diagnostic terms being used by participants across the interviews presented significant practical and theoretical challenges for the researcher. Thus, although children and individuals described in this study were referred to as having “intellectual disability” or experiences relevant to intellectual disability, the generated narratives might in fact capture a multitude of experiences with varying level of relevance to intellectual disability. Therefore, more consistent and systematic approaches to defining intellectual disability will be needed to enhance communication among stakeholders and particularly among researchers and to make sure that future research findings can be reliably interpreted and generalised across contexts.

Lastly, the research has relied on parent and professionals’ perspectives to examine the constructed meaning of intellectual disability while leaving out the voices and perspectives of children and young people themselves. Historically, people with intellectual disability have been sidelined from participating in research, even as respondents. In the past 40 years, inclusive research was born out in part from the changes that took place within social sciences, to empower and create social change for the vulnerable groups. In the field of developmental and intellectual disability, participatory and co-produced research has also been recognised among priorities for future research (Tomlinson et al., 2014). Moreover, engaging with people with disability in research challenges western-based knowledge about disability and power relations among researchers, activists and people with disability in Vietnam’s post-war contexts (X. T. Nguyen et al., 2019). Indeed, the current study was inspired in part by previous research by Aldersey (2012) in Congo and Vu (2014) in Vietnam which involved children and adults with intellectual and developmental disability through creative, adapted data collection tools. While employing an inclusive research design and approach was not feasible due to technical and ethical considerations beyond its scope, the project adds to the limited body of knowledge on understanding of and response to intellectual disability and the surrounding systems which set the context for exploring the lived experiences of children and young people with intellectual disability. It is hoped that as the field intellectual disability in Vietnam expands, inclusive research will also receive greater attention, considerations, and effort among researchers.

Chapter 7: Conclusion

Vietnam has in the past decades made significant strides in improving the services and support for children and young people with developmental and intellectual disabilities. Thus, there is a need for increased research in intellectual disability and to build a strong evidence base for the development, implementation and delivery of support and services that meet the varying needs of the children, young people and their families. However, much of the existing knowledge on developmental disability and intellectual disability have come from research conducted in English and developed, western countries that might be limited in terms of relevance to low-resourced settings. This project seeks to make a small contribution to the existing knowledge about intellectual disability in a new cultural context of Vietnam. Through a collaborative effort between the researcher and CCIHP – a local organisation, the project has the potential to create meaningful changes for children with intellectual and developmental disability by informing the design and implementation of CCIHP's future programs and activities at the two project sites.

This study provides the first sets of data and findings pertaining to the understanding of and response to intellectual disability from the multiple perspectives of parents in professionals in Vietnam. Findings suggest that parents and professionals' conceptualisation of intellectual disability featured elements of the medical and psycho-educational perspectives of intellectual disability, as well as the medical and pathology-based model of intellectual disability that dominated the field of intellectual and developmental disabilities in the past. Such deficit- and pathology-based approaches underlies the current "readiness approach" to designing and delivering service and support, in which children with disability are considered best served in specialised settings and required to demonstrate prerequisite skills ("readiness") before being granted access to community settings and activities.

A major focus of this research is to understand response to intellectual disability and support needs from the perspectives of parents and professionals, recognising their crucial roles in providing the earliest and life-long support for people with intellectual disability. The results suggest salient issues in the current state of service and support provided for the children and their families, as well as unmet needs. The study adopted recent developments in ecological system theory to identify and conceptualise the intersecting influences of multiple settings – the family and professional microsystems, parent-professional meso-systemic interaction, parents' employment, and support network exosystem and disability policies exosystem - on the access and provision of educational and healthcare services for children and young people with intellectual disability. Such interactions occur within a macrosystem characterised by negative cultural beliefs towards intellectual disability and evolve as a function of time and timing.

The research has important theoretical and practical implications for researchers and practitioners in the field of intellectual disability in Vietnam. It is argued that a broader and more comprehensive perspectives and construction would be needed to better capture the lived experiences of children and young people with intellectual disability and their families, and more importantly to guide the country's development and implementation of support provision for this population. Specifically, the strength-based approach (Wehmeyer et al., 2017), the supports paradigm (Thompson et al., 2017) and an integrative conceptual framework (Schalock et al., 2018) to understanding disability are introduced as evidence-based approaches that might serve this purpose. From a practical standpoint, these findings and recommendations might be used to inform the design and implementation of CCIHP' s programs and activities to enhance the knowledge and capacity of education and healthcare professionals and parents, improve access to information and peer support for parents, and raise community awareness. Through this partnership, the project contributes to allowing opportunities for change at multiple levels.

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Appendix A: Semi-structured Interview Schedules

For parents/caregivers

1. Please tell me about yourself and your family
2. Please tell me about [name - child with intellectual disability]
3. How would you describe [name]?
- strengths,
- interests,
- Challenges/difficulties, if any
4. Please tell me about [name]'s diagnosis/condition
- How did you get the diagnosis?
- What do you think about this diagnosis that was given to [name]? Do you think this diagnosis/label accurately describe [name]? Why or Why not?
5. What are the impacts of having [name] in your family?
- What are the positive aspects?
- What are the challenges?
- Have these aspects changed over time?
6. How have you and your family responded to [name]'s challenges/difficulties?
- What kind of services have your sought?
- How about healthcare and education for [name]?
7. How have you and your family responded to the challenges, if any, as a result of having [name] in your family?
- What are the areas that you need help with most?
- What kind of supports have you found most helpful?
- Who/where do you come to when you need help?
- Do you find it easy to find/enlist/access the support you need? Why or why not?
- Any services you know about but cannot access?
8. What are your plans for future?
- How do you envision the future for name in the short and long term?
- What do you think will be necessary for [name] and your family to achieve this plan or goal? (discuss both personal/subjective and environmental/objective factors)

For Healthcare Professionals

1. Please introduce about yourself
- age, institution.
- professional background; years of experiences supporting children and families living with intellectual disability
2. Please tell me about your work relating to services/supporting people with intellectual disability
- How did you start this job/position?
- Please describe your specific roles/responsibility in supporting/providing services for people with intellectual disability?
- How/where have you received training about ID and/or to support your clients with intellectual disability?
- Have these roles/responsibilities changed overtime?
3. Can you describe how you understand intellectual disability?
- What are the causes and characteristics?
- What are the areas of challenges for your clients with intellectual disability?
- How do you set the goals for your clients?
4. What do you know about healthcare support for people with intellectual disability and family?
- What types of services or support that are available locally or that you are aware of/know about?
5. What do you think about such support?
- Do these services meet the needs of the family? Are they accessible to the family? Are they utilised by the family? Why do you think that is the case?
- Whose responsibility is it to provide healthcare services and support for people with intellectual disability and family?
6. What do you think about the roles of healthcare professionals in supporting people with intellectual disability?
7. Please tell me about the positive aspects of your job
8. What have been challenging for you to do your job
9. What kinds of support, if any, do you need in the future to better support clients with intellectual disability?

For Education Professionals

1. Please introduce about yourself
- age, institution.
- professional background; years of experiences supporting children and families living with intellectual disability
2. Please tell me about your work relating to teaching students with intellectual disability
- How did you start this job/position?
- Please describe your specific roles/responsibility in teaching student with intellectual disability?
- How/where have you received training about intellectual disability and/or teaching students with intellectual disability?
- Have these roles/responsibilities changed overtime?
3. Can you describe how you understand intellectual disability?
- What are the causes and characteristics?
- What are the areas that students with intellectual disability need help with the most? What types of support are necessary?
- What are the areas of challenges for your students with intellectual disability?
- How do you set the goals for your students?
4. What do you know about educational services for people with intellectual disability and family?
- What types of services or support that are available locally or that you are aware of/know about?
5. What do you think about such support?
- Do these services meet the needs of the family? Are they accessible to the family? Are they utilised by the family? Why do you think that is the case?
- Whose responsibility is it to provide healthcare services and support for people with intellectual disability and family?
6. What do you think about education opportunities for students with intellectual disability?

- What are the benefits and/or disadvantages of inclusive and specialist educations for students (with or without intellectual disability?)
- What do you think about alternative educational opportunities for students with intellectual disability? (in special schools)
- Do you think students with intellectual disability are currently supported in inclusive and/or specialist schools? Why or why not?

7. What do you think about the roles/responsibility of special education teachers in educating students with intellectual disability?
8. Please tell me about the positive aspects of your job that involves teaching a student with intellectual disability.
9. What have been challenging for you to do your jobs? (or what you imagine would be challenging?)
10. What kinds of support, if any, do you need (or envision you would need) in the future to better support your students with intellectual disability?

Debriefing question (for all Participants Following researcher's short summary of topics and major points)

- Is there any information you have shared that you do not want me to include in our analysis?
- Is there anything you want to share that we have not covered during our conversation?

Appendix B: Participant Information Sheet and Consent Form (Professionals)

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

For Education and Healthcare Professionals

Understanding intellectual disability in Vietnam:

Perspectives of parents and healthcare and education professionals.

Researcher: Giang Le
Flinders University, South Australia
Supervisor: Dr Fiona Rillotta
Flinders University, South Australia
Tel: +61 8 8201 2108
Supervisor: Professor Sally Robinson
Flinders University, South Australia
Tel: +61 8 7421 9845

Center for Creative Initiative in Health and Population
Dr Ha Song Vu
Vice-Director
Hanoi, Vietnam
Tel: (+84) 96 655 8285

My name is Le Huong Giang, and I am a Flinders University Masters student. I am undertaking a research project about intellectual disability in Vietnam as part of my degree and I would like to invite you to participate in the study. This research will explore: 1) the understanding of Vietnamese parents and professionals about intellectual disability; 2) support needs of parents; and 3) the experiences of professionals who provide education and healthcare services to children and families living with intellectual disability. This study is supported by the College of Nursing and Health Sciences at Flinders University in Australia and the Center for Creative Initiatives in Health and Population (C.CIHP) in Vietnam.

Benefits of the study

It is hoped that findings from this research will help to inform future policy and programs to better support individuals with intellectual disability, parents and families. The information you provide may also help the project team at C.CIHP to improve their projects to better serve children and families in Thua-Thien Hue and Quang Nam.

Participant involvement

If you agree to participate in the research study, you will be asked to attend a one-on-one online interview with the researcher through platforms you are familiar with such as Zoom or Zalo. A member of the research team will contact you to organise a time for the interview. The interview is expected to go for approximately 1 hour. If you agree, the interview will be voice recorded so that the information will be accurate. The following is a list of possible topics that we might discuss:

- How you understand and describe intellectual disability;
- Your experiences in providing services for people and families living with intellectual disability;
- How you think about the current state of services, support and practices relating to intellectual disability;
- How you can be better supported in your work.

Potential risks

The researchers do not expect that participation in any part of this research will cause any harm to you or your client. However, you might find that sharing your experiences might cause some emotional discomfort. You might find support by calling The Peace House free counselling service at 1900969680. If you would like, we can also arrange for you to speak to a counsellor in person at no cost.

Withdrawal Rights

You may, without any penalty, decline to take part in this study. If you decide to take part and later change your mind, you may, without any penalty, withdraw at any time without providing an explanation. To withdraw, please inform the researcher to terminate the interview or you may just refuse to answer any questions. Your decision to participate in the study will not affect your entitlements and benefits from any of C.CIHP's past, existing or potential activities and programs. Any data collected up to the point of your withdrawal will be securely destroyed.

Confidentiality and Privacy

Only researchers from Flinders University, including myself and my supervisors, and the Research Assistant who is present during the interview, will have access to the individual information provided by you. The research outcomes will be shared with CCIHP and may be presented at conferences and/or written up for publication; however, you will not be named, and any information included in the writings and publications will not be able to be connected back to you. Therefore, you will not be identifiable, and your privacy, confidentiality and anonymity will be assured at all times. However, please note that if during interview, there is disclosure of information that causes concerns for the safety of yourself or your client, the researcher is required to follow actions set out in C.CIHP's Child Protection protocol.

Data Storage

The information collected will be stored securely on a password protected computer throughout the study and stored at Flinders University for at least five years after publication of the results.

Recognition of Contribution / Time / Travel costs

You are not expected to gain any direct benefit from your involvement in this study. However, in recognition of your time and contribution in the study, you will be reimbursed VND 100,000 prior to commencing the interview.

How will I receive feedback?

It is hoped that this research will be published. You can request a summary of the results of the study by contacting myself, my supervisors or CCIHP through details listed above.

Ethics Committee Approval

The project has been approved by Flinders University's Human Research Ethics Committee (Project Number 2031) and Internal Review Board at the Center for Creative Initiatives in Health and Population.

Queries and Concerns

Queries or concerns regarding the research can be directed to the research team. If you have any complaints or reservations about the ethical conduct of this study, you may contact the Flinders University's Research Ethics & Compliance Office team via telephone +

61 8 8201 3116 or email human.researchethics@flinders.edu.au (for English) or [insert CCIHP IRB contact].

Thank you for taking the time to read this information sheet. If you are interested in participating in the research, please read the attached Consent form and respond to us via [insert RA Contact Details].

CONSENT FORM

Consent Statement

☐ I have read and understood the information about the research, and I understand I am being asked to provide informed consent to participate in this research study. I understand that I can contact the research team if I have further questions about this research study.

☐ I am not aware of any condition that would prevent my participation, and I agree to participate in this project.

☐ I understand that I am free to withdraw at any time during the study and that my withdrawal will not affect my relationship with Flinders University and its staff and students, my relationship with CCIHP and its staff, and my future participation in CCIHP programs and activities.

☐ I understand that I can contact Flinders University's Research Ethics & Compliance Office if I have any complaints or reservations about the ethical conduct of this study.

☐ I understand that my involvement is confidential, and that the information collected may be published. I understand that I will not be identified in any research products.

I further consent to:

☐ participating in an interview

☐ having my information audio recorded

Signed:

Name:

Date:

Appendix C: Participant Information Sheet and Consent Form (Parents)

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

For Parents/Caregivers

Understanding intellectual disability in Vietnam:

Perspectives of parents and healthcare and education professionals.

Researcher: Giang Le
Flinders University, South Australia
Supervisor: Dr Fiona Rillotta
Flinders University, South Australia
Tel: +61 8 8201 2108
Supervisor: Professor Sally Robinson
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Benefits of the study

It is hoped that findings from this research will help to inform future policy and programs to better support individuals with intellectual disability, parents and families. The information you provide may also help the project team at C.CIHP to improve their projects to better serve children and families in Thua-Thien Hue and Quang Nam.

Participant involvement

If you agree to participate in the research study, you will be asked to attend a one-on-one online interview with the researcher through platforms you are familiar with such as Zoom or Zalo. A member of the research team will contact you to organise a time for the interview. The interview is expected to go for approximately 1 hour. If you agree, the interview will be voice recorded so that the information will be accurate. The following is a list of possible topics that we might discuss:

- How you understand and describe your child’s intellectual disability,
- How your family, friends and the community respond to your child’s intellectual disability.
- The sources of support available to you, your child and your family,
- Your experiences with the healthcare and education systems.
- Future plans for your child and how you want to be supported.

Potential risks

The researchers do not expect that participation in any part of this research will cause any harm to you or your family. However, you might find that sharing your experiences might cause some emotional discomfort. You might find support by calling The Peace House free counselling service at 1900969680. If you would like, we can also arrange for you to speak to a counsellor in person at no cost.

Withdrawal Rights

You may, without any penalty, decline to take part in this study. If you decide to take part and later change your mind, you may, without any penalty, withdraw at any time without providing an explanation. To withdraw, please inform the researcher to terminate the interview or you may just refuse to answer any questions. Your decision to participate in the study will not affect your entitlements and benefits from any of CCIHP's past, existing or potential activities and programs. Any data collected up to the point of your withdrawal will be securely destroyed.

Confidentiality and Privacy

Only researchers from Flinders University, including myself and my supervisors, and the Research Assistant who is present during the interview, will have access to the individual information provided by you. The research outcomes will be shared with CCIHP and may be presented at conferences and/or written up for publication; however, you will not be named, and any information included in the writings and publications will not be able to be connected back to you. Therefore, you will not be identifiable, and your privacy, confidentiality and anonymity will be assured at all times. However, please note that if during interview, there is disclosure of information that causes concerns for the safety of yourself or your child, the researcher is required to follow actions set out in C.CIHP's Child Protection protocol.

Data Storage

The information collected will be stored securely on a password protected computer throughout the study and stored at Flinders University for at least five years after publication of the results.

Recognition of Contribution / Time / Travel costs

You are not expected to gain any direct benefit from your involvement in this study. However, in recognition of your time and contribution in the study, you will be reimbursed VND 100,000 prior to commencing the interview.

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61 8 8201 3116 or email human.researchethics@flinders.edu.au (for English) or [insert CCIHP IRB contact].

Thank you for taking the time to read this information sheet. If you are interested in participating in the research, please read the attached Consent form and respond to us via [insert RA Contact Details].

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Consent Statement

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☐ I am not aware of any condition that would prevent my participation, and I agree to participate in this project.

☐ I understand that I am free to withdraw at any time during the study and that my withdrawal will not affect my relationship with Flinders University and its staff and students, my relationship with CCIHP and its staff, and my future participation in CCIHP programs and activities.

☐ I understand that I can contact Flinders University’s Research Ethics & Compliance Office if I have any complaints or reservations about the ethical conduct of this study.

☐ I understand that my involvement is confidential, and that the information collected may be published. I understand that I will not be identified in any research products.

I further consent to:

☐ participating in an interview

☐ having my information audio recorded

Signed:

Name:

Date:

Appendix D: Key characteristics of selected studies from the scoping review

	Authors (Year)	Location / Language	Sample	Methodology
[1]	Shin et al. (2008)	Hue / English	106 mothers and 93 fathers, 57 teachers.	Quantitative
[2]	Shin et al. (2006)	Hue / English	106 mothers and 93 fathers	Quantitative
[3]	Shin and McDonaugh (2008)	Hue / English	106 mothers and 93 fathers	Quantitative
[4]	Park et al. (2010)	Hue/ English	106 mothers of children with Intellectual disability, 120 mothers of typically developing children	Quantitative
[5]	Shin and Nguyen (2009)	Hue/English	106 mothers of children with Intellectual disability, 120 mothers of typically developing children	Quantitative
[6]	Ngo et al. (2012)	Hue / English	70 parents of children with intellectual disability	Mixed methods: (quantitative survey with open ended question).
[7]	Rydstrom (2010)	Hanoi / English	Giai Phong Mainstream School, Kien Thuc Integrated School, and Tu Do Specialist school	Qualitative; Observation
[8[	Do and Cao (2010)	TP. HCM / Vietnamese	Parents of children with Intellectual disability at 4 specialist schools	Quantitative
[9]	Dinh (2015)	3 Provinces / Vietnamese	78 Teachers at mainstream schools	Quantitative

[10]	Pham and Nguyen (2012)	Hue / Vietnamese	15 managers and teachers, 25 parents of children with intellectual disability from 3 specialist centers	Quantitative
[11]	Mai et al., (2020)	TP. HCM / Vietnamese	64 parents	Quantitative
[12]	Nguyen, S. (2014)	Hanoi / Vietnamese	Parents of students at a specialist centre.	Quantitative
[13]	Nguyen (2017)	TP HCM / Vietnamese	107 parents of children from 2 Hospitals and 1 specialist schools	Quantitative
[14]	Nguyen, M.T. (2015)	Hanoi / Vietnamese	50 teachers at a mainstream school, 15 parents, 15 students	Mixed methods: surveys, interviews, group discussion, observation
[15]	Hoang (2014)	Hanoi / Vietnamese	390 survey respondents (educators, parents, students)	Quantitative
[16]	Trinh et al. (2011)	An Giang and Dong Nai	24 participants in focus groups (parents and children with and without disability, mainstream school teachers); 21 in-depth interviews (educational and healthcare professionals, local administrative officers; managers at social care centers); 6 home observations and 3 case studies	Mixed methods
[17]	Dexter et al. (2009)	Da Nang	Quantitative data: 150 People aged 18-69 Qualitative data: 5 children with disability; 28 parents of children with and without disability	Mixed methods