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It takes a village:
Caring for children with autism spectrum disorder in Hanoi, Vietnam

Master’s thesis in International Social Welfare and Health Policy

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Oslo 2019

ABSTRACT

The aim of this project is to better understand parents' or caregivers' experiences of care for their children with autism spectrum disorder (ASD) in Hanoi, Vietnam. The research explores parental caregiving practices, identifies the autism services and support parents use, and addresses parental challenges and coping mechanisms for those challenges. It uses a mixed methods approach, with a self-administered questionnaire (n = 89) based on Furnham and Buck (2003) and semi-structured interviews (n = 9) that were analysed using thematic analysis.

The results are groups in three themes around parental care for the child with ASD: 1) centeredness of family, 2) parent' developmental goals, and 3) social support. These are organized and contextualized within the three components/sub-systems of the developmental niche framework by Harkness & Super (1986). The three sub-systems are the physical and social setting, customs of childcare and child-rearing and psychology of the caregiver.

The findings show that parents use immediate family to seek advice to make inform health decisions about their child. Parents have goals for their children to develop such as eating, toileting, playing, socializing with people, and listening to parents. Their caregiving values and family structure may originate from traditional and historical practices of Buddhism and Confucianism. Their access to social supports is provided by partners, professionals, families, teachers, other parents of child with ASD, books, internet, and television. They experience challenges of access to autism supports and caregiving stress. Their coping mechanisms are seeking multiple supports and providing love for their children so they can grow happily and healthy.

The findings add to the understanding on the relationship between the parent and the autistic child within the social and cultural context of Vietnam, and thus a cross-cultural and global perspective. Parental experiences on caregiving their children with ASD are recommended to be further explored in other regions of Vietnam.

DEDICATION

This study is wholeheartedly dedicated to my parents. I would like to thank them for immigrating from Vietnam to Canada, starting a family together and having me and my brother. I will never truly understand how they were able to navigate the Canadian system while finding a balance between their own cultural identity with the Canadian cultural identity. Their perseverance, sacrifice, survival instincts and hard work to build a life in Canada has made me proud to be called first generation Canadian. They had to put aside their dreams and aspirations to start a life for me and my brother. I am humble and grateful to conduct research in their home country. I hope to continue exploring my family roots by retelling their stories through my generational lens and use it as a strength to guide me when working with communities in Vietnam. My goal is to foster community engagement by exchanging my knowledge between my western education and social work practice with knowledge from their communities. One day, I hope I can have a greater understanding of the country that shapes their lives, made them the people they are and go to the places they have been which has given my life more purpose. Thank you for everything.

ACKNOWLEDGEMENT

I would like to thank my supervisor, Dr. Ragnhild Dybdahl, for your guidance, kindness and commitment to support my research. I am privileged to have you as my supervisor throughout this thesis journey.

I would like to thank my co-supervisor, Dr. Minh Hoang Dong, for your guidance, oversight of the data collection in Hanoi and mediation of the research team.

I would like to thank my research assistants, Cham Nguyen and Holland Nguyen, for your tremendous help during the data collection. We would not have achieved the data collection goal without you two. Your competencies and technical skills in research have been a strong supportive role for the research and I am truly grateful for your time and commitment.

Lastly, I would like to thank my friend and classmate, Jones K. Adom Danquah, for your research advice, friendship and time throughout my master’s university and thesis journey.

A Dissertation submitted to the Social Sciences department in partial fulfillment of the requirements for the degree of Master of International Social Welfare and Health Policy (MIS) 2019.

Thesis completion date: 15 November 2019 in Oslo, Norway.

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CHAPTER 1. INTRODUCTION

The focus of this research is parental ideas on caring for children with autism spectrum disorder (ASD) or autism in Hanoi, Vietnam. In this study, I explore parental caregiving practices, identify autism services and support parents uses, address parental challenges and coping mechanisms for those barriers.

According to the American Psychiatric Association (APA) (2013), ASD is a neurodevelopmental disorder that has three-character traits which consist of impairments in social skills, communication skills and behavioural skills. Autism behaviour traits may exhibit by the age of 2 years and communication delay may occur by the age of 18 months (McConkey & Cassidy, 2010). These traits may not be evident until the later development. The disorder varies in severity within every individual and may bring challenges to themselves, families and misunderstandings from the public.

ASD affects 1 in 160 children internationally (WHO, 2018), and it is estimated that 1 in every 68 children have ASD in the United States (Centre for Disease and Control and Prevention, 2012). In Western countries autism was recognized in the 1940s (Ying et al., 2012). In Vietnam, autism was recognized in the late 1990s (Giang, 2012; Ying, Browne, Hutchinson, Cashin, & Binh, 2012 & Minh, 2011) and currently, diagnoses of autism among children are rapidly increasing so families are recognizing the need for their children to be diagnosed earlier (Hoang, Le, Chu, et al. 2019). However, the number of child diagnoses are unknown because there is no accurate national disability rate in Vietnam (Ha, Whittaker, Whittaker, & Roger, 2014). This comparison of the international disability rates and American disability rates illustrates autism is not well known in Vietnam and there is a lack of autism research. Throughout this research, I will be using the term autism, autism spectrum disorder and ASD interchangeably.

In terms of children with disabilities and their access to education, UNICEF reported 63 per cent of schools offer inclusive education in Vietnam with 77 per cent in Ho Chi Minh City and 19 per cent in Ninh Thuan (UNICEF, 2015). It is reported that 96 per cent of children with disabilities attend schools in Ho Chi Minh, however, the second major city, Hanoi has no statistics reported. The access of children with disabilities to education demonstrates social participation and inclusion from the education system and society. Inclusive education may contribute to a child's healthy development, but as there are no statistics on education accessibility for children with disabilities, there is no indication of their literacy rate and the level of inclusive education in a major city like Hanoi.

Children with autism may experience barriers to education, social isolation, bullying, and health problems (Howlin, 2005; Ochs et al., 2001). Parents of children with disabilities may experience a burden of stress, mental health problems (Nguyen & Berry, 2013) and a lack of financial and social support from the government (Gammeltoft, 2008). Parents in Southeast Asia reported experiencing psychological stress, physical exhaustion, depression, frustration (Altiere & Von Kluge, 2009) and isolation (Luong, Yoder & Canham, 2009). Parents' experiences of stress and the linkage to mental health problems remain unknown in Vietnam; however, most studies on parents' experiences on stress come from high-income countries (HIC) like the United States and Canada.

Disability and mental health challenges in developing countries is a global concern. If there is a better understanding on the health and wellbeing of parents, it could improve treatment of parents' mental health problems, reduce misunderstandings from the public, develop healthier parenting styles for their children and prevent escalation of mental health and health impairments. Parents are responsible for providing guidance throughout their child's developmental early years. More knowledge about parental experiences and challenges can help identify the needs of parents and the services they use to improve the quality of life for their children with a disability as they grow. Parents' experiences on caring for their children with disabilities and the way they address health concerns can differ from culture to culture, but in every culture, parents play an important role in their child's life. Therefore, a better understanding of what it means to be a parent raising a child with a disability in the Vietnamese social and cultural context will add to the literature on global health.

Although it is difficult to conduct studies in all regions of Vietnam, conducting preliminary studies in Vietnam's major cities like Hanoi and Ho Chi Minh is a beginning to a general overview of parents' experiences in raising their children with disability. Since the prevalence of autism among young children remains unclear in Vietnam while Hanoi has most of its leading hospitals, attention on studying autism in Hanoi should be further explored.

1.1. Objective of this study and research question

The objective of this study is to explore experiences of care that parents and caregivers provide for their children with ASD in Hanoi. This includes understanding how parents provide care, identifying available and needed supports, addressing their challenges and barriers when providing support and explore their coping strategies—all within a social and cultural context.

The research question is: what are parents' experiences when caring for their child with ASD in Hanoi? The overall aim is to the relationship between the parent and the child with ASD. Within the interaction, I want to explore parental ideas and practices that influence the autistic child's developmental process.

1.2. Background

Vietnam has experienced a history of wars that created challenges to the country's economic development. Despite the struggles, the economic growth in Vietnam has increased dramatically over the past decade with a GDP growth rate of 6 per cent (Cuong, 2011). Part of this rapid economic development was from the Doi Moi, a political and economic reformation policy in 1989 (Ha, Whittaker, Whittaker, & Roger, 2014). Currently, Vietnam is considered a low-middle income country with the least economic growth found in rural and mountainous areas (World Bank, 2014). Vietnam's cities and rural areas has an economic difference with 10 per cent of poor children living in cities compared to 40 per cent of poor children living in rural areas (UNICEF, 2010). In Vietnam, a child with a disability lowers the standard of living for the household (MOLISA & UNICEF, 2004; Government of Vietnam, 2006).

Children with disabilities experience difficulties accessing healthcare, education, and employment. A statistic from the Government of Vietnam (2006) stated 183,109 of the 5.3 million people with disabilities receive support from the government. The remaining people must support themselves or are supported by their families. In cities, only 5 per cent of children, and in rural areas, only 10 per cent children, receive any form of financial support from government and/or the community (MOLISA & UNICEF, 2000). In Vietnam, 95 per cent of children with ASD do not receive education support and remain living at home (Villa et al., 2003). This may play a critical role in the literacy development of the child. Overall, the data is not a precise estimation in Vietnam because the country does not have an accurate national disability rate (Ha et al., 2014). This means there is no official data to determine the amount of people diagnosed with autism in all of Vietnam.

Parents' experiences on access to treatment services and early interventions for their children with autism remain unclear in Vietnam. Some families that have access to most autism resources are richer families (Vu et al., 2014), however experiences of families with low financial resources are unknown. Families with financial barriers may experience challenges to seek support for their children which may influence their selection of treatment options. Scholars suggest treatment services and early intervention is considered lifelong and diagnoses have been affective in treating children with ASD in North America and Europe (Tran, Weiss, Khuc, Tran, Nguyen, Nguyen & Dao, 2015). However, families' understanding on the effectiveness of treatment and familiarity with the disorder remains unclear in Vietnam. One study in Vietnam describe the quality of assessment services to be rushed, unclear on clinical guidelines and miscommunicated between parents and doctors (Ha et al., 2016). Although the assessment is not accurate, and parents may be dissatisfied, Ying et al. (2012) argued parents have a respect for doctors because they are in a hierarchal position. Investigating families' experiences of utilizing autism services and their interaction with health professionals in Vietnam will provide an understanding on the quality of health service delivery to families.

1.3. Different views of autism in a social and cultural perspective

Parents' experiences with autism remains unclear in Vietnam and it could be suggested that autism is viewed differently within family experiences in Western countries like Canada and the United States. An exploration of autism could be viewed in different ways depending on the social and cultural context in regions of Asia, Africa, America and Europe. Therefore, if more research is done in Vietnam, a cross-cultural understanding of autism will be established, and similarities and differences can be identified.

The definition of disability according to WHO (2018) is an umbrella term for impairments in the function of the body, activity limitations, and participation restrictions. WHO's framework known as the International Classification Functioning of Disability and Health (ICF) recognizes the integration of medical model and social model. The medical discourse of ASD is described to vary from a low level to high level functioning of autism (Silverman, 2008); it puts an emphasis on impairment and illness. The social discourse of ASD understands autism as a lifestyle and not a disorder. Social discourse of ASD is viewed as a social construction based on societal attitudes and treatment towards people with disabilities, in other words, it is the environment that disables the individual (Meadow-Orlans, 2002). In North America, the interpretation of disability includes people with disabilities as a daily living rather than viewing their life as an illness and a burden of care.

In Vietnam, the general term for disability sometimes is interpreted by society as bringing shame to the individual's family. It can be viewed as a form of punishment towards the family due to sins of previous generations (Gammeltoft, 2008; Ha et al., 2014). In Vietnam, China and Korea there are historical roots of Confucianism, Taoism and Buddhism values implemented in the parental belief system impacting on their caregiving practice (Chao & Tseng, 2002). A study by Danseco (1997), suggests parental interpretation of disability is surrounded by cultural interpretations.

Although most Vietnamese people may not identify themselves strongly with these religious and spiritual roles, they may be influenced by these views of Confucianism and Buddhism (Ha et al., 2014). Some believe a child with a disability is a form of punishment from a wrongdoing or bad behaviour of the family past; disability is sometimes considered as a karmic disadvantage and a sin (Gammeltoft, 2008). This type of belief has caused stigmatization and prejudice in their community. In Hanoi, parents of children with disabilities are viewed as less valuable and a heavy burden on families. As a comparison to Western society, autism is known to be accepted and policies are constantly being adjusted to become more inclusive for people with disabilities (Bagatell, 2010; Hunt, 2012).

1.4. Autism in Vietnam

In the mid 1980s, Vietnam's law changed regarding people with disabilities so that all people with disabilities have the right to political, economic, social and cultural rights (Hugman, Durst, Le, Nguyen & Nguyen, 2009). Although these laws are put in place, the concern is that laws have not been effectively and relevantly applied to practice because there is limited evidence of improved living conditions for people with disabilities. People with disabilities in Vietnam may continue to have challenges accessing healthcare, vocational training, education and employment leading them to have limited skills and resources to care for themselves. Families that are unable to support themselves rely on government assistance, but assistance is very limited, so they seek extended family for support. It is common for families to rely on each other because interdependency is rooted within their collectivistic culture; it prioritizes group goals over personal goals (Chao & Tseng, 2002). An example from a study in Vietnam reports mothers who seek information from health professionals on raising their child with a disability, they use the health information to share it with their family members. In the context of that study, mothers who receive information of their child's diagnosis determines the health decisions they make for their child (Ying et al., 2012).

Scholars like Chao & Tseng (2002) agrees that parents of children with ASD rely on families for caregiving support by communicating their needs and sharing health information with them. When parents are sharing the health information, how they understand the health information and make use of it is unknown. We need to consider the awareness and knowledge families have on autism and its services and treatments. This calls for the implementation of health literacy. Health literacy is "the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Ratzan & Parker, 2000, p. 3 as cited in Berkman, Davis & McCormack, 2010). If families obtain accurate knowledge on the disorder and services and treatments, it may reduce barriers for parents in navigating support, making inform decisions on choosing appropriate services and providing them motivation on caregiving.

1.5. Outline of the thesis

In the upcoming chapters starting from Chapter 2, there will be a literature review on cross-cultural studies on the experiences of parents of children with ASD, parenting styles, family cultural belief systems, parental support systems, challenges and barriers and coping mechanisms.

In Chapter 3, I will discuss the conceptual framework of the developmental niche by Super and Harkness (1986, 1994, 1996 & 1999). I will use the framework to examine the relationship between the parent and autistic child in their social and cultural environment and explain the use of the framework within this study.

In chapter 4, I will present the method and analysis of the research. It will explain the rationale of the methods, setting of the field work, recruitment of the research team, procedures for soliciting participants and data collection followed by ethical considerations. At the end of the chapter, I will describe the data analysis design that determines the themes of the research.

In chapter 5, I will present the results of qualitative and quantitative data that answers the research question with reference to the conceptual framework.

In chapter 6, I will provide a thorough discussion on interpreting the findings in conjunction with the conceptual framework, examining the limitations of the research, identifying ethical matters and the trustworthiness of the research.

In chapter 7, I will generate recommendations and conclude with a restatement of the thesis, discuss the supporting findings that answers the research question, and end with closing comments on the research.

CHAPTER 2. LITERATURE REVIEW

2.1. Strategy for literature review

Although this was not a systematic literature review, I searched EBSCO Host, NCBI, ORIA, Academic Premier, Medline, ProQuest, PsycArticles, ProQuest Global Dissertations and Theses, Sage, Sage Research Methods and Taylor & Francis databases for relevant literature. In addition, the statistical information was found in these following resources: World Bank, WHO and UNICEF. I used specific terms and phases for this study which includes: *autism in Vietnam, parental experiences of on child care in Vietnam, autism care in Vietnam, thematic analysis, mix method study, mix method research on autism, Doi Moi, autism in Vietnam, autism in Asia, autism in Canada, autism in United States, parental ethnotheories, developmental niche, parental care in cultural context, autism care, qualitative and quantitative research.* The terms use during the online search were all peer reviewed journals. They were useful on searching for parents' experiences on autism care in Vietnam, Asian countries and Western countries, parental theories on childcare, healthcare practices of autism in Vietnam, developmental niche, mixed methods research and thematic analysis on qualitative data. The textbooks were valuable in providing information on mixed methods research, parental ethnotheories and conceptual framework.

2.2. Family support

Parenting in Asia

Across cultures, parents and caregivers have different parental practices and beliefs on how their child should be raised, and the variation differs within countries and communities. Parental practices change with times and changing contexts. Thus, “Asian parenting” does not imply that there is one way. This section will discuss common Asian parenting styles, expectations, beliefs and familial roles in childcare shared by several scholars.

Asian families rely on social networks with a focus on the ‘person within the group’ thinking. Wolf (1970) argued mothers and fathers play complementary roles for their children to grow into ethical and responsible individuals. Soloman (1971) argued that although fathers did not provide the emotional support for their children, they feel compassion and love for their children; fathers’ lack of showing emotional support is controlled by traditional and historical familial roles in their culture (as cited in Chao & Tseng, 2002). In caregiving, fathers participate less during their child’s early childhood stages and increase disciplinary practices as the child matures. However, a study by Shwalb, Nakazawa, Yamamoto, and Hyun (2003) review on Chinese, Japanese and Korean culture argued that fathering is affected by many contexts including history, changing families, work roles and marital relationships. Ho & Kang (1984) argued in a patriarchal system fathers use greater decision-making power than do mothers (as cited in Chao & Tseng, 2002). Despite a similar patriarchal structure in Vietnam, Zhou (1998) argued that Vietnamese mothers are highly engaged in family finances than most families in East Asia (cited in Chao & Tseng, 2002).

Yee, Huang, & Lew (1998) argued parents and other elders (i.e., grandparents, aunts, uncles, older siblings, and cousins) uses greater authority than do younger family members. Family roles in most societies from Asia are structured largely by age. They are expected to be highly involved, responsible for decision making and caring for children throughout their lives. Yu & Liu (1980) supported Yee et al., (1998) that parents should provide advice and guidance after the child becomes an adult and moves out of the household. Children are expected to consult with parents and other family members on important decisions. Gibson (1988) noted that male adults consult with their parents and siblings before making decisions on issues about marriage and finance (as cited in Chao & Tseng, 2002). The reliance on family members is evident in this literature review. Luo, Tamis-LeMonda, & Song (2013) argued the honouring of elders derived from Confucius inspired family and filial piety values.

A type of parental authority in Asia is parental expectations of the child’s obligations to their parents, these expectations are stronger than European American parents (Fuligni, Tseng, and

Chan, 1999; Phinney, Ong, & Madden, 2000). Baumrind (1971) supported these studies and found that authoritative and authoritarian parenting is shown through the children's compliance of their parents' instructions. However, Chao & Tseng (2002) argued while within childhood and adulthood, children are socialized to believe they should respect and follow the guidance of their parents, specific obligations depend on child's developmental stage, gender, and socioeconomic status.

Cheah, Leung, Tahseen & Schultz (2013) argued authoritative parenting comes from family cultural beliefs such as Confucianism and Buddhism.

2.3. Cultural beliefs about families

In Confucian-based societies in parts of East Asia and Southeast Asia, filial piety has been identified as a parenting belief, specifically, ideas of family interdependence. Confucian philosophy regarding filial piety has shaped parenting within China, Japan, Korea, and Vietnam (Ho, 1994; Sung, 1995; Zhou & Bankston, 1998 as cited in Chao & Tseng, 2002). As mentioned earlier, in Vietnam, respecting elders, family reputation and status are Confucian based family and filial values (Khanh, 1998, McLeod & Nguyen, 2001 as cited in Ha et al.,2014). The culture in Vietnam requires that children give parents and elders respect, care and obedience; this shapes the upbringing of the child. Wolf (1970) supported this idea with an example that sons are raised to be the caregivers of their elder parents, whereas daughters are raised for someone else's family. Among modern families, Jankowiak (1992) has found that Chinese parents in China have a closer relationship with their daughters than their sons. However, Harkness et al., (2000 & 2006), argued there are no exact cultural boundaries that shape the construct of the self. These examples show that even though some Asian cultures adopt the same philosophy, the roles and practice of filial piety varies within cultures.

Ho (1996) indicated filial piety is traditionally viewed as a rigid system of respect for age and patriarchy. In addition, Gammeltoft (2008) supported Ho (1996) that filial piety contributes to the perceptions of disabilities and ASD in Vietnam because there are prejudice and discrimination towards people with disability. People with disabilities are placed in society's perspective as the lowest status structure within the hierarchy of Buddhist structure. Wang, Power & Shen (2010) argued that due to globalization there may be a decline of filial piety, however, the social order in

Vietnam carries traditional and historical roots that continues to influence social relations with family members.

Some cultural beliefs consist of shame and blame among families in Asia. Grinker (2007) argued in Asian countries like South Korea, a child with autism is hidden from the public and is considered a hereditary disorder. Gammeltoft's (2008) example supported Grinker (2007) that some mothers were blamed by their husbands and the mother accepted the blame for the birth of the child.

According to Ha et al., (2014), in Vietnam, there are few studies that discuss Buddhist origins within families. Danseco (1997) suggested that parental beliefs adopt biomedical beliefs and distant themselves away from "magical, religious, supernatural or metaphysical beliefs" (p. 46). This could be interpreted as the reason why their may be few studies on Buddhist origins within families.

Gammeltoft (2008) argued karmic beliefs are associated with Buddhist conceptions. Moral consequences shape the structure of one's life, so if one does a good deed it brings positive effects and if one does a bad deed, it brings negative effects. Ha et al. (2014) supported Gammeltoft (2008) and contributed that the society's interpretation of karma influences family perceptions leaving parents feeling ashamed and guilty. If there are more studies on karmic beliefs among families of children with ASD, there will be a better understanding on the construction of family cultural beliefs and its impact on parental practices for the child with ASD.

Reciprocity

In line with Confucian philosophy, reciprocity plays a role within the cultural beliefs of families in Vietnam. There is a social expectation of exchanging of care between parent and child, this is also connected with interdependence family values and 'person within group' values (Chao & Tseng, 2002). There is a social assumption from parents that expect the care they provide for the child is to be returned to the parents when the child gets older. A child with a disability is a different case. Gammeltoft (2008) argued the social assumptions of a child with a disability diminishes the idea of a 'normal life' person and it impacts the child with a disability chances of being integrated into society, which removes the idea of the child returning the care to the parent. Palmer, Groce, Mont, Nguyen & Mitra (2015) supported Gammeltoft and added that parents perceives it creates a burden of childcaring and if the child with disability reaches adulthood, this leaves parents to fear concern for their child's future.

However, Goodnow (1996), argued the reason for adopting reciprocity as a practice is followed by regular procedures that emphasize the roles, duties and obligations. The role expectation parents have for their children is a type of interdependence embedded in the cultural care pattern of a Confucian collectivist belief.

Individualism and collectivism

Interdependence in Asian families are strong implications for the socialization process and connection of social relations between family members. This is a contrast between Western Europe and North America families that puts emphasis on independence. According to authors, the cultural emphasis of interdependence in Asian families has been a model for all relationships including education, religion, economics and politics (Kim Choi, 1994 & Ho, 1996 as cited in Chao & Tseng, 2012). It is a collectivistic culture that values interdependence which means it prioritizes group goals over individual goals. Ha et al. (2016) supported Chao & Tseng (2002) on the concept of collectivism that places group concerns such as group harmony and cohesion over personal concerns such self-enhancement and self-oriented goals. It is in contrast with individualism that places individual concerns above the group.

A study by Chao (1995) on the comparison of childrearing beliefs among immigrant Chinese mothers and European mothers discuss the interdependency and independency parental roles. It was found that both groups of mothers stressed the importance of loving the child, however, Chinese mothers fostered the parent–child relationship compared to European mothers that encouraged the child's self-esteem. Although both mothers desire to achieve the same outcome, Chinese mothers were motivated towards building a relationship goal and European mothers were motivated towards building independency within the relationship goal.

The study by Chao (1995) supported Trembath et al. (2005) argument that cultural minority groups – most of them are from collectivist cultures teach their children to function cooperatively within groups whereas cultural majority groups from individual cultures tend to raise children to be self-directed learners and independently oriented.

Ennis-Cole et al. (2013) argued that a family’s cultural beliefs and values directly influence their decisions about diagnosis, early intervention and ongoing therapies for their child with an ASD. Danseco (1997) supported that culture affects diagnosis and early intervention; some cultural groups believe treatment is not necessary in terms of delay of social and language skills for a child with a disability but instead, they believe it is a natural process for the child to grow out of it. This delay in diagnosis may impact the effectiveness of early intervention and impact the family’s choice of ASD treatment.

Tamis-LeMonda et al. (2008) argued individualism and collectivism should not be binary from each other meaning they should not be understood as mutually exclusive concepts and instead, complement each other (as cited in Penderi & Petrogiannis, 2011). Understanding both concepts of individualism and collectivism provides a complex understanding of cultural boundaries and implies there should be more cross-cultural studies between Western and non-Western studies to understand the cultural models of individualism and collectivism.

Parental goals

Goals depends on the parenting styles among cultural groups and every style differs between majority mainstream culture and minority ethnic culture; parenting styles vary based on the context. However, there are universal goals that may be shared cross-culturally. Coll & Pachter (2002) argued parents have goals for their children which is to promote successful transitioning from their early years of childhood into self-sufficient adults. Parents have universal goals for their children such as, ensuring the child is physically safe, an environment for the child to develop successfully and the child to carry socially accepted values.

Goodnow & Collins (1990) argued that rationales of goals for the child is either an action of compliance from the child or a negotiation and cooperation from the child. A study by Luo et al. (2013) reported that children from Mainland China who show obedience and compliance to their parents’ instructions, their parents are mostly likely to reward them. Showing respect and obedience to a parent is a goal desired by parents in Mainland China. This comes from Confucius value of filial piety as the parent will not show affection to the child if the child does not show love to parents. Respect and obedience are considered love in this context. Chan, Bowes & Wyver (2009) reported similarities in Hong Kong where parents believe filial piety is an important goal for children.

Baumrind (1971) argued that children who obey their parents without instructions is a type of authoritative and authoritarian parenting. Luo et al. (2013) argued parental developmental goal might reflect on the parental practices, however developmental goals and practices are affected by a broader context of family. Goodnow & Collins (1990) supported Luo et al. (2013) that goals may reflect on environmental factors while others reflect on traditions. This suggest that some parents' developmental goals are affected by forces outside of Confucian philosophy.

2.4. Social support and parental experiences

Experiences with finding support

According to Cobb (1976), social support is the belief of the individual "that one is cared for and loved, esteemed and valued, and belongs to a network of communication and mutual obligations" (Cobb, 1976 as cited in Buchanan, 2011, p. 4).

When it comes to social support, research from Western countries are strongly supported by scholarly institutions and government that provide funds, policies and services to help people in the ASD community, however it is not a perfect system and parents continue to experience challenges with access to services. Ha et al. (2014) argued that in Vietnam, there are few studies of families' experiences when caring for their children with ASD and understanding the resources they used, so the information of receiving support from government, institutions and community are unclear. It is unclear to whether autistic children ask for help directly to their parents because they do not actively seek physical contact and do not react strongly around the presence of family members (Beauchesne & Kelley, 2004), therefore it may be difficult for parents to show attachment behaviours with their autistic child.

The delay of waiting for diagnosis, travelling to services, paying for services and seeking quality services are a concern for parents in Vietnam (Tran, et al., 2015), Taiwan (Duong et al., 2017), China (Xueqin et al., 2012) and South Korea (Grinker & Cho, 2013). For most Asian countries, the time between the diagnosis and acceptance into the hospital day care program is a crucial period for parents beginning their care for their autistic child. In other treatment centres, the choices of quality treatment and support may not be standardized and approved by officials. Ha et al. (2014) argued the practice of Chinese and Vietnamese alternative medicine including acupuncture, spiritual practices, and worship are used as interventions for children with ASD, but they are costly and unknown to be effective.

Tran et al. (2015) argued this period can also have long-term effects since parents' emotional state and fear of the unknown may lead to excessive treatment seeking or unwillingness to continue treatments in the future. The emotional state of parents can be stressful for them and they may need to learn how to cope with the stress, however, little is known about the coping mechanisms used by parents in the period of post diagnosis.

From a Western perspective, parents of children with ASD in Canada (Shepherd & Waddell, 2015) and the United States (Hunt, 2012) experience delays between diagnosis and utilizing services within their community, this affects the transitions from childhood to adulthood, school services and early intervention strategies. Tran et al. (2015) argued that although Canada and the United State experience similar challenges, they have standardized quality assessments to assess parents' and caregivers' stress experiences, therefore they can develop better family treatment plans.

Government support

According to ILO (2013), the government in Vietnam adopted number of polices to protect and promote people with disabilities. This includes, The Constitution of the Socialist Republic of Viet Nam which protects people with disabilities, The Viet Nam National Law on Disability (2010) which establish barrier free access for people with disabilities, and The National Action Plan to Support People with Disabilities for 2012-2020. As for the requirements under the United Nations Convention on the Rights of Persons with Disabilities (CRPD), the policies are not implemented efficiently within communities in Vietnam. Policies around people with disability are said to have included "intensified social and political interest in childhood disability" (Gammeltoft, 2008, p. 828). A study by Palmer et al. (2015) on the economic lives of people with disabilities in northern Vietnam reported families experience burdensome because of essential needs such as education, health care, assisted devices and supports for people with disabilities due to high cost, access and availability. Ha et al. (2014) argued since the economic reforms of the Doi Moi emerged, it created disparities for health and education systems, therefore policies lack the capacity to provide such services.

According to UNICEF on the National Survey of People with Disabilities (2016), people with disabilities are poorer than the average population and children with disabilities are less likely to access school than children without disabilities. Ha et al. (2014), reported parents experience challenges in enrolling their children in schools in Hanoi. Le et al. (2009) added that high fees of services for disability, inaccessible transportation and bureaucracy within health care system creates barriers for people with disabilities. Mak & Kwok (2010) argued the barriers are because of the social attitudes towards people with disabilities, particularly autism.

Bagatell (2010) reported in contrast with the United States, there are policies, funds and services to support people with autism. They have policies on the inclusion of children with a focus on specialized devices such as wheelchairs to access public spaces, this has transformed the lives of children with disabilities (Harkness, Super, Sutherland, Blom, Moscardino, Mavridis, & Axia, 2007).

According to Palmer et al. (2015), governments can build a stronger and integrated system for people with disabilities in Vietnam. However, it is difficult for the government to know the amount of people to support if there is no national disability rate (Ha et al., 2014). If more is known about parents' experiences with government support in Vietnam, we can understand what parents need from the government and what the government needs from parents to improve the lives of children with disabilities.

In response to the lack of government support, parents and families have collaborated to create parent-led groups to provide interventions and train teachers and health professionals to care for their children with ASD (Ha et al., 2014). However, some organizations are not recognized by government authorities.

Experiences of shame and stigma

In some countries in Asia, there is often a stigmatising cultural attitude towards disability which affects families, caregivers, friends and service providers (Mak & Kwok, 2010). Xueqin et al. (2012) reported in China, parental concern of losing reputation and the issue of stigma causes some families to not seek professional help. Grinker & Cho (2013) reported in South Korea, mothers with autistic children have the fear of being socially excluded and stigmatised from teachers and families so they tend to resist diagnoses but feel pressured to accept advice from professionals.

In traditional settings in Asia, children's success is influenced on the parents' caregiving abilities and parents are blamed if they have a child with a disability (Le, 2013). In Taiwan, some parents of an autistic child are criticized by the grandparents because they believe the parents are responsible for their child's autism (Duong et al., 2017). Some parents deny their child is autistic and if they accept their disorder, it means they acknowledge their child is different. Tait et al. (2016) argued the effects of family stigma is continued by internalized stigma affecting the levels of care burden and family dysfunctions.

Ha et al. (2014) argued stigma may arise through the mistaken association of ASD with schizophrenia. Jorm (2000) argued the association of developmental disability with mental health is because of the limited mental health awareness among the population including teachers and students which indicates a lack of health literacy. Health literacy is defined as the knowledge of how to seek information, the risk and factors, self-treatments and professional support (Van Der Ham, Wright, Van, Doan & Broerse, 2011). Vuong, Ginneken, Morris, Ha, & Busse (2011) argued this may explain the reason for high stigmatization and discrimination against those with ASD.

Huang, Kellett, & St John (2010) argued the impact of stigma on families with a child with a disability can result in anxiety and stress among parents. Weitlauf et al. (2014) added stress results in lower relationship satisfaction with their partners. Kim Wang, Orozco-Lapray, Shen & Murtuza (2012) supported Huang et al. (2010) and added the construction of stigma makes families reluctant to seek medical help.

Shu et al. (2000) reported in Taiwan, mothers of autistic children experience greater stress and develop mental health disorders compared to mothers of children with other disorders; thus, it prevents them from finding help for their children and themselves. Shin et al. (2006) presented results from parents of children with cognitive delays in Vietnam showed that mothers experience more stress than fathers in caregiving, however both parents experience stress when it comes to stigmatization.

According to Deater-Deckard (1998), parental stress is the experience of distress or discomfort that results from demands associated with the role of parenting. It is important to consider distress may arise for many reasons that are not directly linked to having a child with a disability and may be rather linked to environmental factors.

Coping strategies

A study by Fleischmann (2005) on parents of children with disabilities have found to adopt two types of coping mechanisms such as, seeking information and seeking formal and informal support (Dunn et al. 2001, Gray 2003, Luther et al., 2005 as cited in Mancil, Boyd & Bedesem, 2009). The first type are parents who actively seek information health support for their children. When parents first learn their child's diagnosis, they acquire information from healthcare providers, other patients, and online resources (Fleischmann, 2005). The second type are parents who seek help from social support systems, including professionals, relatives and friends (Dunn et al. 2001, Gray 2003, Luther et al., 2005 as cited in Mancil et al., 2009) to cope with the heavy burdens of caregiving and to prevent burnout (Higgins et al., 2001). Overall, a coping mechanism for parents is seeking help from support systems.

2.5. Summary

A vast amount of literature was presented to demonstrate a cross-cultural understanding of parents' experiences of care for their children with ASD across Asian countries and some Western countries. The literature review provided supported ideas to help answer the research question. The next chapter will discuss parental ethnotheories and introduce the conceptual framework.

CHAPTER 3. CONCEPTUAL FRAMEWORK

3.1. Introduction

Parental cultural belief systems explore different cultural contexts and the development of human behaviour (Harkness & Super, 1996). This section will present an interactive model that is a framework based on parental cultural belief systems, it explores the interactive relationship between the parent and child explained and organized by concepts. The purpose of this chapter is to explain the development of the framework and how and why it will be used to help answer the research question. Based on the framework, there will be three components that addresses the culturally constructed daily life of the autistic child: (1) physical and social settings, (2) customs of childcare and child-rearing and (3) psychology of caregivers.

3.2. The developmental niche framework

A conceptual framework that has been often used to structure the context in which a child lives is *the developmental niche* developed by Super and Harkness (1994). It is essentially a cultural model that guides the child's developmental process and determines their social behaviours. This framework was influenced by the construction of anthropologists: Ruth Benedict, Margaret Mead and Beatrice Whiting, as well as Bronfenbrenner's ecological Model (1999) (Gardiner, 2018). The developmental niche presents a connection between the development in different cultural contexts and studies of children's behaviour (Harkness & Super, 1994).

The developmental niche is suitable for exploring the environments of individuals with disabilities interacting with key actors' assumptions and perceptions about "what constitutes an agenda for successful development" (Harkness, Super, Sutherland, Blom, Moscardino, Mavridis & Axia, 2007, p. 33). Key actors are whoever is centrally present in the child's developmental life such as parents, family members, friends, neighbours, doctors, teachers etc. This framework describes an open and interactive system around the child with ASD while their cultural environment is facilitated by their parents' and caregivers' care. Identifying patterns of interactions between and within relationships are crucial when implementing this framework because the interactions between the child and parents mediates the development of the child in their early years. Parents hold certain ideals and beliefs when interacting with their child, this is a significant impact on the caregiving routine the child receives.

The developmental niche is an open system with interrelations between the sub-systems (components) within the larger system. The larger system could be external forces such as socioeconomical or historical change that influences the child. The components do not operate as a coordinated system meaning the child may change or adapt to their environment, an example is an alternation of the family structure such as grandparents and siblings helping parents care for the autistic child to support the his or her needs.

The framework will examine the interactive system between the autistic child in their cultural environment facilitated by the caregiving of parents and caregivers. The framework will be conceptualized into three interrelated components (Super and Harkness, 1994): (1) physical and social settings, (2) customs of childcare and child-rearing and (3) psychology of caregivers. These components will be represented in a way that addresses the culturally constructed daily life of the child with ASD and exploring parental caregiving experiences.

3.3. Three components of the developmental niche

The developmental niche is a conceptual framework because the three concepts are interrelated components that acts independently while interacting with each other in an 'open system' (Gardiner, 2018). These components form the micro-environment of the child which includes the physical and social settings of child's life, caregiver's psychology and customs of caregiving and child-rearing.

The first component is the daily physical and social setting surrounding the child's life which may focus on family structure, size of the physical environment and/or any physical/social objects surrounding the child. At home or treatment centres, there is a group thinking for children to sit on the floor with other children in their physical environment. In treatment centres, items such as toys and school supplies are placed around the children to facilitate a learning environment. Other items such as schedules are posted around the room to indicate a structured routine for the children such as: class time, play time, school chores, mealtime and nap time. Toys are present around the autistic child such as electronic devices and sensory games to stimulate learning of the child. There are some communicative electronic devices that are used to communicate with teachers and are used as a 'reward system' when the children achieved a desirable behaviour.

The second component is the customs of childcare and child-rearing which is the cultural parenting styles and childcare practices. The practice of family members caring for other family members is an example. Parents, siblings of parents, siblings of child (if old enough) and grandparents' plays a role in caregiving the autistic child. This type of care could be feeding, bathing, toileting, teaching and playing. Informal learning takes place in the household if the child is not ready to attend school yet. Parents learn treatment practices from teachers and doctors and uses these practices at home. Parents participate in teaching social, behaviour and communication skills to the child at home is highly encouraged by teachers and doctors; it is crucial to keep treatment practices consistent at home and outside of home.

The third component is the caregiver's psychology which is the socially and culturally constructed ideas of the parent or caregiver, developmental expectations and psychological characteristics of the parents (Gardiner, 2018). Parents play an important role in shaping the early years of the child; it is a strong contribution to the child's developmental stages as they grow older. The caregiver's psychology could be known as the belief and/or value systems of the parents' parenting style, in other words, they are ethnotheories.

Parental ethnotheories

Parents and caregivers are main actors on deciding the care for their child and they may play a potential role in creating a healthy environment for their child. Parental practices may come from parental ideas about the development and caregiving practices of their children (Palacios & Moreno, 1996). Parental beliefs may be in congruent with parenting skills. While many parents are starting to look for support when they detect a problem in their child, how they look for support and use the support to care for their child remains unknown. Therefore, to understand how parents think and why they make the decisions they make, it is important to address ethnotheories.

Parental ethnotheories inform perceptions about the children and their own parenting which they are essentially "related to group differences about parental behaviour and child development" (Harkness et al., 2007, p. 345). It provides an understanding on parents' ideals on the development of their child and addresses the placement of culture within the context. Culture is placed within the larger category of beliefs and provides an observable link between beliefs and behaviour. Examining the cultural context of the child's life can provide knowledge on the needs of the child to grow and develop healthy in an environment.

Parental ethnotheories explain parents’ motivations, beliefs, attitudes or behaviours in shaping the relationship of care they provide for their children. According to Srivastava, Torquati & Guzman (2018), parental ethnotheories are “culturally structured belief systems about child development and childrearing practices that are developed in the course of growing up in their culture” (p. 728). Goodnow (1996) supports Srivastava et al. (2008) that ethnotheories provides a way to understand parental actions and ideas as one aspect of “social context” within child’s development. Culture provides a specific way for parents to behave among social relationships.

Parental ethnotheories explains parental priorities and values; for example, parents have a goal for their child to sit down and eat a meal with family. If parents did not prioritize these practices, then they would less likely engage with early intervention strategies and treatment for their children. Parents influence the routines of their child in their everyday environment whether it is caring, toileting, feeding, teaching, etc. which makes it imperative to examine their customs of care and routines. To present the understanding of parental care for children with ASD in a conceptual manner, the developmental niche is adopted and will be used throughout the entire study.

External systems of the developmental niche

Beyond the three components, there is an outer layer that is interconnected to the components. The developmental niche is a “constantly evolving system” (Harkness & Super, 1994, p. 223) which means external forces can come inside and outside the system such as political, socio-economic, historical and cultural influences. A few examples could be changes in policies, civil movements, climate change, natural disasters etc. The system is viewed as a larger layer of culture and ecology that influences the interacting components. Simultaneously, these components continue to focus on the developing child in its environment. The larger layer may or may not affect the components concurrently which means the sub-systems are never congruent with each other. Overall, the use of the developmental niche collects and organizes information on the parental caregiving experiences into sub-systems and it presents the complexity of family within their own lived experiences; this helps develop human understanding at a greater scale.

3.4. The developmental niche in other studies

A growing number of scholars have shown the usefulness of the developmental niche in their studies (Harkness & Super, 1994;1996; Dybdahl, 1996; Harkness et al., 2007; Penderi & Petrogiannis, 2011). This section will present examples on usage of the framework to understand the certain phenomenon. The aim of this section is to provide justification on the effectiveness of the conceptual framework in diverse studies and support the decision for using the framework in this current research.

A study by Harkness and Super (1994) on analyzing the household production of health uses the developmental niche to collect and identify information on household factors to determine the health outcomes within varies countries including, Malaysia, Kenya, Bangladesh, India and the United States. It uses the framework to develop a cross-cultural understanding of each country's household production of health. The collection of the systematic data that is shown in the three components and its implications to health provides tools to develop interventions linking to health outcomes. This example of the developmental niche used in this study presents a useful technique to assessing health needs of the individual in the environment while using a cross-cultural lens.

Another example is a study by Dybdahl (1996) who explores the childhood within the sociocultural context of Somalia using the developmental niche. The author collected data from interviews and came up with several themes related to Somali childhood. As a recommendation, the author indicates the need for more studies of children within the culture and context. After the research, the author follows up with the study to design a psychological intervention program for children and parent families in the context of Bosnia and Herzegovina (Dybdahl, 1996 cited in Gardiner, 2018). In this study it describes how research from the theoretical and conceptual approach can be develop as a practical approach. It encourages the use of more research on studying the child within their social-cultural context considering that most studies are dominated by Western research.

The examples shown above illustrates the usefulness of the developmental niche in diverse research by examining the linkage of parenting between the development of the child and the culture. The framework creates a visual space to conceptualize the collected data so interpretations can be made. This provides practicality on post research by informing and enhancing interventions utilized by professionals to support the development of children.

3.5. The developmental niche in relation to the research question

I used the developmental niche framework to explore parental care for their children with autism in Hanoi. The framework is used to structure the development of the child shaped by cultural and social influence of parental care. It helps formulate views and perspectives of parents on the care they provide for their child. Little is known about Vietnamese parents and caregivers' caregiving experiences relating to the type of care provided for child, the access to supports and services, addressing challenges and coping with challenges. Therefore, the developmental niche framework will help explore cultural and social factors that contributes to parental belief systems, parental expectations and parental styles that influences the management and care of autistic children in Hanoi.

3.6. How the developmental niche is used in the study

The developmental niche is utilized as a tool to identify, analyze, interpret and summarize the findings of the research with a focus on the child with ASD. It organizes the findings within the three components mentioned. Although the framework puts attention to a single individual (the child) from one families experience, in this study, the emerging themes from the findings had generalized family experiences and merged the attention into a single community of autistic children located in Hanoi.

The application of the developmental niche framework was used in two parts. The first part of the developmental niche was based on the existing components that had its own indicators; this created a lens to help identify potential themes from the findings of the research. The use of the lens provided a focus point to identify and develop themes that answered the research question. Once the themes emerged, it was refined which will be explained in Chapter 5. The second part of the developmental niche used the finalized themes from the findings and was referred to the structure of the framework. The aim was to connect the themes to one or more component of developmental niche. Therefore, the themes become the niches of parental care for children with ASD in Hanoi. Throughout the process of applying the themes to the framework, it was ensured that the components are open and interactive with each other. It was understood that not all indicators of each component were found in the findings.

The approach of using the developmental niche within the study provided an understanding of the complex layers of the three components surrounding the development of the autistic child. The findings were organized into these components to give a clear visual interpretation of parental experiences of autism childcare. It explains the layers of systems with a detailed focus within the microsystem while recognizing there is an interaction and facilitation of the macrosystem. It is the natural integration of culture within the whole system of the framework. In a microsystem that is centered on the development of child with ASD, it identifies the micro forces such as the availability or lack of autism services and resources, parental ideas on caregiving, expectations of familial roles, interaction of stakeholders and factors of daily routines. In a macrosystem, it illustrates greater forces such as political, historical and socioeconomic changes, spiritual/religious belief systems and natural environmental changes. This parent-child in the environment interaction justifies an important use of the conceptual framework because it gives reasons to understand parents' decision making on caring for their child and the impact of those choices on the child.

3.7. Summary

Super and Harkness's concept of the developmental niche involves a combination of psychology and anthropology research that provides an understanding on the daily life activities which can be used to understand children with ASD within their cultural and social environment. This cross-cultural human development model provides a foundation for determining the relations between components that influences the development of the child with ASD. It is a model to see more of in the future. In the next chapter, techniques on how the data was collected and analyzed will be explained.

CHAPTER 4. METHODS AND ANALYSIS

4.1. Introduction

The purpose of this chapter is to describe the various research activities I took to answer the research question on the experiences of parents and caregivers raising their children with ASD in Hanoi. I will elaborate on the rationale of choosing the mixed methods, the recruitment of the research team, the recruitment of the participations, the instruments used, the data collection procedure, the ethical considerations, and finally, the analysis of the research.

4.2. Rationale for mixed methods

This research is an exploratory design using mixed methods design, it was chosen due to its helpfulness in answering the early stage of the research question. The flexibility of the exploratory design allows the data to formulate a hypothesis (Creswell, 2011) and it contributes to filling in the knowledge gap while present literature cannot. The primary data is the qualitative approach that uses face-to-face semi-structured interviews to understand the human behaviour and the social and psychological side of the parents' experience in caring for their autistic child. Interviews provides a natural setting for parents to share their experiences in a humanistic way. The secondary data is the quantitative approach that uses a standardized tool of measurement, it provides a statistical understanding on the parents' beliefs and ideas on treatments of ASD. Most social scientists use either a quantitative method or a qualitative method when exploring parental styles and coping styles on raising a child with ASD in Vietnam (Luong et al., 2009). Mixed methods use strengths of both qualitative method and quantitative method to compliment each other fruitfully, which can help understand how parents and caregivers care for their autistic child.

Mixed methods present participants' perspectives from diverse views using a combination of demographic questionnaires, Likert scale surveys, open ended semi-structured interviews and informal observations. I used both qualitative and quantitative methods to collect data in concurrent timing then analyzed the data separately and brought it together during interpretation; this is called a convergent mixed methods design (Creswell, 2011). It is important to note that this mixed methods design is fixed mixed methods meaning I predetermined qualitative and quantitative methods at the beginning of the research (Creswell, 2011). I decided to use the qualitative data from the interviews as the primary source while to use the quantitative data from surveys as the secondary source. Although, augmenting qualitative findings is part of the method, there is equal importance to both methods addressing the research question. The qualitative data from interviews explore parents' experiences in supporting their children which cannot be explained by quantitative data. The quantitative data from surveys explore parents' perceptions of health seeking behaviour and treatment approaches for their children. Therefore, quantitative data provide statistical trends that enhances the qualitative data. This makes it appropriate to develop themes in relation to the conceptual framework of the developmental niche.

4.3. Study area in Hanoi, Vietnam

I chose Hanoi as a study area for two reasons. Firstly, I needed to know someone who would host my research and provide me access to collecting data in certain areas of Hanoi. My co-supervisor had connections to private treatment centres and the Vietnam National Children's Hospital in Hanoi, therefore I was able to establish contact with the sites to collect data. Eight weeks were recommended by my co-supervisor based on her experience with data collection in Hanoi, the sample size of participants, administration, preparation for the data collection package and extra time for translations.

Secondly, Hanoi is the second largest city in Vietnam and has most of its leading hospitals (Ha et al., 2014) with medical and health resources for children and families based in the urban areas of Hanoi, this led me to select this study area. Based on the gap of knowledge on understanding parents' experiences on autism and childcare, I was determined to find meaningful data in this study area.

Map of Vietnam [Map of Vietnam showing study area]. (2019)
Retrieved from https://www.lonelyplanet.com/maps/asia/vietnam/

4.4. Recruitment of research team

The recruitment for the research team consisted of two volunteer research assistants' position - qualitative research assistant and quantitative research assistant. The research assistants had to speak and write English and Vietnamese, hold a formal education from a post-secondary education, present some research experience and have a clear understanding of research ethics. Volunteer contracts were provided to research assistants that outlined the following: description of research, tasks and responsibilities, time plan, research ethics and intellectual property (please see Appendix D). Training for the research assistants were provided before the data collection began and it took place in Hanoi.

4.5. Pilot test

The data collection package was pilot tested in English in Canada. This was a pragmatic decision that worked for my convenience as I was presently in Canada during that time. I recruited mock participants to participate in the research. The participants were caregivers, special needs teachers, and/or parents who had children with ASD/disability. The mock surveys and open-ended face-to-face semi-structured interviews were timed and recorded so I had a sense of time for each participant. After the interviews, feedback was given by participants to address if any interview questions did not make sense to them. I made notes of this experience because it was a good practice for me to perform in the actual research. There were small modifications made to the interview questions based on their feedback. The second round of pilot test was done in Vietnam; the data collection package was translated from English to Vietnamese by the research team. The survey and interview were timed to predict the duration for future participants and feedback was given by participant to check if the translations were accurate. The feedback resulted in minor changes to the translations.

4.6. Participants

The participants were recruited by convenience sampling with the goal to collect 8-15 interviewees for the qualitative study, and 80 – 100 survey participants (survey participants included 8-15 interviewees). The participants are parents who seek help for their children with autism spectrum disorder (ASD). Participants included any primary caregiver who cares for the autistic child such as parents, family relatives, friends, or neighbours etc. The child must be diagnosed with autism or ASD. The child can be diagnosed at any age. To reach the target number for surveys, each parent who had a partner was given the survey as well. Some parents were single, so they were only given one survey. I will use parents and participants interchangeably throughout this research.

Socio-economic background of the participants

The socio-economic background of the participants are females and males, married, divorced, separated, 18 – 54 years old, holds an education of post-secondary school, post-university, university, college, vocational school, high school, secondary school, no school, and works in various occupations. There are no ethnic groups and religion specified (please see Table 4. for Parent Demographic. The participants in the study had pseudonyms to protect their identity. Please see Appendix G for Interview Guideline.

The background of the participants' children was diagnosed with autism or autism spectrum disorder, aged 1 – 9 years old, and diagnosed by doctor, psychologist, specialist, family, teacher or other. Please see Table 5. for children's demographic.

4.7. Data collection procedure

The research team met the directors of treatment centres and Children's National Hospital in Hanoi, explained the project and recruitment process in Vietnamese and distributed the surveys. There were 20 surveys distributed to each of the three treatment centres and 40 surveys to the hospital; altogether it was 100 surveys. The strategy was to give the survey package to the parent and their partner. A total of 48 participants participated in survey from the treatment centre and a total of 41 surveys were completed from the hospital. The director self-administered the package which contained consent form, demographic questionnaire and survey provided to the participant. Participants had the choice to complete it at the centre/hospital or take it home then return it to the director. It is important to note the research team made sure the participants understood their protection of private information in the study which is also indicated in the consent form (please see Appendix D). The surveys that were not completed were returned to the research team. The duration of the demographic questionnaire and survey was approximately 15 minutes.

A tracker sheet was used to remind the research team the completion date of surveys were seven days apart so then the recruitment for interviews can begin. It was a strategy to limit biases from the survey that may influence the interviews (please see Appendix H for compensation tracker). Seven days after the completion of the survey, participants were contacted by phone for interview invitations, this was determined by whoever conveniently responded first. Three interviews took place in the treatment centres and six interviews took place in the hospital. The duration of the interview was 30 minutes – 90 minutes length, this included the time for Vietnamese and English interpretation. For the setting of the interview, participants were able to choose where they wanted to be interviewed. Interviews were performed continuously until the researcher noticed a similar pattern of themes; this pragmatic practice I used employs "what works" to address the research question (Murphy, 1990).

Survey questionnaire

The survey response scale questions were borrowed from Furnham and Buck (2003). The survey was used to understand the cognitive perceptions of parents' health seeking behaviours, causes of autism and their treatment approaches. To note, questions #5, 6, 7, 13, 14, 15, 21, 22, 23, 24, 29, 30, 31, 37 & 38 were developed by myself. The knowledge was built from Furnham and Buck's questions because the authors' addresses treatment approaches, however they did not address where and how parents seek help for their children. The Likert scale ranges from 1 to 7 which strongly disagree = 1, disagree= 2, somewhat disagree = 3, neutral = 4, somewhat agree = 5, agree = 6 and strongly agree = 7.

Interviews

I designed the interview questions based on the desire to explore the research question and to identify convergence and/or divergence in the findings. The interviews were audio-recorded and used hand-written field notes. A research assistant was present for interpretation of the interviews.

Informal observation

During my off-site field work, I had the time to network with private treatment centres that provided treatment for children with autism. I had the opportunity to ask them questions about the centre and their knowledge on autism and families in Vietnam. I understood these findings cannot be generalized to the population, so I did not include them in my findings, however it provided background knowledge for the research.

4.8. Ethical considerations

Informed consent

An approval from the Norwegian Centre for Research Data - Norsk senter for forskningsdata (NSD), Vietnam National University, College of Education and Vietnam National Children's Hospital in Hanoi granted permission for the research project to take place. In the Vietnam Children's National Hospital, the international department, scientific council and ethical committee approved the data collection to take place within the hospital. To ensure the integrity, transparency and impartiality of the research, the Guidelines for Research Ethics in the Social Sciences, Humanities, Law and Theology (NESH, 2018), the National Association of Social Workers (NASW) code of ethics and Vietnam's code of ethics in research were followed. Such codes followed are service, social justice, dignity and worth of the person, importance of human relationships, integrity, and competence (NASW, 2017 & NESH, 2018). The confidentiality and anonymity of participants were respected. The project is funded by Oslo Metropolitan University Social Science Scholarship 2018.

Consent from private treatment centre and Vietnam National Children's Hospital

The private treatment centres were easily accessible and complied with the data collection procedure. The director understood the recruitment process and it was confirmed a trust-based relationship was already established from with the co-supervisor. However, contacting the Vietnam National Children's Hospital in Hanoi was time consuming and a lengthy process. After the approval of all sections, data collection in the hospital began. Please see Appendix C for approval of scientific research department, international research department and the ethics committee.

Compensation for research

As stated in the consent form, each participant was compensated with 100,000 VND (approximately 35 NOK) for participating in the survey and a second 100,000 VND for participating in the interview; this was for participants' travel time and time spent participating. The money was marked on the tracker to indicate the proof of compensation for each participant. Please see Appendix E for consent form and Appendix H for tracker.

Data storage, access and dissemination

My role as a researcher is to be responsible to the ownership of the data while liable to the protection of participants' data. All collected data such as interview guideline, survey and demographic questionnaires, consent forms, tracker sheet and interview notebook are kept safely in a lock cabinet. All electronic data such as audio recordings and data from surveys has been anonymized to protect the security of participants and kept in a USB stick and locked in a cabinet.

ANALYSIS

4.9. Data analysis

Qualitative analytic approach

To develop the emergent of themes from the data of interviews, I used thematic analysis (TA) by Clarke and Braun (2006). TA is post-positivist framework that is used to identify themes, the development of reliability coding, generating codes and interpreting codes (Boyatzis, 1998; Guest, MacQueen, & Namey, 2012). It organizes the qualitative findings and provides a passage from the exploratory findings of the research. I argue it provides a strong link to bridging the gap between qualitative and quantitative research and facilitates a guidance to answering the research question of the current study. TA is often favoured by qualitative researchers (Selvam & Collicutt, 2013 as cited in Clarke & Braun, 2017).

TA provides a systematic way to organize patterns of ideas and generate them into codes and themes from my interviews, non-formal observations and field notes. TA helps understand and interpret participants' experiences, perceptions, ideas and beliefs and connect to their feelings, thoughts and actions. Due to the flexibility of the TA (Clarke & Braun, 2017), it provides an understanding to the research question in a meaningful way evolved from coding and development. TA is followed by a six-phased guide as ordered: familiarizing with data, generalizing initial codes, searching for themes, reviewing themes, defining, naming and renaming themes and producing final themes. I collected all the qualitative data from mainly interviews, additional data from non-formal observations and field notes assisted me to generate initial codes.

Familiarizing with data

For familiarizing myself with the data, I immersed myself with the data by listening to the recording of the data twice and handwriting it twice. I also reviewed the field notes and asked the research assistants to provide me their notes to begin the transcription. The second time I wrote out the data, I was able to revise what I wrote the first time and observe what I missed. Although it took time, by reading the entire set of qualitative data three times, I was then able to find better meanings and ideas from it. It was suggested by the author that immersion is part of reading the data in repetition (Braun & Clarke, 2006). During transcription, I was aware to stay true to the original nature of the data so that is why I put extensive time into the early stages of transcribing the data. After I wrote out the transcription twice, checked observational notes and used the notes the research assistants provided, I checked the audio recordings again as a final check for accuracy.

Generalizing initial codes

After I was familiar with the data, I generated a list of ideas about the findings in the data and what was interesting about it. In this phase, it was the first step in producing the initial codes. The raw data allowed me to see it in its true and real form without any filters and the coding process allowed me to determine how to put the raw data into sections. I generated labels (codes) to these ideas and it was helpful to use the notes I made for coding from the first phase in familiarizing the data. I started generalizing the data to find patterns of meanings and unique/interesting data that contributed to answering the research question. From the entire set of data, I generated forty codes that were ready to be clustered for the next step.

Searching for themes

In this phase, I had a long list of codes there were produced that had to be organized into clusters of themes. All the codes had to be sorted into potential themes and the appropriate coded data had to be extracted with the identified themes. This is where I started to analyze the codes attentively while considering they could be potential themes. I used a mind map to help me visually see the representation of the work with the forty codes I produced. This helped me review the practicality of the development of each theme where I was able to think of the relationship between the code and the theme. As a result, I clustered the codes into fifteen categories labelled: ‘parents’ concern of daily life,’ ‘dependent on family,’ needs for specialize services,’ ‘recognized diagnosis earlier,’ ‘socialization for child,’ ‘constantly thinking of child,’ ‘how parents seek help,’ ‘parents positivity,’ ‘how parents decide on right information,’ ‘family support,’ ‘karma,’ ‘sacrifice,’ ‘alternative treatment methods,’ ‘stories about autism from other families,’ and ‘expectations of normal versus abnormal child.’ As I gathered the codes into themes, I acknowledged the themes may change due to analysis process.

Reviewing themes

At this phase, it involved reviewing the themes against the set of data and the process of refining themes. It became apparent that some themes were not themes because some did not have enough data to support it and some of the data was too distant from the data set. I checked to see if the codes matched the themes for the entire data set; codes that were refined had been combined and codes that stood alone and could not match theme were omitted. Some themes were refined such as: ‘dependent on family,’ ‘socialization for child’ and ‘how parents seek help family support.’ While some themes like ‘alternative treatment methods,’ and ‘stories about autism from other families’ were omitted. In this process, I realized a lot of themes had shared meaning that supported the main concept. However, I did not feel the need to go back re-code the data because the data was a good fit. Overall, I felt the categories I refined were able to represent the data set and it answered the research question.

The first stage of the refined themes were: i) choice of support is based on observing child’s need, ii) centrality of the family and family interdependence, iii) parents’ developmental goal for the child, iv) parents prioritize their children’s needs before their own, v) importance of early intervention, vi) parental sources of information and lastly, vii) importance of loving a child.

Defining, naming and renaming themes

I focused on each of the seven themes to determine the best representation of the data. Braun & Clarke (2006) emphasizes the representation of the ‘story’ must reflect the overall data while answering the research question. I did not have to produce a sub-theme within this process. This process also entailed renaming the theme into an informative and useful theme that is readable to audience and significant to answering the research question.

In Figure 2, it presents the formulation of the seven original themes into three new themes. The first theme is the combination of ‘family interdependence,’ and ‘centrality of the family,’ ‘parents prioritize their children’s needs before their own,’ and ‘importance of loving a child’ are refined into new theme one, ‘centeredness of family.’ The second theme is the compilation of ‘choice of support is based on observing child’s needs,’ ‘parental developmental goals for the child,’ and ‘importance of loving a child’ is refined into new theme two, ‘parents’ developmental goals.’ The last theme is a compilation of ‘parental sources of information,’ ‘importance of early intervention,’ and ‘importance of loving a child’ is refined into ‘social support.’

Producing the report/final themes

After defining, naming and renaming themes, I weaved together an analytic ‘story’ of data extracts while analyzing the concepts surrounding the existing literature and conceptual framework. This process helped me produce the final themes. I asked myself questions to provide myself clarity on the themes: ‘what story each theme, or all themes reveal?’ ‘What does each theme mean?’ The following new themes will be used throughout the chapters: centeredness of family, parents’ developmental goals and social support. Lastly, I confirmed the final themes were connected to research question, literature review, conceptual framework and the whole analytical narrative. In Figure 2, it presents the first seven refined themes that were refined into the three themes that will be used to contextualize the literature review, the overall data and conceptual framework.

Quantitative analytic approach

I collated the data from the surveys and input it into IBM SPSS Statistics 25; a data analysis program that helped me organize and analyze my quantitative findings. The Likert scale format was used on the surveys to which they agree or disagree with the statement. I used descriptive statistics to organize the data, for example the number of children who are male or female or the average age of parents. The descriptive statistics I used were frequencies and descriptive statistics. I used the frequencies to determine the number and percentages of the categorical questions. I used descriptive (measures of central tendency: mean, median and mode) and frequency statistics to produce summary information about the demographic questionnaire items and survey items.

4.10. Data analysis design

Side by side comparison table

I collected both qualitative and quantitative data concurrently and analyze the information separately then merged the two databases together, this is called a convergent design approach (Creswell & Clarke, 2011). In terms of decisions for merging the data concurrently, I used the themes derived from the qualitative analysis and used the quantitative statistical results and literature review to support, integrate and relate it back to the qualitative results. I designed a summary table adopted the Side by Side Comparison Table by Creswell (2011) that presents the three sets of data: a set of qualitative data, quantitative data and literature review data. Please see Table 3. The side by side data shows that each theme has evidence of the primary qualitative data supported by the secondary quantitative data alongside with the literature review.

The data collected for the side by side comparison table

I extracted data from the qualitative and quantitative data and literature review to complement the three themes. Some ideas from the mixed methods data and literature review related to the themes from Table 2. For centeredness of family as theme 1, it had any related ideas such as decision making, parental sacrifice, present parent in child's life, filial piety and family interdependence. For parental developmental; goals as theme 2, it had any related ideas such as parental observations and choosing the right support based on parental ideas. For social support as theme 3, it had any related ideas such as family support, stigma, coping mechanisms and the importance of loving a child. The table organized and summarized the findings to make interpretations and discussions to answer the research question. Please refer to Table 3.

Integrating themes into the developmental niche

After the merging the themes with the three components, they have become the developmental niches of parental care for children with ASD. Please see Figure 3. for placement of themes on the developmental niche framework model.

In Figure 3, the themes with the presented findings from the qualitative and quantitative data created a comprehensive and visual understanding on parental and caregiving practices for their children with ASD. The collected findings were organized in the model of the developmental niche framework that was originally designed by Super and Harkness (1994). The theme of centeredness of family relates to the physical and social setting component, the parents' developmental goal for their child relates to the psychology of caregivers and the last theme of social support relates to the customs of childcare and child-rearing.

The themes are not rigidly connected to these niche components (sub-systems) because there may be changes from the social, political, cultural and economical forces that may impact caregiving experiences and can result in a movement of themes within the framework model. From the flexibility of the themes and components, I was able to make the association between the sub-system and the association between the sub-systems and the larger system. A comprehensive understanding of the associations will be explained in Chapter 6.

CHAPTER 5. RESULTS

5.1. Introduction

This chapter presents my findings from the interviews and surveys I have collected to explore experiences of parents caring for their children with ASD in Hanoi using the developmental niche framework. The results I found from interviews were refined into three themes: centeredness of family, parents' developmental goals and social support. This was to simplify and provide conceptual clarity to help answer the research question. For each theme, I will present findings of the primary data from the interviews supported by the secondary data from the surveys. The linkage of the theme will be connected to each of the three sub-systems of the developmental niche: 1) physical and social settings indexed by centeredness of family, 2) psychology of caregiver indexed by parents' developmental goal and 3) customs of childcare and child rearing indexed by social support. Under each theme, there will be sub-themes presented to organize and structure the findings and to show the approach for the development of each theme. I will present the interview data with support from survey and demographic questionnaire data.

5.2. Centeredness of family - Theme 1

The concept of centeredness of family is the first theme and it is about family focusing on the direct care to the child with ASD. This concept is in line with the sub-system of the physical and social settings from the developmental niche. During my data collection, I realized that in Hanoi, a family is made up of parents and immediate family members such as grandparents, aunts, uncles, siblings or even friends who are considered ‘family.’ The findings in this section will present the sub-themes of centeredness of family such as decision makers and parental sacrifice.

Decision makers

Findings from my interview and administration of questionnaire reveals that mothers and/or fathers make decisions on the type of care provided for their children with ASD, the diagnosis decision and the way they seek support.

Findings from interview of parents

Throughout the data collection process, seven interviewees who had partners that consist of a wife and husband sought each other for decision making in terms of raising their child except for two interviewees who are single mothers.

According to mother Le, a mother with a child with ASD shares that her husband is the decision maker, he is the primary source on finding information and taking decisions to support their child with ASD. Le said*, “my husband persuades the grandparents to bring the child to the hospital, he has a positive attitude in making decisions and shows his empathy.”*

In an interview with Binh, a father of a child with ASD shares that him and his wife made decisions of treatment care after the child’s diagnosis, “*we were shocked and stressed at first and we both decided to find information of what ASD is. We discussed on the solutions and made the agreement equally. Treatment is expensive, it was a decision we had to make as soon as possible.*”

In an interview with Hoang, a single mother of a child with ASD stresses her challenges, *“I am the only decision maker, paying for treatment centres and hospitals are too expensive for me, I have to do all the work alone for the child.”*

Findings from survey

The revelations made by Le and Binh are supported by findings from Table 7. which shows that 97.7 per cent agree of parents seek help from their family and 93.3 per cent agree they seek help from their partner. However, findings for single parents were not collected.

Parental sacrifice for their children

Findings from my interview and administration of questionnaire reveal that parents make time to care for their children and make sacrifices for their child. All nine interviewees expressed that their daily routine is focused on their child with ASD.

Findings from interviews of parents

In an interview with Hoang, a single mother with an ASD child expresses her challenges saying, "*I am the only one who can care for myself, but I feel I have no time due to my work; I need the money for my family. The business is in the evening while the child is at school. I put the smallest amount of time to play with the child. Sometimes I fall asleep while playing with the child*."

In an interview with Le, a mother of a child with ASD describes her daily activities with the child, "*when I interact with the child, I spend a lot of time teaching him and repeat the activities a lot. It is really boring, but I have to do it. It is difficult to teach him to eat, sit and listen*."

Another type of parenting support style is when parents prioritize their child's needs before their own. In an interview with Thinh, a mother of a child with ASD, she said, *"I wonder about the child."* She expresses the caring for the child has affected her working life, she said, *"I spend most of my time with the child by bringing him to intervention and doctor appointments*."

In an interview with Binh, a father of a child with ASD describes his daily time with his child, *"while the mother is caring for newborn, I play with the child in the morning then work until 5:00 PM, then come home in the evening and teach him how to play football and ride a bike. The teacher provides 50-minute intervention while I am at work."*

In an interview with Tu, a mother of a child with ASD had to send her child without disabilities to the care of the grandparents while she moved away from home with her autistic child to be closer to the treatment centre. She said, *"moving away from home was challenging, I had to change jobs, home and get used to living in Hanoi so just he can be near a treatment centre."*

Findings from survey

The revelations made by Hoang, Le, Thinh, Binh and Tu reveal findings from the survey Table 8. which presents parents have responded with a mean score of 5.08 for Q.8 that the strategies they use for their child are useful and 88.6 per cent strongly agree or agree that they would like more help for their child for Q. 15.

In Table 8 for Q.7, parents have responded that 75 per cent strongly agree or agree with a mean score of 5.92 that they need to make sacrifices when taking care of their child.

In Table 4, the parent demographic shows most parents in Vietnam have at least two children in their household and 94.4 per cent of the second child does not have ASD/ a disability.

5.3. Parents' developmental goal for the child - Theme 2

The concept of parents' developmental goal for the child is the second theme. This concept is in line with the sub-system of psychology of caregiver from the developmental niche. Parents have goals for their child to develop healthily. The findings in this section will present sub-themes of parents' developmental goal for the child such as parental observations and choosing the right support based on parental ideas.

Parental observations

Findings from my interview and administration of questionnaire reveal that parents use their own observations of their child to determine how their child should grow. By observing their child's need, most parents decide to take their child for early intervention and/or therapy. Parental support styles vary from parent to parent, it is consistent from the interviewees that parents based their child's choice of support by observing their child's needs.

Findings from interview of parents

A set of developmental goals parents desire such as improvement on listening, socializing, playing, eating, toileting, and cooperating were indicated in the findings. During the interview, the question asked, 'tell me in detail about the things you have done to help your child before you have found out,' seven out of the nine interviewees showed parents observe their child's interactions and they notice they are different from a 'normal' child. Parents notice their child's unresponsiveness in following and listening to parents and teachers' directions and playing with other children

In an interview with Thinh, a mother of a child with ASD noticed her son would play alone and was constantly hyperactive. She brought him to hospital where he diagnosed with ASD and ADHD. Her sister referred her to a treatment centre for early intervention. Thinh said*, "some children with autism likes to sit still, my child likes to climb, run and whatever he likes- his focus is 100* per cent *on them. It is difficult to get my child to play with others and cooperate with teachers and myself."*

In an interview with Hang, a mother of a child with ASD shares that she makes the decision to do a mix of treatment and kindergarten based on observing child's needs. She said, *"I noticed my child's social skills increased but lacks the language so then first part of the day, I take my child to treatment centre and second part of the day, I take my child to kindergarten. I have tried different treatment centres, it cost a lot of time and money, but I have to do it."* She also mentioned the comparison between a child with and without a disability, "*a child with no autism, I put 1X effort but a child with autism, I put 100X effort."*

In an interview with Chu, a mother of a child with ASD, she compares her child to a child without autism said*, "the care of the child is 3x harder than the normal child. It is different with my child than normal children because the toileting and eating skills are difficult to manage. The child does not sit with us when the family eats together."*

When I interviewed the parents, I had a chance to see the treatment centre and I noticed a staff provided an award for the child because the child 'behaved' in the way the teacher wanted. The staff teaches the parents to do this training by teaching the parents in person how to practice it, therefore parents had to observe this treatment to understand that it is effective.

Findings from survey

The revelations made by Thinh, Hang, Chu reveal findings, in Table 8 for Q.8. people with autism can be helped to improve their behaviour through one-to-one therapy had a mean score of 5.89 which means they agree it helps. In Q.3 giving 'rewards' for 'normal' behaviour can reduce autistic behaviour had a mean score of 5.10. In Q. 35, treatment of autism can help a person overcome autism with a mean score of 5.07. In Q.9, autism can be best helped by encouraging people with autism to interact with others who are 'normal' had a mean score of 6.26, this means parents agree that socializing with a normal child can help their child develop. Parents must observe this idea to know that interacting with other children helps their child develop or become ‘normal.’

Choosing the right support based on parental ideas

Findings from my interview and administration of questionnaire reveal that parents choose autism services and supports based on what they believe will help the child develop. The findings support that parents say that they believe in therapy and early interventions. Three of the nine interviewees express their concern about the quality of treatment their child receives, they believe the solutions provided from the health professionals were inappropriate and ineffective for the child. Some parents have tried two to three different treatment centres because they did not believe the interventions were helping their child’s skills improved.

Findings from the interviews of parents

Findings from the interviews of parents sought family suggestions, professional advice, television, internet, books and therapy/early interventions based on what they believe is helpful for their child. They are willing to try different strategies in supporting their child; however, there are challenges such as, the multiple choices that overwhelm parents, misdirection from professionals, and uncertainty of the effectiveness of the supports and services.

In an interview with Dang, a mother of a child with ASD said her family suggested a television as a motivational support, it was a television show about a story of a family with autism. According to mother Dang, the television shared supportive words such as, *“keep trying and child will be better.”* She added*, “I don’t have support from teachers because they only have professional knowledge on intervention - only doctors and families influence my personal decision.”*

In an interview with Le, a mother of a child with ASD uses internet and books to find information on the care for her child and understanding autism, this was given from her doctor. She uses the word, ‘effect’ which refers to the strategies used to support her child. She said, *“I believed every strategy has its own effect and the effect may be only a short-term effect and unsustainable. What I use is useful right now, but I don’t know how much useful it will be later.”*

In an interview with Hang, a mother of a child with ASD tried three treatment centres suggested by other mothers of children with ASD and, the internet. She felt her child should have been diagnosed at 9 months old, but she followed the doctor's suggestions. "*I feel I missed the early intervention because the doctor advised me to seek help only when my child turned two years old."*

In an interview with Binh, a father of a child with ASD was asked to identify services that has helped his child and he mentioned the importance of early intervention supported by institutions. He shared his frustration on finding the right support for his child. *"There are a lot of treatment centers through marketing and public relations. It looks good, but it is also hard for parents to know which one works efficiently and parents need to be on successful cases rather than information on marketing. Some kindergartens refuse to accept the child."* I asked him to describe services that works well for his child. He said, *"I will listen to everyone's advice and think critically on what is good for the child. In Vietnam, there are networks for job support for people with disabilities, but the government does not have a policy for them. We need more support and policy from the government."* It is noted that during the interview, the father physically brought books about autism and autism care to show me and research assistant.

Findings from survey

The revelations made by Dang, Le Hang and Binh reveal that they use difference resources such internet, books and television to support their child. In Table 7, data shows 75.3 per cent of participants uses internet to support their child. In Table 8 on Q. 8, presents a mean score of 5.89 that people with autism can be helped through one-to-one therapy. In Table 8 for Q. 35., a mean score of 5.07 was for treatment of autism can help a person overcome autism. In Table 8 for Q.2, a mean score of 2.91 was for the best way to treat autism is by using appropriately prescribed drugs; most parents did not agree using drugs to treat their child. In Table 5, 81.5 per cent report that their children are diagnosed by doctors and the rest are diagnosed by psychologist, specialist, teachers, family or other. In Table 4., shows most parents over 70 per cent have education above high school (12.6 per cent – post-university, 50.6 per cent – university, 9.2 per cent – colleges, 5.7 percent – vocational school) that could influence how parents choose the right support for their child.

5.4. Social support – Theme 3

The concept of social support is the third theme. This concept is in line with the sub-system of customs of caregiving and child-rearing from the developmental niche. The findings in this section will present sub-themes of social support such as multiple supports, stigmatization and coping mechanisms.

Multiple supports

Findings from my interview and administration of questionnaire reveal supports are from professionals, friends, schools, books, internet, media, other parents of children with ASD, religious leaders and teachers. The data from the interviewees shows not all support works effectively while some works better than others; this depends on parents' experience.

Findings from interviews of parents

In an interview with Thinh, a mother of a child with ASD. I asked how she finds support when caring for her child, she responded, "*I talk to the treatment centres, they understand my child's characteristic and when I am at home, I contact the staff on how to provide care for my child.*"

Thinh hopes the school system can improve and specialize their education in autism. She said, *"I hope public schools are specialized in autism and close by. I live far from the centre* - *15 km to take my child to the centre and back home."*

In an interview with Hoang, a single mother of a child with ASD expresses the support from television that teaches parents about autism and autism care. She said, "*T.V is effective, villagers watch a lot of T.V, they should have a T.V program about what autism is and how to support the child to be normal.*"

In an interview with Dang, a mother of a child with ASD feels she did not receive support from doctors and teachers. She said, *"the doctor said there is no more need for improvement, I disagree. Teachers have no knowledge of autism; I have to teach my own child. If teachers were autism aware and have training skills, they would have been helpful."*

This is similar to an interview with Chu, a mother of a child with ASD who experienced putting her child through three different treatment centres because she did not see the improvement in her child. She said, "*my child was diagnosed far too late and this was recommended by the doctor. The second treatment centre I took my child to, the teacher want to do tongue exercises by pulling my child's tongue; this was their strategy to get my child to speak. I did not believe in that treatment and removed my child out of the centre right away."*

In an interview with Hang, a mother of a child with ASD describe that the teachers do not understand autism and the mother teaches the teachers. She said, *"most of the information I received are shared from parent groups and then I share it with new parents. I only learn information from them and then I also share it with the teachers in the treatment centres."*

Family support in these findings demonstrates there is an interdependence among families in Vietnam. Although most primary decision makers are mothers and fathers, immediate family members can take place of the parents.

An interview with Nguyen, a grandmother of a child with ASD is the primary decision maker followed by the mother who was the secondary decision maker. Nguyen took the responsibility to care for the child with ASD while the mother was pregnant with the second child. Nguyen was interviewed while the mother was busy working at her job. Nguyen took the child to the hospital and treatment centers and assisted the mother by teaching the child eating and toileting skills. Nguyen said, *"I brought the child to the National Hospital then to see a psychologist for intervention. At home, I help mother by teaching the child eating, toileting but the development is still low."*

Nguyen also expressed that herself and the mother of the child understood the meaning of autism before the child's diagnosis while the father side of family was said to be *"uneducated of autism"* and thought the child is only going through a developmental delay.

In an interview with Hang, a mother of a child with ASD said she has her three sisters and her mother that helped her by looking for autism information on the internet. She said, *"my sisters always provide useful information for me by connecting me to other mothers who have children with ASD. It's hard to know what services are out there and they are expensive."*

In an interview with Thinh, a mother of a child with ASD describes the support from grandparents, she said, "*my husband is far from home due to work and cannot care the child. Grandparents take the son to school and caregivers."*

In an interview with Le, a mother of a child with ASD describes the roles her family members play in decision making. She said, "*my family is a second part of making decisions, first is my husband."*

Although most parents rely on family to support them, some parents had to educate their immediate family members about autism before they can receive help from family.

In an interview with Le, a mother of a child with ASD had to educate her grandparents, brothers and sisters on the term autism. She said, *"once they understood it, they [family members] were very supportive and gave advice for early intervention."*

Findings from survey

The revelations from Nguyen, Hang, Thinh and Le reveals similar findings from the survey on Table 8 for Q. 37, 57.3 per cent participants agree and with a mean score of 4.90 that when a parent is not around, there is someone helping the child. This mean most parents somewhat agrees with the statement.

Thinh, Dang, Chu and Nguyen mentioned they sought professional help and the survey reveals, 97.7 per cent agree they seek help from professionals, but Dang thought professionals were not helpful. Thinh, Nguyen, Hang and Le sought help from families and the survey reveals, 97.7 per cent agrees. Hang sought help from teachers and the survey reveals, 93.1 per agrees, but Hang did not find they were helpful, however she found help from other parents were useful which the survey reveals 84.1 per cent agrees. Hoang sought help from television which was not collected in the surveys. There was no mention about religious leaders and friends from interviews, however, 6.8 per cent on survey shows parents seek help from religious leaders and 69. 4 per cent show parents seek help from friends.

Stigmatization

Findings from my interview and administration of questionnaire reveal that stigmatization which parents may experience when there is a lack of social support.

Findings from interviews of parents

This example presents parents' experiences of stigmatization from the public and community which may result in parents feeling shame.

In an interview with Le, a mother of a child with ASD describes societal perceptions on disabilities. She said, "*I do not hate my child, but I find other mothers who have an autistic child experiences discrimination from society and dislikes the child."*

In an interview with Tu, a mother of a child with ASD experiences public discrimination and felt embarrassed or ashamed to show her child. She said, *"I am the first family with an autistic child in my village, I did not want to show my child in public."*

In an interview with Dang, a mother of a child with ASD does not mention her child to the neighbours, she said*, "it's hard to share my story and the hometown does not accept autism. They ignore the problem if the child has a problem, they just think the child is normal. I do not care what they say."*

In an interview with Hoang, a single mother of a child with ASD shares experiences about the lack of support from her community in her home village, "*villagers talk and thinks about how he [her child] is abnormal, they do not understand ASD. They think my child has schizophrenia."* She describes a situation about another child with a disability in her village and wanted to socialize with that parent, however she was afraid of approaching that parent, *"if I mention the other child has a disability, the other parents would shout at me, I have to be careful what I say to them."*

Findings from survey

The interview findings from Le, Dang and Hoang are in line with the findings from the survey which reveals in Table 8 for Q. 30. I am afraid others may think my child has autism which has a mean score of 3.31. This means most parents somewhat disagree.

Coping mechanisms

Findings from my interview and administration of questionnaire reveal that parents deal with challenges and barriers and some may have coping mechanism to address these challenges and barriers. It is important to note that the findings emphasize that parents show love for their child with ASD.

Findings from interviews of parents

In an interview with Dang, a mother of a child with ASD described her husband works in partnership with her to support their child. She said, "*my husband is very supportive and shares* *the housework, teaches the child intervention and plays with the child -it decreases the stress for me."* A type of family support can be shared household and caregiving duties with the partner, this relieves the other partner from the stress of full-time caregiving.

Dang uses multiple sources of information from family, hospital community and the media to cope with caregiving their child. Dang describes a helpful television show about a story of children with autism, she says "*the show encourages me keep trying and child will be better. This show helps me with my stress."* The support from media gives the parent hope that her child will become better.

In an interview with Tu, a mother of a child with ASD felt her sisters, husband and other mothers support her in an emotional way. She finds sharing her stories with other mothers in the hospital makes her motivated. She said, "*without them* [other mothers], *I want to die, I want to hold the baby and cry and I don't want to live anymore.*" Tu also mentioned that sharing her experiences with me and the research assistant made her feel better and relieved.

In an interview with Hoang, a single mother of a child with ASD expresses her difficulty being a single mother and only having support from the doctor. It was observed that she cried a lot during the interview. She said, "*doctors are the only professionals who can help me, nobody in my community will help me because they don't accept my child. It is stressful to not have support."*

This example emphasizes parents' motivation on continuing to care for their child. All parents show hope, love and acceptance for their child with ASD. The importance of loving a child can provide hope for parents, this could be type of coping mechanism. In an interview with Binh, a father of a child with ASD was asked if he would like to share anything else with the interviewer, he responded*, "every small improvement of my child is a success. I will believe in myself and child, show all my love, try to help my child development and always play with the child."*

In an interview with Tu, a mother of a child with ASD said*, "I hope all parents with my experience spend more time with their kids, show love and bring them into interventions right away."*

In an interview with Hoang, a mother of a child with ASD shared that accepting her child can lead to loving the child which then eases the problem of caregiving. She said, "*at first, I could not accept child and now I learn to accept child and not push the child hard. It is easy to teach my* *child if I am patient. I must be patient and now I have learned to love my child. Once I started to accept, I see solutions not problems."*

Findings from survey

The interview findings from Dang, Tu and Hoang are in line with the survey findings of Table 8 for Q. 37, for when I am not around, there will be someone helping my child has a mean score of 4.90.

In Table 7, when it comes to help seeking, Dang and Tu compliment the findings from survey such as 93.3 per cent seek help from their partner, 84.1 per cent seek help from other parents and 97.7 per cent from families. Dang and Hoang compliment the findings of 97.7 per cent agree they seek help from professionals.

Revelations from Binh, Tu and Hoang are in line with findings from Table 8 for Q. 17, 93.2 per cent agrees that providing a warm and loving environment can help people overcome autism. However, a question like Q. 11 shows that cold and unloving homes are a frequent cause of autism with a mean score of 4.75. This means most parents are in between agreeing and disagreeing that a cold and unloving home causes autism.

5.5. Summary

The findings from this mixed methods study is organized under the three themes that are linked with the sub-systems of the developmental niche framework. These sub-themes within the themes are connected to the three sub-systems of the framework. The themes to the sub-systems all have relatable components with each other. It is important to keep in mind that social and cultural influences can cause themes to shift between sub-systems. The interpretation and discussion of these themes and niches will be further explained in the next chapter.

CHAPTER 6. DISCUSSION OF FINDINGS

6.1. Introduction

The aim of the study is to understand the experiences of parents raising their children with ASD in Hanoi by understanding how they care for their child, identifying services and supports they use for their child, addressing barriers and challenges and finding coping mechanisms they use to face barriers and challenges.

I will present a discussion of the results from this research in three sections. In the first section, I will define and interpret the themes with findings and relate it to the developmental niche. The three themes are: i) centeredness of family ii) parents' developmental goal for the child and iii) social support. In the second section, I will interpret and discuss the relationship between the sub-systems of the niches. In the third section, I will interpret and discuss the relationship of the sub-systems with the larger system. These findings may affirm and refute other scholar's work and my own results. The interpretation of the findings will be justified with literature review and presented results. At the end of the chapter, I will discuss the limitations of the study, trustworthiness of the study, ethical matters and summary of important aspects within the findings.

6.2. Centeredness of family– Theme 1

In this study, the findings from research show the concept of centeredness of family. Family is the primary support for children with ASD. Family shows strong implications for the connection of social relation between family members. Family members may include mother, father, brother, sister, aunts, uncles, grandparents etc., however it does not necessarily need to be blood related. Family is a group of people whose goals of development influence and intersect with one another, in greater detail it is focus on the developmental goal of the child rather than the independent goals of family members (Goodnow & Collins, 1990). The descriptions of families may take an individualist or collectivist approach and such ideas impact the developmental upbringing of the autistic child.

Decision makers

Supporting literature has shown that families are involved in each other's lives for social, political and economical reasons and they play a strong role for the children to grow responsibly.

Duong (1985) indicates that within traditional families in Vietnam, health care decisions are made by immediate families let alone the parents. Shwalb et al. (2003) supports the idea and states mothers and fathers play a complementary role for their children to grow into ethical and responsible individuals. This displays interdependency between family members (Chao & Tseng, 2002). The current findings from the interview show decision-making on diagnoses and treatments for their child's health is predominantly made by mothers, fathers, siblings and grandparents.

Parents receive information from health professionals, inform and seek advice from immediate family members and then parents would make the final decision on the types of support their child should receive. This shows immediate family members are active in contributing to decisions that involves the care of the child with ASD.

The findings show seven of the nine interviewees had the husband and the wife as decision makers. These findings from the interviews support the survey statistics of 93.3 per cent agreed that they seek help from their partner. This supports findings from Yu & Liu (1980) that states parents are expected to be highly involved and responsible for decision making for their children throughout their lives. The findings from the current research and literature review were as expected as it showed parents are the decision makers for their child.

The findings support the literature review about parents' decision making (Chao & Tseng, 2002; Yee et al.,1998; Yu & Liu, 1980; Wolf, 1970) on the care and diagnose decisions for the child and reliance on their partner. There were a few single mothers in the interviews and according to the findings and literature review, most families are married or in a partner relationship. However, the experiences of raising an autistic child from a single parent were not found in the literature review, so the phenomenon of the experiences remained unclear.

In the interviews from this study, participants spoke about their partner that either husband or wife share the same decision-making power when making health decisions for their child. The interviews were eight females and one male, however female participants discussed about equal decision making with their partner. This contrasts with Hong & Kang (1994) statement that fathers used greater decision-making power than mothers due to the patriarchal system in Asia. Zhou (1998) argues that despite the patriarchal system, mothers from Vietnam possessed a larger share of power and managed family finances. These studies showed a different insight of families in Vietnam. If there were more fathers as interviewees, perhaps the findings may have shown different results. I argue that decision making on how the child with a disability receives care, how to look for care and what is the best care are shared between both parents. Now that society is becoming more modern, there are changing work roles and caregiving roles within the family structure; it challenges the traditional and historical familial roles.

Mothers and fathers share the decision-making role in terms of caring for their child. The current study did not measure how much decision making was made by each parent, so it was uncertain about the balance of decision-making power each parent holds. When it comes to the physical caregiving, it varies based on which parent decided to work or if both parents decide to work. These statistics suggest two parents work within the family structure; therefore, it is not based on gender and the caregiving role could change based on who carries more responsibility in working.

The results demonstrate that parents are in partnership to support their child with ASD, they make decisions together to determine what is best for their child. The reason may come from Vietnamese collectivist culture that emphasizes group goals are prioritized over personal goals which are common familial roles and expectations in the family structure in Vietnam (Chao & Tseng, 2002). The findings support the authors of Shin et al., (2006), Chao & Tseng (2002) and Ho (1996) that demonstrates interdependence and filial piety is rooted in Asian families while independence is placed in Western families. Interdependence is the reliance that family members have on each other, in this case, the wife and husband seek each other for advice. Filial piety is when children are expected to consult with parents and other family members on important decisions. This supports the findings of the results because parents are present to make solutions for their child. The developmental niche of the physical and social settings illustrates that mother and father are physically present in the setting of the child's life and that they make decisions in front of the child. The child will always have an adult in close proximity while making health solutions for the child. The interdependence of the family can also relate to the customs of care because parents play the role as the decision maker for the child and the interdependence of family are rooted in Asian cultural traditions; it organizes the lives of families and children (Super & Harkness, 1994).

Ideas of filial piety and family interdependence stem from Confucius and Buddhist based systems in South East Asia (Ho, 1994; Sung, 1995; Zhou & Bankston, 1998 as cited in Chao &

Tseng, 2002). These sociocultural roots of filial piety were supported from the findings in the interviews that most families sought help from their siblings and grandparents. This type of help can be suggestions on health treatments, the decision of designated caregiver, teaching the child skills taught from the professionals and helping parents look for autism resources. Chao and Tseng (2002) and Ho (1996) argues family roles in most Asian countries are structured by age and that parents and elders' user greater authority than do younger family members. This could be the reason why parents seek help from them, but it is not determined if the siblings are older than the parents. It is well understood the grandparents are the elders and parents sought advice from them. The survey also supported the involvement of immediate family members with a high percentage of parents that seek support from family members.

This relates to the physical and social setting of the developmental niche because immediate family members such as the grandparents, aunts, and uncles are physically present in the child's setting. This component supports the evidence of interdependency within the family structure because the family members depend on each other for help to care for the autistic child; it is a group goal for the autistic child to grow healthy. This component could also fit into the customs of childcare within the developmental niche.

In terms of spiritual/religious beliefs in relation to Confucian and Buddhism, the survey shows participants' results with a low mean score when asked if a belief in God can help a person overcome autism and a low percentage agreed they seek help from religious leaders. The statistics shows that parents in this study do not show a belief in religious/spiritual guidance to support their children with ASD. Ha et al. (2014) argues parental practices are rooted within parents' belief systems, but they do not openly disclose this belief and it was also not clearly defined by participants in this research.

The cultural tradition of centeredness of family in the care for the child with ASD is still found in the customs of caregiving component. Based on the literature, it is understood parents do not publicly disclose this belief, but it could be embedded within parents' psychology which is strongly related to the psychology of caregivers within the developmental niche; this will be discussed in the later sections.

Parental sacrifice

The current study presents parents who care for their children with ASD are physically and actively involved in the child's life. All interview and survey findings show parents make sacrifices of their own social life, work life and the caregiving of their other children to care for their child with ASD. Parents in Hanoi want what is best for their child, they are willing to make sacrifices to care for them. This can result in parents quitting or laying off their jobs, reducing social time for themselves and changing the lifestyle they had before their child's diagnosis. When parents are present with their child, they are constantly nurturing and observing the child. If parents are physically away from the child, they are mentally thinking of the child. In all interviewees, parents describe their child as a priority when providing care, finding treatment and seeking support.

The interviews describe most families have two children including one child with ASD, so some parents have no time to care for their other child due to their full attention to their child with ASD. It was described in one interview, that one parent had to send their child without disabilities to the care of the grandparents while the parent had to move away from home to be closer to the treatment centre. This means parents are willing to put their time and energy to care for the child with ASD even if it means reducing attention to the second child, asking family members to care for the second child, moving homes to be closer to treatment centres, quitting their jobs, and starting a new life in a new place.

Due to the sacrifices parents makes, they feel there is a lack of self-care and limited balance between caregiving practice, work life and time for themselves. Participants reported feeling stress, tired and uncertain about child's future after they found out about their child's diagnosis. Based on observations during the interview, it was evident to me and the researcher assistant that participants were upset, and some had tears while answering the question. These findings are in line with findings from Bitsika & Sharpley (2004), that parents from Western countries reported feeling depressed, anxious and stress. This brings an interesting finding that parents experience stress in Asian and Western cultures and also, self-care is limited for parents. Parents are constantly caring for their child so they forget to care for themselves. Higgins et al. (2001) argues this type of care can lead to caregiving burnout.

The theme of centeredness of family is related to the physical and social settings of the developmental niche because the physical presence and involvement of the parents is evident in the setting of the child’s life. Parents prioritize their child’s needs over their own needs and are willing to make sacrifices. The child is also surrounded by different physical environments such as homes, treatment centres, schools, and family members due to the care and treatment routine the parent has organized for the child. The child could also be surrounded by overworked parents who feel stress, tired and burnout due to caregiving. Parental sacrifice could be a type of parenting style that relates to the customs of caregiving component. This parenting style is practiced by all families in the findings and it could shape the type of care the child receives.

In chapter 4, it is mentioned that the themes from the findings are not rigid to one component and it can move freely depending on the context of the situation. It is worth mentioning that the experiences of children without ASD was not found, however it would be interesting to explore sibling’s role within the family and caring for the child with ASD.

6.3. Parents’ developmental goal for the child – Theme 2

In this study, the findings from research show the concept of parents’ developmental goal for the child. Most often every parent has an expectation on how they want their child to grow up, but the expectation differs from cross cultures and family experiences. Understanding parents’ expectation on the qualities they want to see in their child as they develop provides insight as to why parents want to have children and what they expect from them. The qualities parents want to see from their children may be different qualities parents want or need for themselves (Goodnow & Collins, 1990). In this current research, the findings show the importance of developmental goals for parents and caregivers in Hanoi. In this section, I will explore possible reasons as to why parents chose these developmental goals and how their decisions impact their children’s development.

The theme of parents’ developmental goal for the child results show parents have an expectation on the behavior, communication and social development of their child. Parents have specific qualities they want they children to develop and these expectations are constructed from cultural beliefs and values in the family. The findings show parents make observations on their child which influences their decision making. This was done by parents comparing their child with autism to a child without autism. Rewards are also given to children who are ‘behaved well’ this means parents have an interpretation of what is desirable behavior and undesirable behavior. The findings also show parental ideas on how they care for their child are influenced by family suggestions, professional advice, television, internet, book and one-to-one therapy or early interventions. These multiple sources provide parents the information on caring for their child and then they make the decisions on what is the most appropriate choice of care for their child. Since most parents have their child diagnosed by doctors, it is assumed they are most likely to seek advice from them.

Chao & Tseng (2002) and Ying et al. (2012) argues practice such as family suggestions are based on interdependence and filial piety of Confucianism in Vietnam. Khanh (1998) and McLeod & Nguyen (2001) argue the tenets of filial piety is about honouring family, reputation and respecting education. I argue that if a child is born with a disability, the honour, family reputation and education may change the family perceptions on what they expect their autistic child to achieve compared to a non-autistic child. The changes of family perception based on child's disability supports Harkness et al. (2000 & 2006) argument that not all families carry the same filial piety values because there are no cultural boundaries despite families adopting the same philosophy of Confucianism. It could be the multiple sources of support such as professional advice, television, internet books and early interventions that could influence parental ideas on childcare. Parents can integrate their own modified beliefs and values within the family structure and those beliefs and values could shape their ideas on what they want their child to be.

The theme of parents' developmental goal for the child relates to the psychology of caregiver – one of the components from the developmental niche. The belief and ideas of parents hold directly impact child giving practices (Super & Harkness, 1986). The way parents perceive their children to grow can be influenced by collectivist culture, spiritual/religious beliefs, historical and societal perceptions. These ideas could be found in family suggestions, professional beliefs, television, internet, books, and/or naturally embedded in parents' belief systems based on their culture. Goodnow & Collin (1990) argue goals may reflect on environmental factors while others reflect on tradition. I argue that parental actions are determined by their thinking and their thinking is determined by their cultural, historical and societal values that centers on families.

Health and educational professionals' actions may be determined by their values as well. Ennis-Cole et al. (2013) argue professionals' influence parents' decisions on diagnoses, early interventions and ongoing therapies. For example, in the interviews, some teachers and doctors advise parents to wait for the child to 'grow out' of the condition and then wait for interventions.

A possible reason for this could be that some professionals do not accept that the child has a disability, or they lack knowledge on early intervention strategies. As a result, the delay in diagnosis may impact the development of the child and the effectiveness of the early intervention. It could a financial burden for families who must pay for more intense treatment interventions if their child is developmentally delay.

Authoritative parenting

Some studies argue families from Asia have strict and authoritative parenting style that requires physical discipline, but for a child with a disability, parents exclude the child in the family life (Chao & Tseng, 2012; Gammeltoft, 2008; Phinney et al. 2000; Fuligni et al. 1999; Baumrind, 1971). Fuligni et al. (1999) and Phinney et al. (2000) supports these authors that there are specific obligations children are expected to follow such as respect and obedience to their parents. Authoritative parenting style stems from traditional cultural beliefs of Confucianism (Cheah et al., 2013).

In this current research, parents did not say that they practice authoritative parenting style. Instead, they share their desire to engage with their children through teaching social, communication and behavior skills and life skills such as, helping with household chores. Parents show love their children through playing with the child and prioritizing their child’s needs over their own. The data from interview and survey are in line with interpretation that participants indicated the importance of loving the child and fostering a closer parent-child relationship. Overall, parents agreed that providing a warm and loving environment can help overcome autism. In addition, parents did not use the words ‘respect’ and ‘obedience’ with the hope their children meet caregiving obligations to families, however parents did describe their children should follow parental directions and learn how to treat others respectfully.

A study by Chao (1995) supports the findings of this current research and shares similar case examples of families in Europe and Asia that emphasize the importance of loving a child to foster the child’s self-esteem. However, Kim et al. (2012) argues parental authority exists in all cultures, both Western and Asian cultures for children to grow up independently and become self-reliable. Studies from the literature review support and contradict the findings of this current research which suggests specific parental obligations are contextual and differ across culture, developmental stage, gender and socioeconomic status.

Another type of parenting practice that the current findings from this research did not support is the parental style of reciprocity. According to Chao & Tseng (2002) and Gammeltoft (2008), they state reciprocity is practiced within parenting practice in countries from Asia. Reciprocity plays the role of 'repaying' parents for their sacrifices and care and this includes a fulfillment in financial and caregiving obligations to families. The authors argue parents expect their child to develop these skills so the children can one day care for their parents when they are older. Wolf (1970) agrees with the authors and reports that sons are raised to be caregivers of their parents. There were no findings from the current research to support the idea, however, if the purpose is for children to show respect and obedience to parents, an autistic child who lacks social and communication skills may not fulfil these specific obligations to families.

It is interpreted that the findings from the current research contradicts with the authors from the literature review because parents in Vietnam are becoming modern and stepping away from some traditional cultural parenting practices, thus learning to adopt an alternative parenting practice that is less authoritative. Most of these studies refer to parenting styles for children without disabilities while some studies refer to parenting styles for children with disabilities did not specify the disability. If the disability is unclear, it could be viewed that raising a child with autism is different than raising a child with a different disability. This led to the interpretation that parental practices may differ depending on the socio-cultural and developmental status of the child.

The relationship of these findings to the developmental niche shows the psychology of the caregiver and the customs of caregiving. Authoritative parenting style falls into the conceptualize component of the customs of caregiving because parenting styles are everyday routines that facilitates the child's development. The construction of authoritative parenting style comes from the belief system of Confucianism; however, the findings did not support this belief system. Aside from Confucianism, parents' expectations become parental psychologies of how they want their child to develop such as hoping their child improves on social, language, communication and behaviour skills. There is a difference between what parents want their child to achieve and what they want from their child after they achieve their goals. These could be responsibilities and obligations parents expect their children to fulfill—depending on one's age, gender and culture, however there is a belief their disability may hinder these responsibilities. It could be that parents want their child to develop certain skills so in the future they can decrease their caregiving abilities and increase the child's independency.

Overall, it is assumed that the qualities parents want to see from their children will influence their caregiving decision for their autistic child regarding autism supports, early interventions and ongoing therapies. Additionally, parental perceptions may affect their decision to formulate goals; this may affect the health of the child. Furthermore, the findings show parents present attentiveness, concern and the willingness to do what it takes to care for their child.

Karma

Recent studies argue that karma is practice within families from Asian countries (Ha et al., 2014; Hunt, 2012; Gammeltoft, 2008; Danseco,1997). Hunt (2012) describes karma as those who committed good behaviours in life will be rewarded with a happier rebirth while those who committed bad behaviours will be punished by being born with a low social status, this includes being born with a disability. Gammeltoft (2008) argues karma goes beyond individuals and may extend to relatives. The author goes on to describe children with disabilities are a status of burden with an inability to contribute to families and society.

In this current research, parents did not describe their belief systems are based on religious or spiritual influences. This shows spiritual and religious leaders had no influence on parents' health seeking and caregiving practice which can be interpreted that karma may not be embedded in their beliefs.

However, based on observation, one interviewee showed an interesting finding after the interview was over and the voice recorder was turned off. A parent shared her perspective and revealed that she has done good in her life but did not understand the reason as to why her child was born with autism. She asked me, "what did I do to deserve this?" She asked in a heart felt manner and started to cry. Her emotions and words were signs of obvious destress which presents the reality of challenges and stress parents experience after their child's diagnosis. Her response also indicates a belief in karma. She expressed the goodness she has done in her past which makes her believe she deserves to be blessed with 'good' in her life. The 'good' could be interpreted as the mother giving birth to a child without ASD.

Another example that was formally shared during the interview was from a father who expressed his interpretation on societal perceptions of disability in Vietnam. He stated that he thinks families in Vietnamese society believe in karma. Although the father did not agree with societal beliefs, he perceived that society believes it that way. This could be a challenge for parents seeking treatment if society views disability as a punishment due to parents' 'wrongdoing' in their past life. If society believes in karma, then people within the society may be reluctant to provide help for parents because they believe it is the parents' fault for their child's disability.

These findings support Ha et al. (2014) argument about the concept of Buddhism and Confucianism are formally unspoked in public and is instead, rooted in parents' ideas and decision-making. I argue that the relevance of formally discussing Buddhism and Confucianism among families in Asia are not the mainstream and scientific thinking. Instead, evidence-based knowledge and science are the desired modern-day conversations which may be why families shift away from some traditional beliefs of Buddhism and Confucianism. However, their sociocultural roots of practice Buddhism and Confucianism remains difficult to define and unclear in this research.

These findings relate to the psychology of caregiver of the developmental niche because as mentioned in the beginning of this chapter, traditional and cultural beliefs influence parental goals. In this case, most parents from the findings did not disclose about that beliefs of spiritual and religious ideas help their child with ASD, however there was an assumption from one parent who indicated society believes in karma and another parent disclosed her thoughts about karma in an informal way – after the interview ended. Although the findings of karmic belief systems were mainly found in the literature review, the findings did support authors that argue karma is not openly mentioned and is considered a private subject. The evidence from the findings suggest some parents may believe in spiritual and religious leaders and the impact of karma, however these beliefs are kept in a private manner. This means deeply embedded belief systems of karma could construct parents' ideas on creating goals for their children to achieve. It could be assumed that if parents really did believe in karma then they will do 'good deeds' in their life so they can be rewarded with 'goodness' in their life. However, parents who believe they have been punished in the past which results in them having a child with a disability may feel a sense of hopelessness and self-blame themselves. This could diminish parents' motivation to seek help for their child.

Health literacy

Another factor as to how parents developed goals for their child with ASD could depend on their health literacy. Health literacy is an important factor in making decisions around health and disability. Ying et al. (2012) argues there is no health literacy data in Vietnam.

The findings in the current research presents there are some limited health literacy among parents in the study. The findings from the interviews shares that parents did not know much and had to seek professional help and other parents who have children with ASD. In terms of parents' education, parents have an education greater than high school. This means that parents are educated but they do not know much about autism. This could mean information on autism may not be common in Hanoi and/or there may be limited access to such information. I argue there is limited information due to the limited awareness of autism and the limited access to accurate resources. Parents receive professional advice from teachers, doctors, the internet but how they make use of the information is uncertain. If parents fully understand the disorder, they can make better decision on how they want they child to develop and where to look for these services and treatments to achieve their child's developmental goal.

In the current research, some participants shared that they had to educate their partner and family members because they did not understand the condition. Some parents reported they had to educate the teachers on autism because the teacher did not have knowledge on autism. This supports Ha et al. (2014) that argues parents from activist groups for autism had to train teachers and parents on autism.

The results interpret health literacy as topic in this study because it points to the importance of what parents do with the health information and the practice of disseminating to family members, other parents and even teachers. Health literacy emphasizes on parents educating the community which shows there may be a lack of health literacy among the community. It could be that the shared information on autism may be inaccurate and/or insufficient if parents hold limited knowledge of autism.

The findings from the interviews have shown parents concern for their children's future because they do not have long-term care plans for their child. Overall, the findings show parents want their child to develop social, communication and behaviour skills to integrate into society but have limited knowledge on autism and autism treatment. When they seek professionals for help, some professionals also lack knowledge on autism. This may hinder parents' from achieving developmental goals for their autistic child which results in parents feeling uncertain of their child's health development in the future. Therefore, parents are concern for their child's health abilities when they start to grow into adulthood.

Health literacy relates to the psychology of caregiver of the developmental niche because heath literacy is a tool for parents to make educated health decisions. If health literacy is increased for parents and families in Vietnam, they may perceive autism in an accurate way to make inform decisions on how they want their child to develop and where to seek resources to achieve their child's healthy development. If parents understood the information (e.g. diagnoses and treatment) they receive from health professionals and other resources, they can create short-term and long-term goals for their child. If health literacy is increased for educational and health professionals, they can feel confident in providing accurate information to parents seeking help, strengthen the professional care relationship with parents and optimize their capacity in providing quality health care for autistic children.

6.4. Social support – Theme 3

In this study, the findings from research show the concept of social support. The definition of social support is considered as any type of help from any individual in a difficult life situation and the belief that "that one is cared for and loved, esteemed and valued, and belongs to a network of communication and mutual obligations" (Cobb, 1976 as cited in Buchanan, 2011, p. 4). In this case, social support can come from individual, communities and institutions that contributes to a positive impact on parents and caregivers raising their children with disabilities. I will describe the concept of social support in three parts by exploring the multiple sources of support provided for parents, the experiences of navigating the right choices of support for parents and the coping mechanisms for parents. Lastly, I will explain the relationship between the social support theme with the niches of the conceptual framework.

Multiple supports

In this current research, findings show participants have many forms of support from partner, family, professionals, teachers, other parents of children with ASD, internet, books and television. Parents are willing to seek any sort of help for their child with ASD because all parents are concern for the needs of their child.

The findings show family support has given parents a relief from caregiving the child so parents can have time to work while their family members or partner cares for the child. This type of support gives parent space away from the child so they can destress and focus on their own daily routines.

Parents seek support by speaking to other parents who have children with ASD. This exchange between parents provides reassurance for parents they are not the only family to have an autistic child and they can receive recommendations of autism resources from other parents. Ha et al. (2014) discusses that parent-led groups in Hanoi provide interventions, train teachers and health professionals to care for their children with ASD because the support from the government is limited. This supports the findings of parents supporting other parents.

Parents reported using multiple forms of support that can provide them many options of help for their child. However, not all the support has the same effect and some support is preferred over others. It can be challenging, overwhelming and time consuming for parents to decide which support to use for their child. It could be a dual responsibility for parents to look for help and provide care for the child, this could lead to caregiving burnout. If parents experience burnout, the child may experience limited quality of care from parents that can hinder their developmental growth.

These findings of multiple support refer to the customs of childcare of the developmental niche because the child’s setting is surrounded by multiple supports such as family, friends, professionals, teachers, other parents of children with ASD, internet, books and television. The usefulness of these resources facilitated by parents can contribute to the developmental growth of the child.

Support in treatment centres

In this current research, most parents say that they seek early intervention services and therapies after the diagnosis of their child; most of the guidance came from parent’s partner, families, professionals, teachers and internet. Professionals could be therapists and doctors in treatment centres and they help parents identify choices on the treatment for their child.

Most of the treatment centres teaches parents how to practice the method at home so the treatment can remain effective for the child. Parents make time at home to teach their child and express that it is time-consuming during their daily routine. Parents express their need for a specialized autism school so the child can learn more skills than what is taught in the treatment centre. Some parents question the long-term effectiveness of treatment for the child provided by the treatment centre. This means they can see the treatment intervention may work in the present moment, but they are unsure if the treatment can be followed through in the future.

These findings support Ha et al. (2016) that states Vietnam lacks the quality of early interventions and appropriate and accurate diagnosis assessments. Shin et al. (2006) supports Ha et al. (2017) that Vietnam does not have a standardized screening process and reliable tools to measure autism.

Ha et al. (2014) argue the practice of Chinese and Vietnamese alternative medicine including acupuncture, spiritual practices, and worship are used as interventions for children with ASD and can be costly while the effectiveness is unknown. This may be due to the assessments that may not be standardized and approved by officials.

All parents from the interviews agree access to the services such as the travel time and cost brings challenges for the parents. This finding supports Tran et al. (2015) that argues parents in Vietnam experience difficulties trying to get help for their child with ASD because there is a delay of diagnosis, far travel to services, high cost of services and lack of quality services. Although most parents are working, they express their financial burden when paying for services to treat their child.

The findings indicate that some parents did not feel they receive the best support for treating their child. However, parents of newly diagnosed children reported feeling grateful for any help they receive from professionals. The reason for this could be because parents who have newly diagnosed children do not have as much experiences in supporting their autistic child and navigating for autism services compared to parents who have an older diagnosis of their child.

Parents' concern of the quality and effectiveness of the treatment for their child may cause doubts for parents to continue to seek treatment from doctors and therapists or seek excessive treatments from multiple professionals. There needs to be a sense of hope and security for parents to continue using services and for them to have a certainty their child can develop healthily. Parents do not want to spend their time and money on uncertainty because they already made sacrifices for their child such as quitting their job, travelling far to treatment centres and financing on costly services. Parents need to feel ensure they are making the proper investments to treat their child's health. It is evident parents are willing to try different methods to care for their child, however it is difficult to determine the best method. If there were standardized methods, then parents would have confidence and trust in health professionals. It would also help parents if methods are approved by officials as standardized methods and to know which methods are effective and used by most families. This is especially important for newly diagnosed families who need the most guidance because they have limited knowledge compared to older diagnosed families.

These findings relate to the developmental niche of the customs of childcare because as a daily routine, the child's life schedule is modified to include therapy based on the parents' decision. The child with ASD may have to travel to different treatment centres, family homes and hospitals as a daily routine. The child receives therapy from professionals in treatment centres who teaches parents so that parents can provide the therapy to the child at home; the child's life is organized by this type of routine.

Support in hospitals

The findings show most parents get their child's diagnosis from hospitals. This may reflect greater of diagnosis awareness and access to care among autistic children. In hospitals, most parents felt their child's diagnosis assessment was short or delayed which cause parents to feel uncertain about their professional practice. This could hinder a lot of opportunity for the child to access early intervention which meant the child could have been treated earlier. This leads to parents looking for their own treatment, but it is uncertain if the treatments they look for are reliable and they may experience poorer quality service.

Ying et al. (2012) argue that parents feel respect for doctors because the position of a doctor is a hierarchal position and is the professional person for parents to address health needs. However, the findings did not show that parents seek doctors for help because of this reason. It could be that parents seek help from doctors because they are responsible for diagnosing the child.

These findings support Ha et al. (2016) that states parents experiences of assessments services in Vietnam are described to be rushed, unclear on clinical guidelines and miscommunicated between parents and doctors.

As mentioned earlier, these findings of parents' uncertainty with the doctors may make parents lose confidence in seeking helping from health professionals or lead to excessive treatment seeking. The trust and security need to be built for parents to feel engaged with health professionals, such as feeling involved in the process of treatment for their child, being comfortable to ask health related questions to their child's care and feeling confident the treatment will work. Parents confidence in health professionals may impact the child's developmental growth and motivate the parent to continue to care for their child and trust health services. If parents are constantly concern and uncertain of what may happen with their child's development, it could affect parents' emotional state which could impact the child's emotional state.

These findings are related to the customs of caregiving component of the developmental niche because the trips to the hospital is integrated into the child's setting. Doctors provide therapy for the child in the hospital setting and parents receives autism care advices from doctors, so parents can use it on their child at home. This indicates the child is exposed to formal learning at the hospital and informal learning at home.

Navigating the right choices

The findings show parents are provided with a lot of resources on autism services and treatment. The challenge for parents is that they do not know the right resource to support their child and is especially more difficult for parents who recently had their children diagnosed. Some parents feel overwhelmed by the abundance of information provided by professionals, teachers, families and the internet. The findings from the interview indicates parents' stress of not knowing the right choices to provide for their child. In the survey, parents indicate they still need support in caring for their child.

In terms of government support, Vietnam's law has given people with disabilities political, economic, social and cultural rights, however people with disabilities continue to experience challenges accessing healthcare, education and employment (ILO, 2013). Parents are aware they need stronger government policy intervention to support people with disabilities. Improvement on policies can reduce the challenges people with disabilities and their family experience. Government support on implementing policies to invest on autism services and supports can reduce financial burden for families and provide effective resources for autistic children to grow and develop healthily.

Parents experiences of difficulty, feeling overwhelmed and stress when looking for the right choices to care for their child may lead to similar effects of parents feeling unsure about the competencies of the health professionals. There needs to be reassurance for parents that health professionals will provide quality care for their child with ASD.

Overall, parents seek advice from their partner, other parents of children with ASD, professionals and television that could be their strategies in dealing with their stress. The literature and current research findings remain limited as to how parents deal with stress directly and the sorts of coping strategies they use.

These findings relate to the psychology of caregivers and the customs of caregiving because parents' beliefs are influenced by these supports and they are actively present in their child's life. The child's setting may be surrounded by their parents searching for resources such as asking family members, professionals and friends and navigating autism services. If parents feel emotional and physical destress from feeling overwhelmed on seeking for support, it may reduce their motivation in caregiving their child and it may affect their personal well-being.

Stigmatization

In the current research, parents share their challenges of public stigma towards their own child in their own community. The public shows a misunderstanding of ASD, gossips behind parents' backs, lack of acceptance of the child and distance away from parent and child. Although findings did not report how parents felt about the public stigma, the literature review (Ha et al., 2014; Le, 2013; Kim et al., 2012; Huang et al., 2010; Mak & Kwok, 2010) indicates parents may experience isolation, shame, guilt and/or helplessness from the lack of public support when their child is openly brought into the community.

It is important to note that most of these findings presents experiences from parents who have partners, however, cases for single mothers may experience a smaller support network and/or an increase in financial burden. This could lead to greater emotional distress and isolation for the single parent.

In the literature review, Ha et al. (2014) reports parents raising a child with a disability experiences sadness, shame and guilt. Huang et al. (2010) supports this argument and explains that stigma can result in stress and anxiety among parents.

Ha et al. (2014) argues the reason for public to show discrimination on people with disabilities and their families is due to karma merit. According to Le (2013), karma is traditionally practiced in Vietnam with the belief that child's success is influenced on their parents' caregiving abilities. Gammeltoft (2008) supports Le (2013) and argues parents feel solely responsible for the care and treatment of their children. Although, the findings did not support parental self-blame, the findings from this current study indicates that parents are aware of the public shaming on parents with children with disabilities.

Mak & Kwok (2010) argues the feeling of shame comes from a concern of losing social status family reputation due to a family member with disability. In this current research, findings did not explicitly show that most parents felt ashamed to raise a child with a disability. It could be suggested parents feel internalized shame, although those findings were not indicated in the current research.

Kim et al. (2012) argues stigma causes families to be reluctant to seek medical help because seeking for help means the parent acknowledges their child is mentally unstable. This was not found in the current research findings. However, the avoidance and limited communication from their neighbours could prevent parents' ability on who they approach for help.

The findings show that stigmatization did not prevent parents from seeking help from other sources aside from their neighbours. Participants within this research are parents who seek help in treatment centres and hospitals, this supports the idea that parents have the desire to seek help for their child. Although the internalized stigma of parents remains unclear, consequently, it can affect the levels of care burden and family dysfunctions for parents.

One way to interpret the findings is that parents may experience limited health literacy. One parent from an interview suggests that ASD was associated schizophrenia. In the interview, the parent states that some parents cannot understand the difference between mental health and developmental disabilities. This indicates there is a low mental literacy in the community (Jorm, 2000; Trinh & Tran, 2014; Vu & Tran, 2014). Ha et al. (2014) argues stigma may arise through the mistaken association of ASD with schizophrenia. The understanding between mental health and ASD amongst families, professionals and communities remains unclear in this research. Nonetheless, the limited knowledge of people from the community could be the cause of high stigmatization and discrimination against those with ASD.

The findings from the interviews presents parents feeling a lack of community support and they believe the public discriminates against parents of children with ASD. The reason for this could be because public may have limited awareness on autism. If parents continue experiencing this type of treatment from the public, they may become emotionally and psychologically distress which could limit parents from receiving help from the public and prevents the child from being exposed in public. Although the findings do not show parents reducing their ability to seek help, stigma could affect parents internally influencing their parental ideas on parenting practice. Their distress could shape their caregiving behaviour when providing care for their child which could negatively impact the child's developmental growth. It is important for the autistic child to be exposed to different environments because it could improve their social skills and help them integrate with the public.

The findings of parents' experiences with stigmatization relates to the custom of caregiving component of the developmental niche because the child's daily routine may be only exposed to treatment centres, homes and schools excluding their neighbours and the public community. The child's setting is limited to only certain environments which means the child's play pattern and the way they socialize are limited to only family members, teachers, health professionals and their parents. I argue it is important for the child with ASD to have a dynamic exposure to the public because the child could foster relationships with the neighbor children through play and socialization.

Coping mechanisms

The discussion of stress was mentioned in the above sections, this section will discuss parents' coping mechanism of dealing with stress. In this current research, there is an association between parents' stress and caregiving their child. Stress is a common theme parents experience when caring for their child with ASD and without tools deal with stress, it could lead to distress and discomfort impacting their roles of caregiving.

Most of this research focuses on the care for the child, however, it is critical to recognize the care for the parent. Bitsika & Sharpley (2014) and Dryer (2013) argues coping mechanism improve challenges such as mental, physical and health issues such as depression, anxiety and stress Higgins et al. (2001) adds coping mechanisms deal with heavy burdens of caregiving to prevent burnout. Doron & Sharabany (2013) argues it improves the relationship satisfaction with partners and Weitlauf et al. (2014) states it also improves relationship with family members. In some of the interviews, social support from partners, professionals, television, family members and other parents provides parents relief and reassurance about caring for their child with autism.

The findings from interviews presents that a type of coping mechanism can be from family support which is the parent’s shared household and caregiving duties with their partner and/or immediate family members. Parents state it relieves the other partner from stress of caregiving. Some parents share that talking to other families of children with ASD and professionals made them feel relieved and distressed.

In the literature review, Fleischmann (2005), Dunn et al. (2001), Gray (2003) & Luther et al. (2005) as cited in Mancil, Boyd & Bedesem (2009) supports the current findings that seeking information from supports is a type of coping mechanisms for parents.

Solomon (1971) as cited in Chao & Tseng, 2002, argues that parents do not physically show affection and love for their children, but they feel compassion and love towards them. Luo et al. (2013) agrees and states because of ideas on filial piety practice, parents will not show affection to the child if the child does not show love to parents.

The current findings from the research, do not support Solomon (1971) and Luo et al. (2013) because parents from interviews state that showing love for their child is a way they cope with their stress and seeing their child developmental growth improving. Parents’ acceptance of their child provides them motivation to seek and receive help from multiple resources and it also opens them up to consider self-care resources. Parents do express the need for tolerance on their child when they are agitated, however parents believe the more love they show to their child, their developmental skills will improve.

Overall, parents dealing with stress is by getting support for their child, loving the child and observing the improvements of their child's developmental growth. It is important to mention that all parents' coping mechanisms are related to the caregiving of the child.

These findings relate to the customs of caregiving because it explores the type of child-parent interaction. Child-parent interactions are created by parents receiving multiple social support, feeling stress from caregiving and external factors, experiencing stigma from the public, and providing love for their children. I argue all these indicators experienced by parents structure the lives of the children's routines and displays a type of parenting practice that is loving, non-authoritative and committed in finding effective and quality resources to help their child develop healthily. If parents practice more coping strategies when confronting caregiving challenges, it can improve the care they provide for their children.

6.5. The relationship between the sub-systems of the niches

Identifying parental childcare practice through the lens of the conceptual framework with the focal point on the three themes: centeredness of family, parents' developmental goals and social support explores a greater understanding of the child's process of development. This can help parents make inform decisions on childcaring. The themes correspond to the components of the niche; however, the themes are not confined to only one type of component because there is an overlap between themes and components. This section will discuss the associations between the sub-systems of the niche in relation to the themes.

Parents' psychology and physical and social settings

Parents and caregivers' ideas and beliefs are related to the physical and social surroundings around the child with ASD. Parents' beliefs on raising their child affects their parenting style while there are specific physical and social elements surrounding the child. Parents are constantly monitoring, observing and nurturing the child which demonstrates the physical presence of the parents are evident in the child's life. Parents determines the location of their child, either at home, treatment centres, family homes or schools. Parents scheduled routine is based around the child and they choose to quit their job to raise the child. It is interpreted that the planning of care happens in front of the child. Another example of social setting is that child is constantly surrounded by adults having conversations about the child's daily care. Parents brings their child to doctors and schools so the child's schedule is modified around childcare. Interventions are taught to parents from health professionals so parents can implement it at home. If parents experience barriers to accessing services (i.e. cost, travel, lack of quality services etc.), parents ask for support from immediate family members or parents stay at home to care for the child.

Another overlap of these two sub-systems are caregivers' psychology and physical and social settings which influences the surroundings in the child's daily life. Considering the impact of stigma affecting parents' ideas on caring for their child, their psychology integrates into the physical and social settings surrounded around the child. Parents who experience public shaming results in parents limiting the exposure of their child to their neighbours so the neighbour children cannot participate in playing with their child. The influencing forces impacted by stigma shows the physical absence in the child's social and play routine, in this case, it is the absent of neighbour children.

Parents' psychology and customs of childcare and child-rearing

Parents and caregivers' ideas and beliefs are related to the customs of childcare and childrearing. The overlaps of the components suggest parenting ideas on raising a child with ASD is congruent with their parental practices. Professionals and families contribute to helping parents make decisions on what is best for their child. A therapist can try to help parents understand what the short-term care for the child may look like, however parents need to change their beliefs on what they believe is a 'perfect child' to what they believe is a healthy life for the child (Harkness et al., 2007). Also, parents rely on their immediate family for advice on health decisions about their child rather than depending on their own decision. Parents have qualities they desire from their child which suggests it is influenced by their upbringing in a Vietnamese household and these traits may have been carried and passed down by their families. The following of directions and respecting elders is a natural process that becomes a natural expectation for families. The cause of such process is from traditional collectivist ideals that are deeply rooted in the psychology of Vietnamese families.

Although parents rely on health information provided by family members, it does not mean the information is reliable and effective for the child with ASD. The knowledge on the diagnosis of autism, effects of autism and the treatment of autism is unclear amongst family members and the public. This makes it challenging for family members to determine the right choices of treatment for the child. Health literacy impacts the ideas of families and it is much needed for families of children with autism in Vietnam. If parents and families have the right information, then they can make informed health choices for their child.

Parents experience barriers and challenges when it comes to caring for their child, looking for services, and experiencing stigma from public scrutiny. These barriers and challenges create stress on parental practice which the child is exposed to and can impact the structure of the child's daily routine. It is interpreted that the stress from parents affects the health decisions and while there is limited self-care of parents, they could result in burnout in caregiving (Higgins et al., 2001). Overall, the implications of these associations demonstrate that ideas influence practices and ideas influence practices.

Physical and social settings and customs of childcare and child-rearing

Physical and social settings and customs of childcare are overlapping systems because the child is exposed to physical and social elements such as: parents, sibling, family members, toys, household items, posters of schedules, pictures on the walls, television, food, and books. Family members show their presence in the child's life such as playing games and teaching the child skills. The child goes through their regular routines and is always with their parent daily. When families eat, they sit on the floor to eat together with child, this reinforces the group thinking of collectivism. Parents will show affection to the child by playing with the child. It is notable that children with ASD often do no reciprocate the socialization provided by parent. However, if parents feel tired and burnout, their energy to teach skills, play, feed, toilet and care for the child will decrease resulting in a change of childcare routine. In addition, the responsibilities of a parent can change if there are internal and external stress factors. Customs of childcare is part of the practical parental activities that is affected by the physical and social elements from the environment.

6.6. The relationship between the sub-systems and the larger system

The developmental niche is an open system that allows forces from the social, cultural and ecological context to potentially change the interrelated components of the niche. Social and ecological changes to the environment in Vietnam, such as the Doi Moi, created socio-economic changes on its demographic and health systems. This resulted in government subsidy reduction in health system and education (Ha et al., 2014). When the environment changes it could impact the living system of the family which impacts the child with ASD. The setting that organizes the child's daily life such as childcare activities, routines and parental beliefs could change if the environment changes.

Gammeltoft (2008) argues that communities in Vietnam were brought up in rice farming had changed due to socioeconomic advancements, so the land has changed to urban development projects and many people had to looks for jobs related to industry, service and trade. In the areas of Hanoi, people who live with a type of income and occupation based on the socioeconomic advancements are considered well off and privileged compared to people living in the rural areas. If a child with a disability is born in rural areas, there is less access to disability support and services. This is supported by MOLISA & UNICEF (2004), that indicates a small percentage of children in rural areas receive financial support from the government (as cited in UNICEF, 2010). According to the demographic survey from the current research, it shows most parents work in banking and finance, government and public administration and private company. Please see Table. 5. Although the parents from the current study are within the middle income, the treatment and services are still costly. The socioeconomic context in which the child lives in is shaped by structural forces that affects the construction of the child's daily life and their parents' agenda of childcare.

Another factor that influences the developmental niche is change of government laws and policies. Beliefs, settings and practices organized in the child with ASD's life can be altered if there are political factors changes outside the sub-systems. Policy changes could affect families positively or negatively. The Doi Moi changed the education and health systems resulting in a high expenditure for health and education that critically affected families living on low income. Due to the overcrowding of public hospitals and overworked health professions, families have no choice but to take private treatment for their child that has higher costs than private care. However, stronger enforced policies to reduce barriers and increased investment in social spending on adequate services for people with disabilities can transform a child life and reduce challenges for families. Ha et al. (2014) argues that although policies are in place, they are not given the capacity to support services for people with autism. Further attention is needed to address health and education systems in Vietnam.

6.7. Limitations of the study

Although the study was conducted with an aim to reduce biases and errors as much as possible, there are limitations to be acknowledged. The participants agreed to participate in the research, and it can only be assumed that the answers they gave were truthful. In the consent letter, parents were informed that the interview questions could have triggered physical, mental and social emotions and although parents were aware of that, it could still have an impact on their answers. A suggestion for future improvements could be giving the parents the interview guideline before the interview so they have time to read and reflect on their answers. However, that could also create a high bias on their answers because they can modify their answers to what they think the researcher would like to hear. The participants who participated in both the surveys and interviews had a seven-day time span between them to limit the bias when participating in the interviews; it is not guaranteed to how effective that strategy was.

The sample size was relatively small, and convenience sampling meant the recruitment was limited to parents who sought help for their children with ASD. In the interviews, most parents who were recruited from the treatment centres already have more experience in raising their children with ASD compared to parents recruited from the hospital. The parents' children from the hospital are newly diagnosed, this means there could be different experiences parents face when raising their children with ASD. Parents' experiences such as support systems, health literacy, coping mechanism, parental goals and belief systems may vary overtime. It would be interesting to conduct longitudinal studies of parents with newly diagnosed autistic children to understand their perspectives over time.

The study area was in Hanoi, which may show different findings from the rest of Vietnam. If central, southern areas and rural areas were focused, it could have strengthened the understanding of Vietnamese parents' experiences raising their children and would have been interesting to compare the findings to identify if there are congruency and divergency.

The sample of the children's age is another limitation as it only looked at early years of children ranging from 1- 9 years of age. There is no discussion on youth, teenagers and young adults which would be interesting to study seeing that the children will grow into these age groups.

In the demographic survey, there could have been more questions regarding the parents' socioeconomic background such as the partner's employment status, ethnic minority status and religion/spiritual belief systems, it could have added a more comprehensive understanding of the parents' background.

Another limitation is the translation and interpretation of the interviews and surveys. The challenges generated from interpreting the meaning from the participant to the research assistant could "hinder the transfer of meaning and might result in loss of meaning and thus loss of the validity of the qualitative study" (Nes, Abma, Jonsson & Deeg, 2010, p. 314). There could have been a loss of context in how parents expressed their meaning during the interview. Although the research assistants translated the surveys questions and interview results in a competent and careful manner, there could be some terminology that are interpreted differently.

Participants were allowed to choose their own time and place to conduct the interview and all of them chose either the hospital or treatment centres which could be another limitation. Factors from the hospital and treatment centre may have had an impact on participants' answers, these factors include: the location of the room, the air quality, the sounds, the feeling people may overhear conversations and the overall environment. According to Elwood & Martin (2010), when conducting interviews, "the relationships of the researcher with the interview participant, the participant with the site, and the site within a broader sociocultural context affects both researcher and participant" (p. 650). This demonstrates the surroundings of the environment can affect participants' answers in the interviews. Also, the power dynamics of the interaction between the researcher and research assistant with the participant may have impact on the comfort level of participants when it comes to disclosing information to two people instead of one person.

Lastly, a challenge for myself as the researcher is conducting research for the first time and employing mixed methods approach without experience doing qualitative and quantitative method separately as suggested by Creswell (2011). However, much time and dedication were put forward within this research while considering the credibility, transferability, dependability and confirmability in qualitative research as well as generalizability, reliability, validity in quantitative research (Creswell, 2011).

6.8. Identifying ethical matters

Mixed methods researchers may experience similar ethical issues as do other researchers, this includes, informed consent, data protection, storage of information, dissemination, confidentiality and sharing personal experiences which can affect the data collected from interviews and surveys. As a researcher, I am aware and careful of the potential risks and benefits when collecting, analyzing and interpreting participants' data.

Genuine informed consent

To confirm there was genuine informed consent for participants to participate in the research, the research assistant read through the consent letter with the participants. Participants was given as much time as they needed to read the consent letter and the research assistant was present to address any concerns and comments participants may have. Please see Appendix E for informed consent of participants.

Dignity and worth of the person

In this research, I followed the core values and code of ethics of the National Association of Social Workers (2017), Dignity and Worth of the Person (NAWS, 2017). As a standard practice of NASW, the research team and I embody the respect when interacting with the participants and professionals involved in the research. The respect for privacy of participants' information were stated in the consent form. It was stated on the consent form that the participants are protected from harm, however participants may experience emotional, psychological or physical stress due to the nature of sharing their genuine experiences of childcaring.

6.9. Trustworthiness

This section will discuss the trustworthiness of the data based on Guba's construct of employing trustworthiness of data: credibility, transferability, dependability, and confirmability (as cited in Shenton, 2004).

Credibility

The authenticity of the research is important throughout the entire research specifically when conducting interviews. I avoided providing answers to participants and refrained from providing positive or negative feedback after their answers. I gave participants the time and space to speak and reflect freely during the interview. Before the data collection, training of research ethics was provided to the research assistants so they knew they had to allow the participants to be authentic during the interview. To confirm if participants' answers were what they wanted to articulate, I would ask them to confirm their answer by asking, "so you said_________, is this correct?" This strategy reduces interpretation of participants' answers. Sometimes parents felt emotional and needed time before they could answer a question, there was space provided for them to do so. As indicated in the consent form, participants had the choice to skip questions they did not want to answer without disclosing the reason. This was considered helpful in ensuring the honesty of participants in contributing to the research (Shenton, 2004).

During the transcription of the data, I performed a member check with one of the research assistants to see if there were overlapping themes and if they were consistent with the themes I found from the interviews. A member check helped improved accuracy and validity of the research (Shenton, 2004). When analyzing the data, I made sure there were matching patterns of the themes compared with the research assistant's themes to make "meaningful comparisons" (Cao, 2007) and ensure the credibility of the qualitative approach. *Trustworthiness and validity of data*

An important aspect of the mixed methods research is the trustworthiness and validation of data. It is identified as one of major mix methods issues to focus on (Tashakkori & Teddlie, 2003a as cited in Creswell & Clarke, 2011). When discussing the validity of data, it concerns phases of data collection, data analysis and interpretation. When using a concurrent mixed methods design, I ensure the qualitative and quantitative samples are drawn from the same population to make data comparison. I separated the data collection procedure and collected data accordingly. The seven days gap was a strategy to limit biases from the survey that may influence the interviews. Some of the questions I used for the interviews and surveys are the same; addressing the same question in both data collection minimizes the potential validity threats. I used member-check in interviews as technique to validate participants' responses and to improve accuracy, credibility, validity, and transferability. For the qualitative themes and quotes, I found statistical results and literature review that matched it. I did a pilot study of survey and interviews in Canada and Vietnam to examine the feasibility of the methods (e.g. cost, time, performance of study design).

I addressed some ways to minimize the threat of validity, however there are current issues that cannot be avoided after collecting my data. Firstly, I obtained unequal sample sizes such as drawing data from large quantitative sample and small qualitative sample. Secondly, I gave more weight to qualitative data than quantitative data due limited parental ideas; interviews provided detailed and meaningful information than surveys alone. Lastly, if I had more time with the research team, I would have had the team evaluate the overall project objectives and discuss the methodological differences. There could have been more time to confirm the qualitative data results with the research assistants by checking with the participants to see if their information were accurate and if they approved the developing themes. This could have increased the validity and authenticity of the data collected for the research.

Transferability

The use of this concept implies if the current research can be applied to other situations (Shenton, 2004). The study population cannot generalize the entire population of Vietnam when the focus of the study area is in Hanoi. However, if the demographic of parents and children are similar to other demographics in Vietnam and share relatable experiences, it could be useful in providing interpterion for other researchers. The underpinning research question facilitated by the conceptual framework can help readers make inform decisions about the applicability of the research findings (Cao, 2007). Considerations to perform transferability should include the location, number of organizations, number of participants, data collection methods, time plan of the data collection and the time period to when the data was collected (Cole & Gardner, 1979; Marchionini & Teague, 1987; Pitts, 1994 as cited in Shenton, 2004).

The design strategy of the convenience sampling and answers to the research question provide enough details for the readers to determine if the information could have a degree of transferability.

Dependability

To ensure dependability, I address the reliability of the qualitative approach by using overlapping methods during the interview with the use of audio recording and hand-written notes taken by myself and the research assistant (Shenton, 2004). As mentioned earlier, checking in with the participants to ensure their answers were the correct answers they wanted to provide and the strategy to perform member checking was in place to ensure the accuracy of the transcription.

Confirmability

To avoid my own biases, I practiced reflexivity (Cao, 2007) throughout the qualitative approach by evaluating if the decisions I made to collect the data, transcribe the data, and analyze the data were appropriate. When collecting the data, I avoided leading questions and attentively followed the interview guideline. The transcription of the data had a lengthy amount of time spent on combining, splitting and/or omitting the themes to reproduce the final themes. The analysis of the data was assessing the entire analytical process and by asking myself, 'how did I make the informed decision to perform this activity?' These strategies helped me make overall judgments when using the qualitative approach.

6.10. Summary

This study has presented findings on parental care for children with ASD in Hanoi organized by the conceptual framework of the developmental niche. Specifically, the findings have shown evidence on parental care when raising their child, autism supports used and needed, parental challenges and barriers when raising their child and understanding parents' coping mechanisms when addressing their challenges. These findings are strongly connected to the three components of the developmental niche which has broaden the understanding of the relationship between the parent and the child with ASD. It was presented throughout the entire research that there is an emphasis on social and cultural factors that revolve around the care of the child affecting parental ideals and practices.

All parents' interviews and surveys reported the willingness in caring for the developmental process of their autistic child. They used family support and their direct presence to help their child. They show love and self-sacrifice within their parenting practice. Their ideas come from traditional and historical beliefs embedded in their caregiving psychology. They use internet, television, books, professionals, friends and other parents of children with ASD for social support. The findings from the literature review of parental styles such as authoritative or authoritarian among parents from Asia were not congruent with the current findings in the research, instead, the current findings show parents in Hanoi show less authority, but a lot of care and love while being highly involved in their child's life.

The findings show that supports and services used by parents were their partner, professionals, families, friends, teachers, books, internet, television, and other parents of autistic children. Although these supports were used, there needs to be an improvement on the quality, affordability and accessibility. These findings from the current research were congruent with the literature review.

Spiritual and religious supports were not explicitly found in the current research while literature review argued they were embedded in the belief systems of parents. The current research did not have enough supportive evidence to contribute to the findings of spiritual and religious supports from the literature, therefore the spiritual and religious supports affecting parental practice remains unclear. Parents' spiritual and religious views need to be further explored.

Parents' challenges and barriers such as cost of treatment services, the quality of treatment services, the accessibility of treatment services, understanding their child's diagnosis, public scrutiny, mental health, self-care and navigating the right services were all apparent in this current research. Though when it comes to better understanding parents' needs, the usage of terms in the study such as, 'strategies,' 'help,' 'support' and 'useful' within the survey and interviews questions are vague. These terms may be perceived differently from parents. It is difficult to add a greater understanding to parents' answers because it does not identify the type of strategies, supports and help and who it is intended for. The word, 'useful' could be short-term or long-term useful for the parent; the sustainability and effectiveness of the answer needs to be further explored.

The strategies parents use to cope with their challenges involved showing love to their child through playing with the child, teaching the child skills, making the child feel happy and celebrating their small accomplishments when the child achieves their developmental goal. Another coping strategy is that parents constantly seek support and finding different methods to help their child grow and integrate into society. Within all these strategies, parents show hope for their children to live a happy and healthy life.

Overall, the improvement of services and supports are needed by parents of children with ASD. A collaboration from families, involvements from government, institutions and communities must put attention to addressing parental concerns while being mindful of the social-cultural factors that impacts the child and their environment.

CHAPTER 7. RECOMMENDATIONS AND CONCLUSION

7.1. Recommendations for research and practice

Based on the findings from this current research, it indicates parents in Hanoi need stronger support when caring for the early years of their children with autism. Most support comes from partners, other parents of children with ASD, families, professionals, and teachers in caring for the child however, the quality, affordability and the accessibility of services need improvement. The effectiveness of treatment services remains unknown while the costs of it remains high. This calls for government intervention for stronger policies in advocating for the rights to access service for people with disabilities and a financial investment in education and health systems to improve the quality of care for children with ASD.

Health literacy

The findings indicate there may be limited understanding of autism services among families, professionals, and communities. Limited health literacy may affect beliefs of ASD, where to seek treatment, and how to determine the effectiveness of treatment. For professionals, it may impact their capacity to provide adequate service and advice to parents, ability to utilize diagnose assessments effectively, understanding ASD conditions, and skills on educating autism to parents and communities. There should be more research on health literacy among parents and professionals and its connection to improving treatment services and interventions.

Parental uncertainty on services

Some parents have show uncertainty with services provided by health professionals and teachers, so there must be a program evaluation on health care provision and special needs education curriculum to ensure parental satisfaction receiving autism care for their child. Training of providing autism care must be in placed for professionals and families so an exchange of knowledge on autism care can be openly practiced between them. The exchange of knowledge can build a trustful, collaborative and secured professional relationship between families and professionals such as doctors and teachers.

Research

More cross-cultural research is encouraged to explore the experiences of parents and caregivers raising their children with ASD, identify effective autism methods and treatments systems, address parental mental health and stresses of caregiving an autistic child, understand different coping strategies for caregiving, explore caregiving on different age groups of autistic children and investigate parental traditional and cultural belief systems on autism. There should be more attention to research in rural areas of Hanoi because the areas have limited literature on autism and fewer medical resources compared to urban cities like Hanoi and Ho Chi Minh. These research recommendations can have a supportive contribution to the global literature of autism.

Parental beliefs

The findings show that Buddhism and Karma are not explicitly stated by parents, however it is subconsciously integrated in parental ideas and practices around their development of the child. A suggestion for more research using the developmental niche to structure the context around parental belief systems can provide a visual and conceptual clarity on the child during their early ages of development.

Societal perceptions

There needs to be a shift of societal perceptions on people with autism by acknowledging autism is a way of living and not a disease and celebrating differences of people with different abilities. Parents are encouraged to speak freely of their experiences, professionals should acknowledge there is more to learn about autism, stakeholders need to collaborate to understand what is needed from each other, government must put their policies into practice, and parent led groups must continue to advocate for their children's' rights alongside with government support.

Children's perspectives

The narratives from children with ASD can help researchers understand their personal experiences using autism services and may inform disability policies. Research is predominantly focused on parents, health care professionals and the government which excludes the voices of the children with ASD. It is a challenging research, but it provides meaningful participation in research about autistic peoples' lives and needs. A few studies have performed photovoice interviews with autistic children (Carnahan, 2006; Ha & Whittaker, 2016).

7.2. Conclusion

Based on the qualitative and quantitative findings with the review of literature, it is evident there is a need for research in understanding parental experiences when raising their children with autism spectrum disorder in Vietnam. The research demonstrates there is a complex understanding of families within their own lived experiences based on parents decision-making on childcare, parental sacrifice, developmental goals for their child, traditional and cultural belief systems, health literacy, autism supports, public stigma on autism and coping strategies to deal with challenges on caregiving. These factors are organized within the autistic child's developmental life which has contributed to a greater understanding of the relationship between the parent and the autistic child. Now that society is becoming modern, there are changing work roles and caregiving roles within the family structure that may challenge traditional familial roles. These changes within family structures calls for more research on parents' experiences of children with autism in Vietnam because there is still little known about parents' understanding of autism, providing and seek autism care, understanding autism services and treatments and addressing challenges of caregiving. Overall, this study is aimed to address the gap of literature about parents' caregiving experiences for their children with ASD in Hanoi, Vietnam and it contributes to the literature on global health.

Restate research question

In this current research, I used a mixed methods approach to address the research on understanding experiences of parents when raising their children with ASD in Hanoi. The research question explores parental caregiving experience, autism services used and needed by parents, challenges and barriers of parental caregiving and parental coping mechanisms.

To help contextualize these findings on understanding on what it is like to raise a child with ASD in Hanoi, the developmental niche by Harkness & Super (1986) was introduced and used within the study. It supports the construction of the themes generated from the findings of the research. The developmental niche has been useful in arranging and guiding the assumptions of the research question categorized in three sub-systems: physical and social setting, customs of psychology of the caregiver and childcare and child-rearing. The developmental niche brings meaning, transformation and organization of the child's environment within the social and cultural context of Vietnam.

The first component is the physical and social surroundings that relates to the theme of centeredness of family. The findings show that parents use immediate family to seek advice to make inform health decisions about their child. The second component is the psychology of caregiver that relates to the theme of parents' developmental goals. Parents want their children to improve on social, behaviour and communication skills. The findings show parents carry a Vietnamese cultural belief system embedded in their psychology. The third component is the custom of caregiving and child-rearing which relates to the theme of social support. Parent uses these social supports for the child within their daily care routine that contributes to the developmental growth.

These themes within the components showed the challenges and barriers experienced by parents and caregivers such as the high cost of interventions and treatments, the time spent on travelling to access supports, the limited understanding of autism, the caregiving burden and stress, mental health challenges and the avoidance of public shaming. To address these challenges and barriers, coping strategies are identified such as parents seeking multiple supports to help their child which provides parents relief and reassurance of caring for their child and having hope their child will grow up healthy and also, their commitment to show love for their child.

Parents' experiences and challenges demonstrates their own strength and commitment to do what it takes to raise their child to develop healthily; however, this care cannot be achieved from the parent alone. The interaction of all stakeholders from a local and national level is vital to addressing the needs of parents and their children's health development.

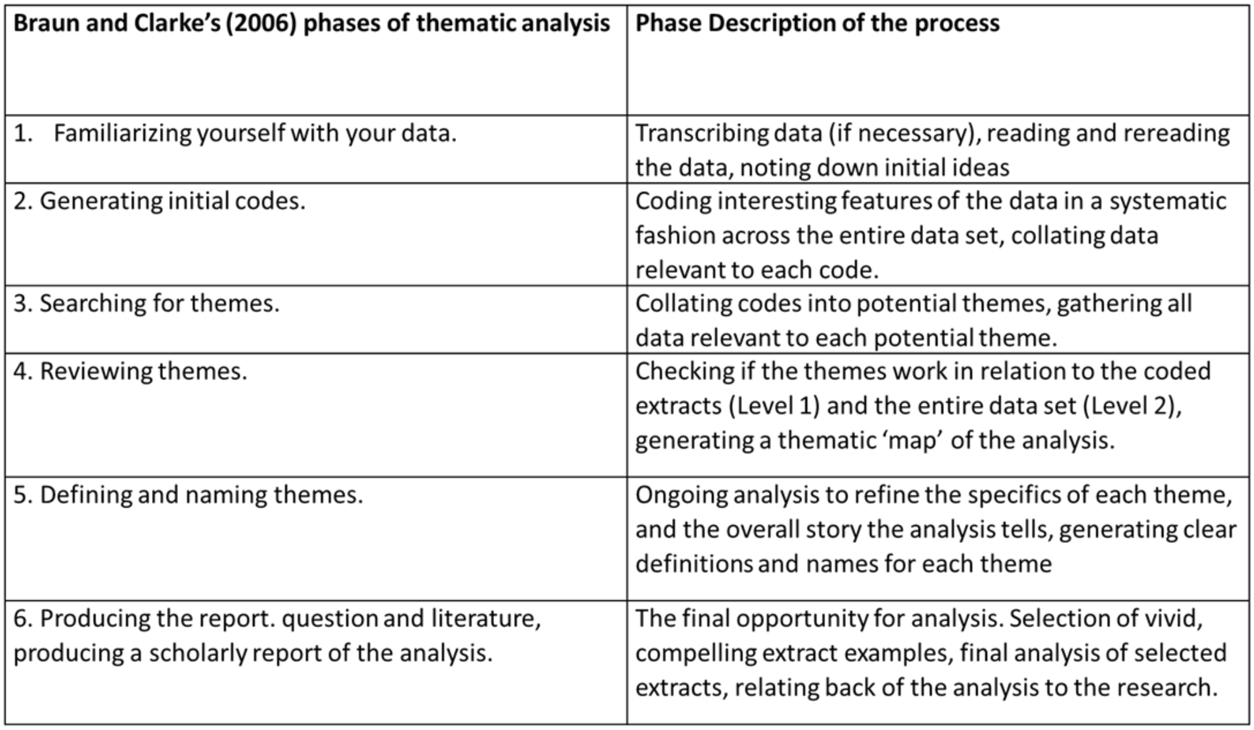
As a strategy for mediation, social workers that works within the social welfare services in local communities of Vietnam can connect resources to parents. Social work is currently a developing profession in Vietnam (Hugman et al., 2009) and there is a demand for them to support families and communities. Social workers can be empathetic to family situations, hold a cultural lens where they can empathically understand family situations, carry cultural appropriate resources and tools for autism, provide direction for parents - specifically families who have a recently diagnosed child and assess parents to understand their needs and their child's needs.

Lastly, an effective strategy can be the development of a guideline for effective engagement with families, communities, institutions and governments where they can actively participate in processes to make good policies on the inclusion of people with disabilities and to deliver quality services, supports and programs. There is an active role that everyone can take part in when caring for the child to develop healthily in his/her environment, therefore it takes a village to raise a child with autism.

TABLES

Terminology	**Definition**
Developmental Niche	**Based on parental ethnotheories, it provides a systematic organization of the environmental and orientation. It is a conceptual framework with three major systems: physical and social setting, daily childrearing routines and psychology of caregiver.**
Physical and Social Setting – component 1	**Observable sources that are physical or social elements organized in the child's environment.**
Psychology of Caregiver – component 2	**Parental ideas and parental roles that influence how the child is raised.**
Customs of childcare and child-rearing – component 3	**Daily care and routine that shapes the child within the environment.**

Table 1. Definitions of Terms



Braun and Clarke's (2006) phases of thematic analysis	**Phase Description of the process**
1. Familiarizing yourself with your data.	Transcribing data (if necessary), reading and rereading the data, noting down initial ideas
2. Generating initial codes.	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes.	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes.	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes.	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme
6. Producing the report. question and literature, producing a scholarly report of the analysis.	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research.

Table 2. Thematic Analysis

THEME	INTERVIEWS	SURVEYS	LITERATURE REVIEW
Family centeredness – Theme 1 ***Making decisions***	***Mother Le said, "my husband persuades the grandparents to bring the child to the hospital, he [husband] has a positive attitude in making decisions and shows his empathy."*** ***In interview 9, father Binh shared their child's decision of treatment care after the diagnosis, "we were shocked and stressed at first and we both decided to find information of what ASD is. Treatment is expensive, it was a decision we had to make as soon as possible."***	**97.7 per cent agree/strongly agree of parents seek help from their families. 93.3 per cent strongly agree or agree that they seek help from their partner.** **Surveys report 91 per cent of parents are married.**	**Chao & Tseng (2002) argues collectivist culture like Vietnam emphasize group goals are prioritize over personal goal.** **Contrast: (Hong & Kang, 1994). Zhou (1998) argued that despite the patriarchal system, mothers from Vietnam possess a larger share of power and manages family finances.** **Wolf (1970) argues mothers and fathers play complementary roles for their children to grow into ethical and responsible individuals.**
Parental Sacrifice/ Parents present in Child's Life	***In interview 7, "I am the only one who can care for myself, but I feel I have no time due to my work; I need the***	**Strongly agree or agree by 39.9 per cent that the strategies they use for their child are**	**Yu & Liu (1980) adds even when the children grow up, parents are expected to**

	money for my family. The business is in the evening while the child is at school. I put the smallest amount of time to play with the child. Sometimes I fall asleep while playing with the child." ***In interview 1, mother Thinh constantly "wonders about the child." She expresses the caring for the child has affected her working life. "I spend most of my time with the child by bringing him to intervention and doctor appointments."*** ***In interview 9, father Binh. "While the mother is caring for newborn, I play with the child in the morning then work until 5:00 PM, then come home in the evening and teach him how to play football and ride a bike. The teacher provides 50-minute intervention while I am at work."***	**useful while 88.6 per cent strongly agree or agree that they would like more help for their child.** **75% agree that they need to make sacrifices when taking care of their child. Please see Table for Survey Response #7. I need to make sacrifices when taking care of my child.**	**be highly involved and responsible for decision making and caring for children throughout their lives.** **Motchan (2012) about parents from Ho Chi Minh, Vietnam make sacrifices for their child for them to succeed. Smith, Greenberg, & Mailick (2014) adds that parents makes personal sacrifices for their child and feels the need to protect the child from harm.**

Ideas of filial piety and family interdependence	**In interview 2, grandmother Nguyen took the responsibility to care for the child with ASD while the mother of the child was pregnant with the second child.** **In interview 1, according mother Thinh, *“my husband is far from home due to work and cannot care the child. Grandparents take the son to school and caregivers.”***	**Mean score of 2.36 when asked *Q. 34. A belief in God can help a person overcome autism (Table #__)* and 6.8 per cent agree/strongly agree they seek help from religious leaders.** **Participant’s socioeconomic background states that over 50 per cent are employment/and or work at home.**	**Filial piety is well integrated within the cultural context in Asian families including Vietnam (Shin, Nhan, Crittenden, Flory & Ladinsky, 2006).** **Ho (1996) argues filial piety is a rigid system of respect of age and patriarchy.**
<u>Parental Developmental Goals- Theme 2</u> ***Parental Observations*** ***Social skills*** ***To Integrate into society*** ***Language skills*** ***Life skills***	***interview 1, mother Thinh noticed her son would play alone and was constantly hyperactive.*** ***Mother Thinh said, “some children with autism likes to sit still, my child likes to climb, run and whatever he likes- his focus is 100 per cent on them.”***	**Q. 8. People with autism can be helped to improve their behaviour through one-to-one therapy. – 72.8 per cent strongly agree/agree.**	**Goodnow and Collin (1990) argue goals may reflect on environmental factors while others reflect on tradition.** **Goodnow & Collins (1990) argues rationale**

Behavior skills *Communication Skills* *Have friends* *Find a job*	*In interview 6, mother Hang makes the decision to do a mix of treatment and kindergarten based on observing child's needs.* *Mother Hang said, "I noticed my child's social skills increased but lacks the language so then first part of the day, I take my child to treatment centre and second part of the day, I take my child to kindergarten. I have tried different treatment centres, it cost a lot of time and money but I have to do it."* *In interview 6, mother Hang compares her child to a child without ASD. She said, "a child with no autism, I put 1X effort but a child with autism, I put 100X effort."*		**of goals for the child is either an action of compliance of the child or a negotiation and cooperation of the child.** **Other studies support this idea about parental roles and expectations in Asia and their child giving goals are impacted by reciprocities and karmic merits (Ha et al., 2014 & Gammeltoft; 2008). Parental perceptions not only affect the decision to formulate the goals, but it affects the health of the child.**
Choosing the Right Support Based on Parental Ideas	*In interview 3, "I believed every strategy has its own effect and the effect may be only a short-term effect and unsustainable."* *"What I use is useful*	**Q. 8. People with autism can be helped to improve their behaviour through one-to-one therapy. – 72.8 per cent strongly agree/agree.**	**Parental goals for the child with ASD because the belief and ideas of parents directly impacts child giving practices (Super**

	right now, but I don't know how much useful it will be later" *In Interview 6, mother Hang tried three treatment centres suggested by other mothers and internet. She felt her child should have been diagnosed at 9 months old, but she followed the doctor's suggestions. "I feel I missed the early intervention because the doctor advised me to seek help when my child was two years old."* *In Interview 9, "There are a lot of treatment centers through marketing and public relations. It looks good but it is also hard for parents to know which one works efficiently and parents need to be on successful cases rather than information on marketing. Some kindergartens refuse to accept the child."* *"I will listen to everyone's advice and think critically on what to determine is good for child. In Vietnam,*	**Survey responses: I go to ________to seek help for my child (n = 89)** **Strongly agree/agree (%)** **Professionals- 97.7** **Internet- 75.3** **Friends- 69.4** **Other Parents- 84.1** **Family- 97.7** **Religious Leaders - 6.8** **Teachers - 93.1** **Partner – 93.3**	**& Harkness, 1986)**

	there are networks for job support for people with disabilities, but the government does not have a policy for them. We need more support and policy from the government."		
Social Support – Theme 3 ***Social Support***	***In interview 7, mother Hoang expresses how television is better than social media. "T.V is effective, villagers watch a lot of T.V, they should have a T.V program about what autism is and how to support the child to be normal."*** ***In interview 1, mother Thinh hopes school can improve. "I hope public schools are specialized in autism and close by. I live far from the centre - 15 km to take my child to the centre and back home."***	**Survey responses: I go to ________to seek help for my child (n = 89)** **Strongly agree/agree (%)** **Professionals- 97.7** **Internet- 75.3** **Friends- 69.4** **Other Parents- 84.1** **Family- 97.7** **Religious Leaders - 6.8** **Teachers - 93.1** **Partner - 93.3**	**Cobb (1976) social support is the belief of the individual "that one is cared for and loved, esteemed and valued, and belongs to a network of communication and mutual obligations"** **Therapists and health professionals help parents identify choices on how to treat the child. Children's life is modified to include therapy (Harkness et al., 2007).**
Family Support	***Grandmother Nguyen said, "I brought the child to the National Hospital then to see a psychologist for intervention. At home, I help mother by teaching the child***	**97.7 per cent agree/strongly agree of parents seek help from their families. 93.3 per cent strongly agree or agree that they**	**Chao & Tseng (2002) argues interdependence is rooted in Asian families while independence is place in Western**

	eating, toileting but the development is still low.” ***In interview 1, according mother Thinh, “my husband is far from home due to work and cannot care the child. Grandparents take the son to school and caregivers.”***	**seek help from their partner.**	**families. Other studies by Ho (1996) and Kim Choi (1994) have supported this describing the effects of interdependence affect religion, politics, economics and education.**
Stigmatization	***“it’s hard to share my story and the hometown does not accept autism. They ignore the problem if the child has a problem, they just think the child is normal. I do not care what they say.”*** ***Villagers talks and thinks about how he [her child] is abnormal, they do not understand ASD.” She shared how there is another child with a disability in her village and wanted to socialize with the other parent, however she was afraid of the other parent’s reaction. “If I mention the other child has a disability, the other parents would shout at me, I have to be careful what I say to them8, mother Chu***	**Q. I am afraid others may think my child has autism. Mean score:** **3.3146 (low mean score)**	**Huang, Kellett, & St John (2010) share similar studies like in China and Taiwan. In Vietnam, the stigma of a child with a disability across increases stress.** **In parts of Asia, stigmatized cultural attitude towards disability and the discrimination of individuals living with autism affects families, caregivers, friends and service providers (Mak & Kwok, 2010). Xueqin et al. (2012)**

	compares her child to a child without autism said, "the care of the child is 3x harder than the normal child."		
Coping Mechanisms	***In interview 5, "my husband is very supportive and shares the housework and teaches the child intervention and plays with child-it decreases the stress for me."*** ***In interview 5, mother Dang describes a helpful television show about a story of children with autism, the show encourages her to "keep trying and child will be better." The support from media gives the parent hope that their child will become better.*** ***In interview 4, mother Tu, "without them [other mothers], I want to die, I want to hold the baby and cry and I don't want to live anymore."***	**97.7 per cent agree/strongly agree of parents seek help from their families. 93.3 per cent strongly agree or agree that they seek help from their partner.**	**Bitsika & Sharpley (2004), parents from Western countries reported feeling depressed, anxious and stress. Hoffan et al. (2008) and Mayes & Calhoun (2009) argue sleep deprivation is also one of the challenges parents experience when caring for their child with ASD.**

The importance of loving a child	***In interview 9, “I will believe in myself and child, show all my love and try to help my child development.”*** ***In interview 7, “at first, I could not accept child and now I learn to accept child and not push the child hard. I must be patient and now I have learned to love my child. Once I started to accept, I see solutions not problems.”***	**93.2 per cent agrees that providing a warm and loving environment can help people overcome autism.** **From the surveys, 93.2 per cent strongly agree/agree providing a warm and loving environment can help overcome autism. The data from interview and survey are in line with interpretation that participants indicated the importance of loving the child and fostering a closer parent-child relationship.** **Mean scores:** **11. Cold and unloving homes are a frequent cause of autism.** **4.7500** **17. Providing a warm and loving environment can help people overcome autism.**	**Solomon (1971) on** **“fathers were expected to assume the role of a strict disciplinarian, they nonetheless, felt a compassion and love toward their children” (p. 63).** **Chao’s (1995)** **“Chinese mothers emphasized the importance of love for fostering a close, enduring parent–child relationship…” (p. 64).** **Confucius value of filial piety as the parent will not show affection to the child if the child does not show love to parents. Respect and obedience are considered love in this context (Luo et al., 2013)**

		6.4659 **33. Having emotionally cold parents often causes autism.** **4.3371**	**. When autistic children ask for help directly to parents, they do not actively seek physical contact and do not react strongly when family members leave (Beauchesne & Kelley 2004), therefore it is difficult for parents to show attachment behaviours with their autistic child.**

Table 3. Side by Side Comparison Table

n = 89	**M/n (%)**	**SD**	**RANGE**	**VALUES**
PARENT DEMOGRAPHIC				
Parent's age (year)	2.36 (*See Values)*	0.63 *(See Values)*	1.0 - 4.00 *(See Values)*	1 = 18 – 24 2 = 25 – 34 3 = 35 – 44 4 = 45 – 54 5 = 55 – 64
18-24	3.4%			
25-34	61.8%			
35-44	30.3%			
45-54	4.5%			
Parent's gender				
Male	24.7%			
Female	75.3%			
Parent's education				
Post-university	14.6%			
University	50.6%			
Colleges	11.2%			
Vocational school	7.9%			
Highschool	4.5%			
Secondary school	10.1%			
No school	1.1%			
Parent's partner education				
Post-university	12.6%			
University	50.6%			
Colleges	9.2%			
Vocational school	5.7%			
Highschool	11.5%			
Secondary school	9.2%			
No school	1.1%			
Parent's marital status				
Married	91.0%			
Divorced	5.6%			
Separated	3.4%			
Parent's employment status				
Employed	**56.2%**			
Unemployed and currently looking for work	**1.1%**			
Unemployed and not currently looking for Work	**1.1%**			
Retired	**3.4%**			
Work at home	**14.6%**			
Self-employed	**23.6%**			

Table 4. Parent Demographic

CHILD DEMOGRAPHIC				
Child’s age (year)	1.79 *(See Values)*	0.65 *(See Values)*	1 – 3 *(See Values)*	
1-3	33.7%			1 = 1 – 3
4-6	53.9%			2 = 4 – 6
7-9	12.4%			3 = 7 – 9
Child’s gender				
Male	90.9%			
Female	9.1%			
Child’s diagnosed year	2.72 *(See Values)*	1.88 *(See Values)*	1 – 8 *(See Values)*	
2018	32.5%			1 = 2018
2017	27.7%			2 = 2017
2016	12.0%			3 = 2016
2015	9.6%			4 = 2015
2014	6.0%			5 = 2014
2013	7.2%			6 = 2013
2012	2.4%			7 = 2012
2011	2.4%			8 = 2011
Who diagnosed the child?				
Doctor	81.5%			
Psychologist	7.4%			
Specialist	2.5%			
Family	3.7%			
Teacher	3.7%			
Other	1.2%			
How many children?	1.84	0.81		
Other children diagnosed with ASD?		0.23		
Yes	5.6%			
No	94.4%			

Table 5. Child Demographic

Occupation	Frequency		Percent (%)		Valid Percent (%)	
	Parent	Partner	Parent	Partner	Parent	Partner
Accounting	1		1.1		1.3	
Agriculture and Fish	2		2.2		2.6	
Architecture and Construction	2	3	2.2	3.4	2.6	4.2
Administrative and Clerical	2	1	2.2	1.1	2.6	1.4
Banking and Finance	8	4	9.0	4.5	10.5	5.6
Customer Service	4	1	4.5	1.1	5.3	1.4
Education and Training	5	7	5.6	7.9	6.6	9.9
Government and Public Administration	8	9	9.0	10.1	10.5	12.7
Health Care	3	3	3.4	3.4	3.9	4.2
Hospitality and Tourism	1		1.1		1.3	
Transportation		1		1.1		1.4
Private Company	15	17	16.9	19.1	19.7	23.9
Home	4	2	4.5	2.2	5.3	2.8
Other	21	23	23.6	25.8	27.6	32.4
Total	76	71	85.4	79.8	100.0	100.0
Missing from System	13	18	14.6	20.2		
Total	89		100.0			

Table 6. Parent Occupation

Survey responses: I go to ________to seek help for my child (n = 89)	Strongly Agree or Agree (%)	Somewhat Agree (%)	Neutral (%)	Somewhat Disagree (%)	Strongly disagree or Disagree (%)
Professionals	97.7	2.2	0	0	0
Internet	75.3	21.3	3.4	0	0
Friends	69.4	21.6	4.5	1.1	3.4
Other Parents	84.1	12.5	0	0	3.4
Family	97.7	0	2.2	0	0
Religious Leaders	6.8	6.8	23.9	4.5	57.9
Teachers	93.1	6.9	0	0	0
Partner	93.3	5.6	1.1	0	0

Table 7. Survey Response on Seeking Help

strongly disagree = 1, disagree= 2, somewhat disagree = 3, neutral = 4,

somewhat agree = 5, agree = 6 and strongly agree = 7.

Questions (n=89)	**Strongly Disagree**	**Disagree**	**Somewhat Disagree**	**Neutral**	**Somewhat Agree**	**Agree**	**Strongly Agree**	**Total %**	**Mean**
Q.2 The best way to treat autism is using appropriately prescribed drugs.	22.5	33.7	10.1	5.6	21.3	5.6	1.1	100	2.91
Q.3 Giving 'rewards' for 'normal' behaviour can reduce autistic behaviour.	4	3	5	10	25	30	12	100	5.10
Q. 4 Complications during pregnancy can cause autism.		3.4	2.2	12.4	42.7	31.5	7.95	100	5.20
Q.5 I go to professionals to find help for my child.					2.2	34.8	62.9	100	6.60
Q.6 I go on the internet to find help for my child.				3.4	21.3	47.2	28.1	100	6.60
Q.7 I need to make sacrifices when taking care of my child.			1.1	6.8	17	48.9	26.1	100	5.92
Q. 8 People with autism can be helped to improve their behaviour through one-to-one therapy.			3.4	4.5	19.3	45.5	27.3	100	5.89
Q. 9 autism can be best helped by encouraging people with autism to interact with others who are 'normal.'			1.1	4.5	8	39.8	46.6	100	6.26
Q. 10 autism is caused essentially by genetic	3.4	15.9	8	34.1	27.3	9.1	2.3	100	4.02

factors.									
Q. 11 Cold and unloving homes are a frequent cause of autism.	2.3	11.4	6.8	6.8	45.5	15.9	11.4	100	4.75
Q. 12. autism is passed to children through genes.	6.8	18.2	11.4	33	22.7	6.8	1.1	100	3.76
Q. 13. I go to a friend to seek help for my child.		3.4	1.1	4.5	21.6	48.9	20.5	100	5.72
Q. 14. I go to other parents to seek help for my child.		3.4		12.5	48.9	34.1	1.1	100	6.89
Q. 15 I would like more help for my child.			1.1	2.3	8	37.5	51.1	100	6.35
Q. 17. Providing a warm and loving environment can help people overcome autism.					6.8	39.8	53.4	100	6.47
Q. 21. I go to family to seek help for my child.				2.2	48.3		49.4	100	6.45
Q. 22. I go to religious leaders to seek help for my child.	28.4	29.5	4.5	23.9	6.8	4.5	2.3	100	2.74
Q. 23. I am confused as to why my child acquired this condition	8	8	5.7	22.7	15.9	27.3	12.5	100	4.63
Q. 24. Having emotionally cold parents often causes autism.	2.2	15.7	16.9	3.4	42.7	11.2	7.9	100	4.84
Q. 28. The strategies I currently use for my child are useful.		3.4	6.7	12.4	38.2	34.8	4.5	100	5.08
Q. 29. I go to teachers to seek help for my child.					6.9	52.9	40.2	100	6.33
Q. 30. I am afraid others may think my child has autism.	14.6	33.7	6.7	15.7	14.6	9	5.6	100	3.31

Q. 32. Having a 'bad upbringing' causes autism.	11.2	25.8	15.7	9	23.6	12.4	2.2	100	3.54
Q. 33. Whether a person with autism gets better may simply depend on luck.	21.3	41.6	11.2	11.2	14.6			100	2.56
Q. 34. A belief in God can help a person overcome autism.	36	32.6	6.7	12.4	9	3.4		100	2.36
Q. 35. Treatment of autism can help a person overcome autism.	7.9	10.1	1.1	9	13.5	37.1	21.3	100	5.07
Q. 36. I go to my partner to seek help for my child.				1.1	5.6	38.2	55.1	100	6.47
Q. 37. When I am not around, there will be someone helping my child.	9	11.2	7.9	2.2	12.4	37.1	20.2	100	4.90

Table 8. Survey Questionnaire

FIGURES

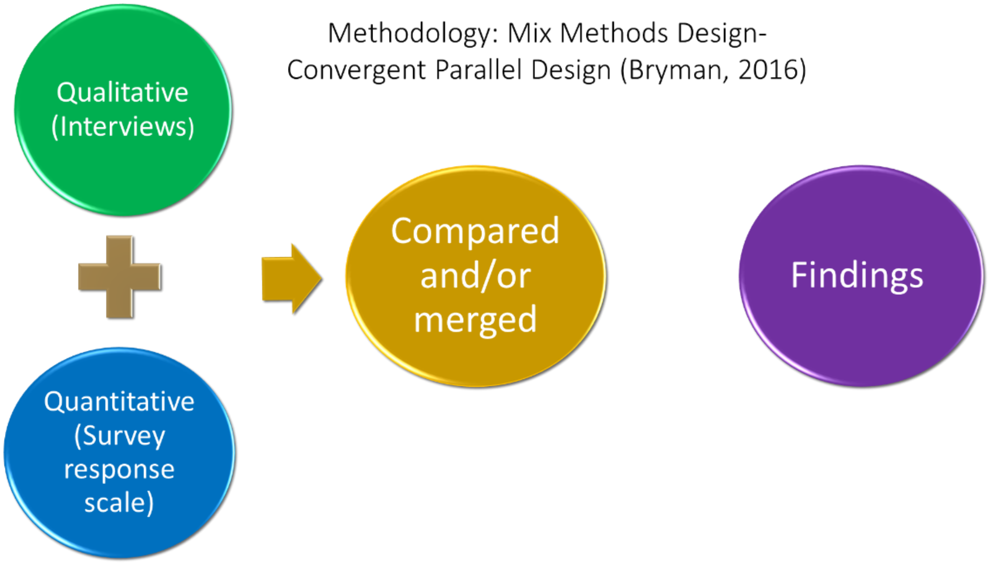


Figure 1. Mixed Methods Design

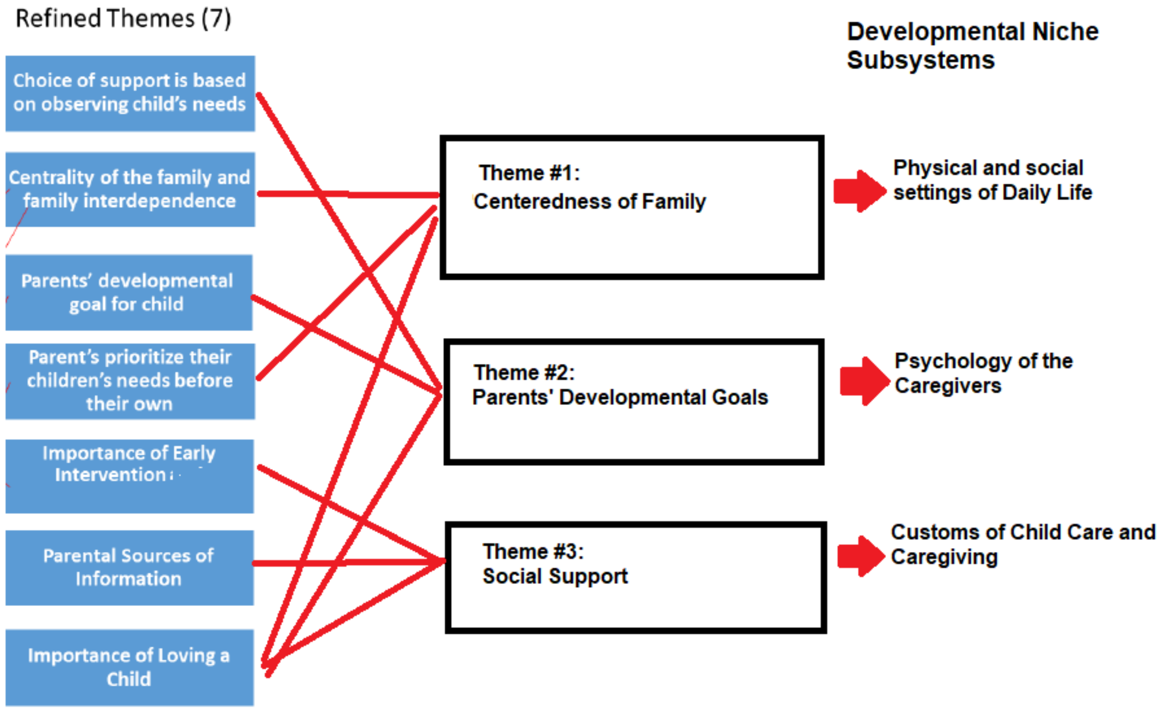
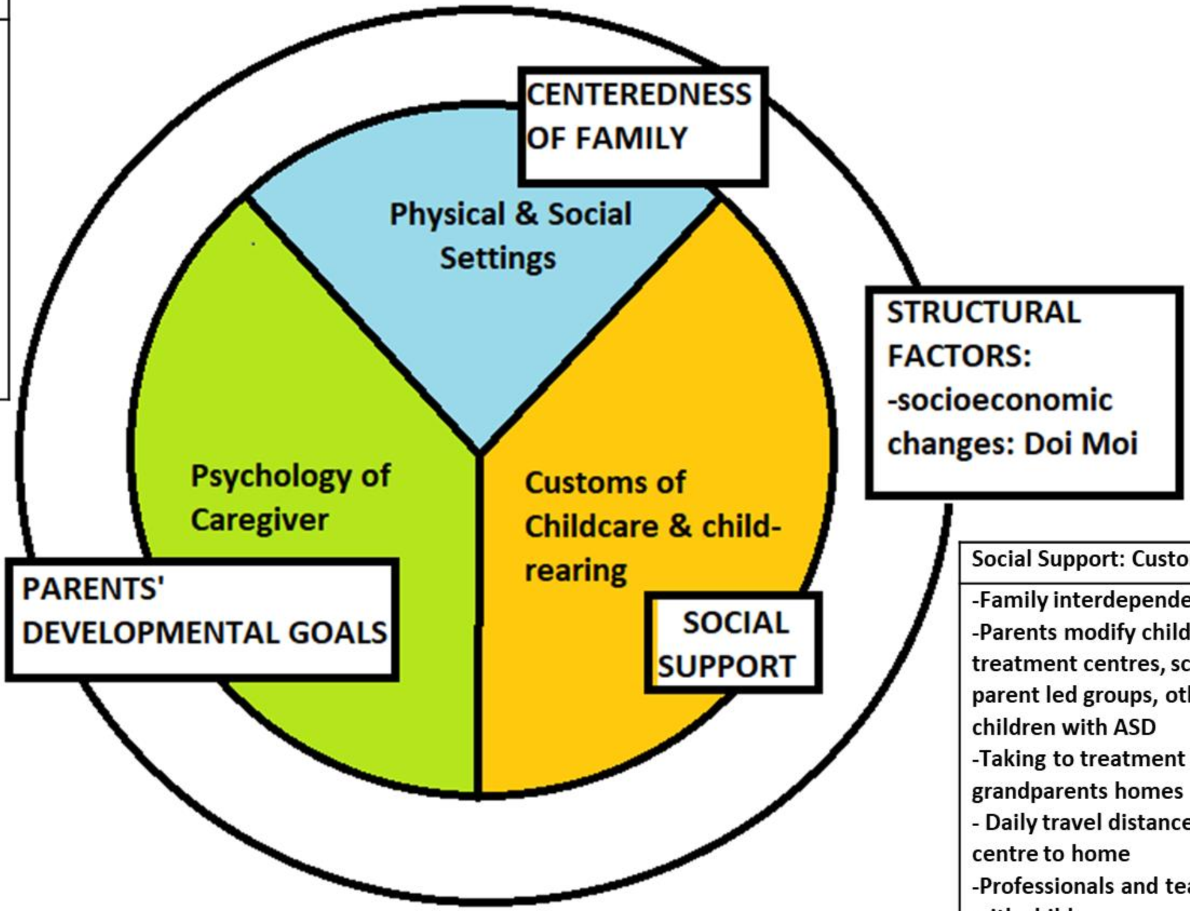


Figure 2. Refined Themes

Figure 3. The Developmental Niche with Themes

Centeredness of Family: Physical and Social Setting
-Parents give toys, schedules, books, television - encourages child to play with other children. -Family members: grandparents, siblings support - Parent brings child to work -Parent playing with child at home -Parents stays with child at treatment centre -Parents prioritize child over themselves



Parental goals: Psychology of Caregiver
-Filial Piety: expects child to listen, respect and follow instructions of parents -Always loving the child so they can grow -Buddhism & Confucianism, good deeds parent done in past = health child -Authoritative versus authoritarian -Parents goal for child to live healthily and integrate into society

Social Support: Customs of Care
-Family interdependence -Parents modify child's routine with treatment centres, schools, hospitals, parent led groups, other parents with children with ASD -Taking to treatment centre, schools, grandparents homes - Daily travel distance from treatment centre to home -Professionals and teachers playing with child -Professionals and teachers teaching the child skills -Lack of support from public, experiences of stigma makes parent stress around the child

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APPENDIX

Appendix A: NSD AGREEMENT

Appendix B: UNIVERSITY AGREEMENT

Appendix C: HOSPITAL AGREEMENT

Appendix D: VOLUNTEER CONTRACT AGREEMENT

Appendix E: PARTICIPANT CONSENT LETTER

Appendix F: DEMOGRAPHIC AND SURVEY QUESTIONNAIRE

Appendix G: INTERVIEW GUIDELINE

Appendix H: COMPENSATION TRACKER

Appendix I: BUDGET FOR ADMINISTRATIVE FEES

Appendix A: NSD AGREEMENT

Ragnhild Dybdahl
Pilestredet 35
0130 OSLO

Vår dato: 13.03.2018	Vår ref: 59027 / 3 / EPA	Deres dato:	Deres ref:

Tilrådning fra NSD Personvernombudet for forskning § 7-27

Personvernombudet for forskning viser til meldeskjema mottatt 07.02.2018 for prosjektet:

59027	*What are parents' perceptions of seeking early intervention strategies for their children with Autism Spectrum Disorder*
Behandlingsansvarlig	*Høgskolen i Oslo og Akershus, ved institusjonens øverste leder*
Daglig ansvarlig	*Ragnhild Dybdahl*
Student	*Davina Hang*

Vurdering

Etter gjennomgang av opplysningene i meldeskjemaet og øvrig dokumentasjon finner vi at prosjektet er unntatt konsesjonsplikt og at personopplysningene som blir samlet inn i dette prosjektet er regulert av § 7-27 i personopplysningsforskriften. På den neste siden er vår vurdering av prosjektopplegget slik det er meldt til oss. Du kan nå gå i gang med å behandle personopplysninger.

Vilkår for vår anbefaling

Vår anbefaling forutsetter at du gjennomfører prosjektet i tråd med:

- opplysningene gitt i meldeskjemaet og øvrig dokumentasjon
- vår prosjektvurdering, se side 2
- eventuell korrespondanse med oss

Meld fra hvis du gjør vesentlige endringer i prosjektet

Dersom prosjektet endrer seg, kan det være nødvendig å sende inn endringsmelding. På våre nettsider finner du svar på hvilke endringer du må melde, samt endringsskjema.

Opplysninger om prosjektet blir lagt ut på våre nettsider og i Meldingsarkivet

Vi har lagt ut opplysninger om prosjektet på nettsidene våre. Alle våre institusjoner har også tilgang til egne prosjekter i Meldingsarkivet.

Vi tar kontakt om status for behandling av personopplysninger ved prosjektslutt

Ved prosjektslutt 30.06.2019 vil vi ta kontakt for å avklare status for behandlingen av personopplysninger.

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

Se våre nettsider eller ta kontakt dersom du har spørsmål. Vi ønsker lykke til med prosjektet!

Vennlig hilsen

Marianne Høgetveit Myhren

Eva J. B. Payne

Kontaktperson: Eva J. B. Payne tlf: 55 58 27 97 / eva.payne@nsd.no
Vedlegg: Prosjektvurdering
Kopi: Davina Hang, davinahang92@gmail.com

Personvernombudet for forskning

Prosjektvurdering - Kommentar

Prosjektnr: 59027

PURPOSE
The purpose of the project is to understand families' health seeking behaviours of early intervention strategies for their children with Autism Spectrum Disorder (ASD). The overall purpose is to understand how parents make sense of their lives and experiences when seeking early intervention services for their children. Vietnam lacks public awareness and education of Autism and the capacity to provide adequate early intervention and healthcare services. It will provide information to researchers and students whose interest involves identifying needs of early interventions services for children with ASD.

INFORMATION AND CONSENT
According to your notification form the sample (parents/guardians of children with ASD, 30-45 years of age) will receive written and oral information and will give their consent to participate. The information letter we have received is well formulated, but we ask that you add that the collected personal data will be anonymised/deleted at the end of the project.

SENSITIVE PERSONAL DATA
You have indicated that you intend to process sensitive personal data about ethnic origin or political/philosophical/religious beliefs, and health.

DATA SECURITY
The Data Protection Official presupposes that you will process all data according to HiOA/OsloMet's internal guidelines/routines for information security. We presuppose that the use of a mobile storage device is in accordance with these guidelines.

DATA PROCESSOR
According to your notification form you intend to use a Vietnamese-English translator in the project, who will sign a contract. The translator will be trained in research ethics in line with Norwegian and Vietnamese guidelines for research ethics.

END OF PROJECT AND ANONYMISATION
The estimated end date of the project is 30.06.2019. According to your notification form you intend to anonymise the collected data by this date.

Making the data anonymous entails processing it in such a way that no individuals can be identified. This is done by:
- deleting all direct personal data (such as names/lists of reference numbers)
- deleting/rewriting indirectly identifiable personal data (i.e. an identifying combination of background variables, such as residence/work place, age and gender)

- deleting digital audio files

Appendix B: UNIVERSITY AGREEMENT

Oslo, 01.08.2018

To whom it may concern

Confirmation of approved fieldwork

This is to certify that Davina Hang, born 14.07.1992, has gained approval for her fieldwork in the Socialist Republic of Vietnam from the Oslo Metropolitan University (former Oslo and Akershus University College), Oslo, Norway.

The fieldwork is part of her master's thesis, which consists of 50 ECTS in total. The student will conduct a qualitative study among families with children diagnosed with Autism Spectrum Disorder. The fieldwork will take place in Vietnam between September 24 2018 and November 24 2018. Her thesis advisor at OsloMet is Associate Professor Raghnild Dybdahl.

Hang has admission to study at Oslo Metropolitan University, Faculty of Social Sciences. She is enrolled in the study program "Master programme in Applied Social Sciences: International Social Welfare and Health Policy." The student has admission from July 20 2017 – August 31 2019.

The Master's programme is organized as a two year fulltime study, with the possibility of using an extra year, consisting of 120 ECTS in total.

Please contact the administration at the Faculty of Social Sciences (infosenter-sam@oslomet.no) should there be any questions regarding this confirmation.

Sincerely

OSLO METROPOLITAN UNIVERSITY
STORBYUNIVERSITETET

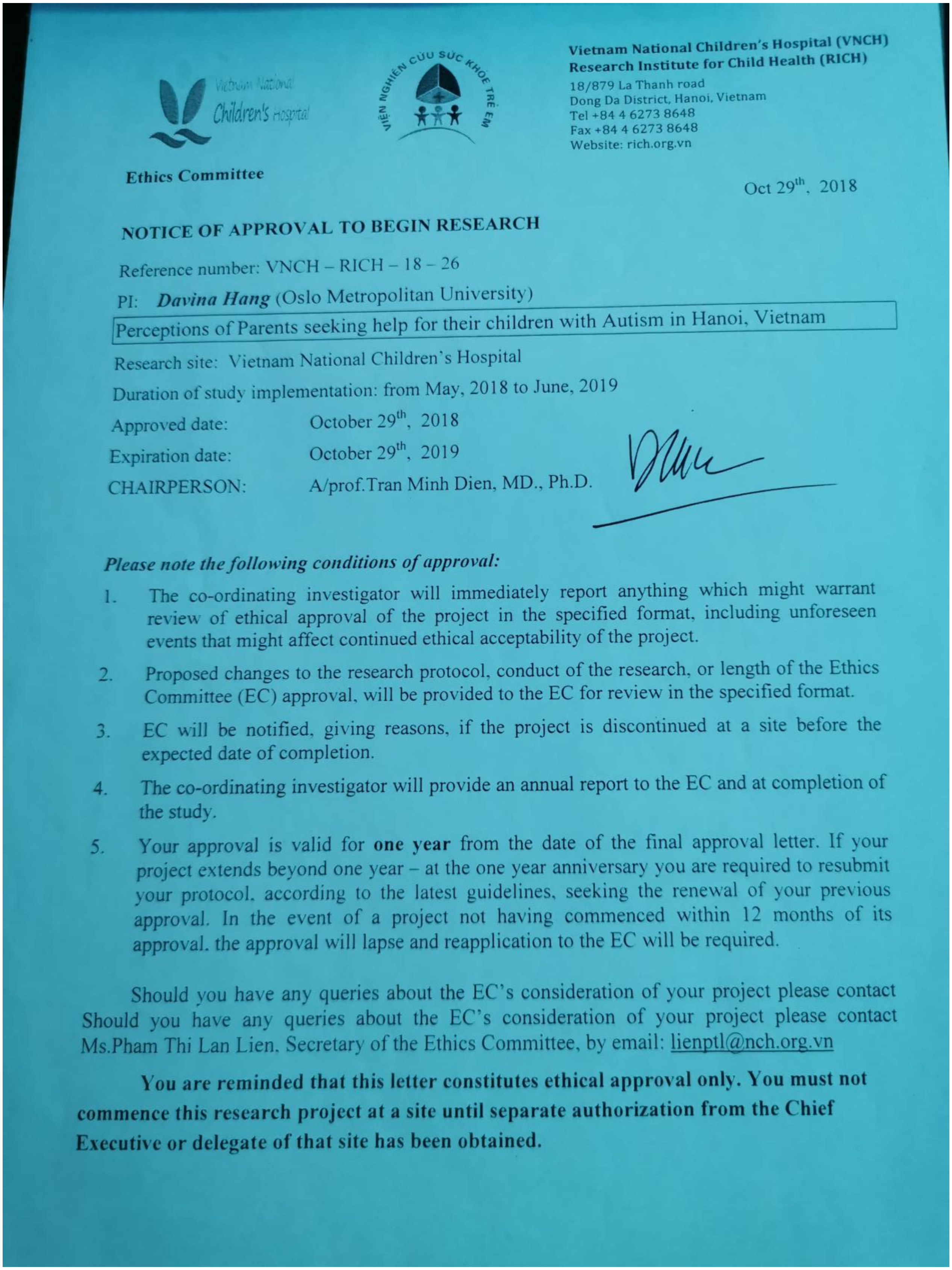
Francis Rønnestad

Francis Rønnestad

Faculty of Social Sciences

Oslo Metropolitan University (former Oslo and Akershus University College of Applied Sciences)

Appendix C: HOSPITAL AGREEMENT



Vietnam National Children's Hospital

Vietnam National Children's Hospital (VNCH)
Research Institute for Child Health (RICH)
18/879 La Thanh road
Dong Da District, Hanoi, Vietnam
Tel +84 4 6273 8648
Fax +84 4 6273 8648
Website: rich.org.vn

Ethics Committee

Oct 29th, 2018

NOTICE OF APPROVAL TO BEGIN RESEARCH

Reference number: VNCH – RICH – 18 – 26

PI: ***Davina Hang*** (Oslo Metropolitan University)

Perceptions of Parents seeking help for their children with Autism in Hanoi, Vietnam

Research site: Vietnam National Children's Hospital

Duration of study implementation: from May, 2018 to June, 2019

Approved date:	October 29th, 2018
Expiration date:	October 29th, 2019
CHAIRPERSON:	A/prof.Tran Minh Dien, MD., Ph.D.

Please note the following conditions of approval:

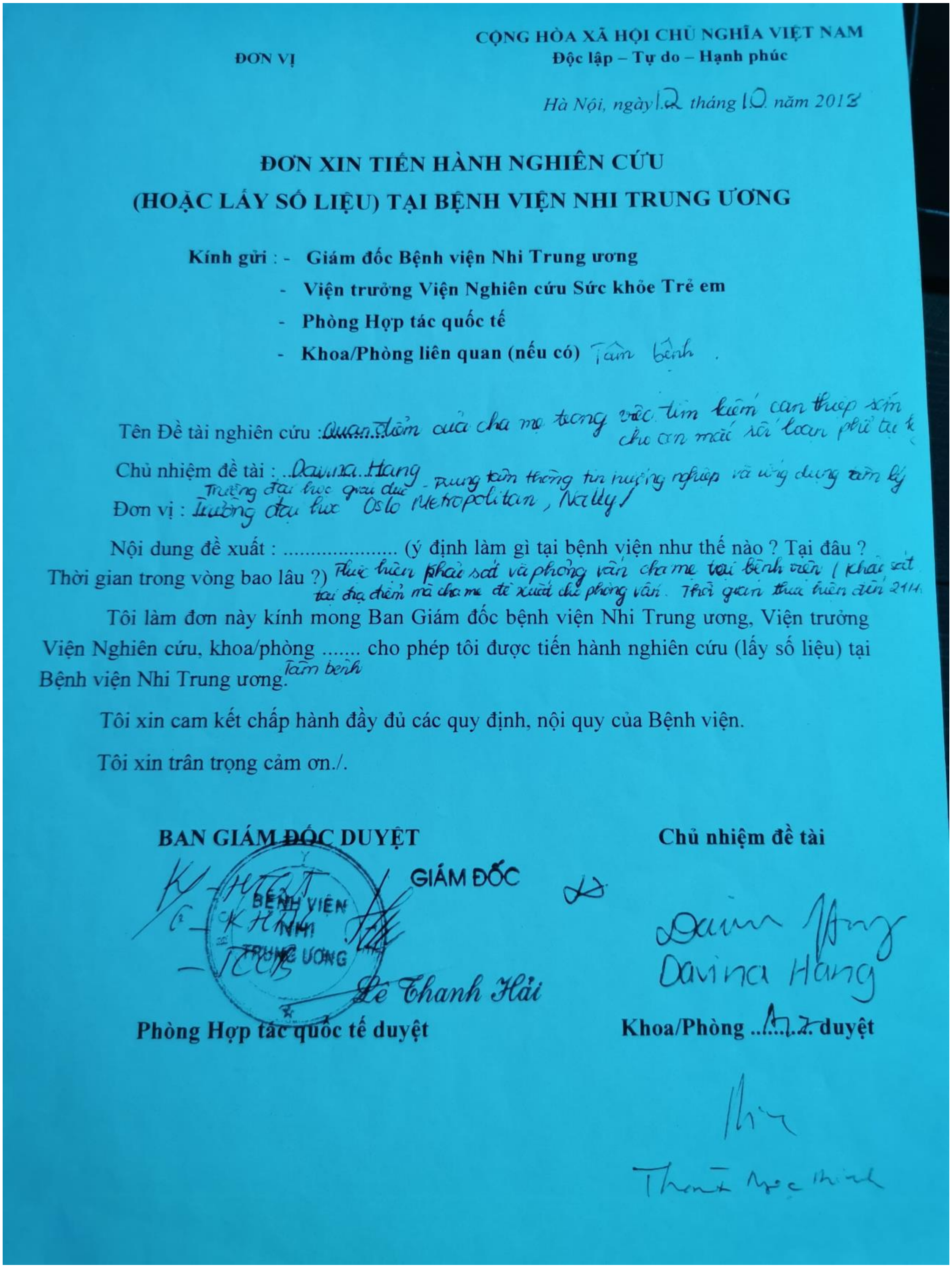
1. The co-ordinating investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including unforeseen events that might affect continued ethical acceptability of the project.
2. Proposed changes to the research protocol, conduct of the research, or length of the Ethics Committee (EC) approval, will be provided to the EC for review in the specified format.
3. EC will be notified, giving reasons, if the project is discontinued at a site before the expected date of completion.
4. The co-ordinating investigator will provide an annual report to the EC and at completion of the study.
5. Your approval is valid for **one year** from the date of the final approval letter. If your project extends beyond one year – at the one year anniversary you are required to resubmit your protocol, according to the latest guidelines, seeking the renewal of your previous approval. In the event of a project not having commenced within 12 months of its approval, the approval will lapse and reapplication to the EC will be required.

Should you have any queries about the EC's consideration of your project please contact

Should you have any queries about the EC's consideration of your project please contact Ms.Pham Thi Lan Lien, Secretary of the Ethics Committee, by email: lienptl@nch.org.vn

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a site until separate authorization from the Chief Executive or delegate of that site has been obtained.

Appendix C: HOSPITAL AGREEMENT



ĐƠN VỊ

CỘNG HÒA XÃ HỘI CHỦ NGHĨA VIỆT NAM
Độc lập – Tự do – Hạnh phúc

Hà Nội, ngày 12 tháng 10 năm 2018

ĐƠN XIN TIẾN HÀNH NGHIÊN CỨU (HOẶC LẤY SỐ LIỆU) TẠI BỆNH VIỆN NHI TRUNG ƯƠNG

Kính gửi :
- **Giám đốc Bệnh viện Nhi Trung ương**
- **Viện trưởng Viện Nghiên cứu Sức khỏe Trẻ em**
- **Phòng Hợp tác quốc tế**
- **Khoa/Phòng liên quan (nếu có)** Tâm bệnh .

Tên Đề tài nghiên cứu : Quan điểm của cha mẹ trong việc tìm kiếm can thiệp sớm cho con mắc rối loạn phổ tự k

Chủ nhiệm đề tài : Davina Hang

Đơn vị : Trường đại học Oslo Metropolitan, Na Uy / Trường đại học giáo dục - Trung tâm thông tin hướng nghiệp và ứng dụng tâm lý

Nội dung đề xuất : .... (ý định làm gì tại bệnh viện như thế nào ? Tại đâu ? Thời gian trong vòng bao lâu ?) Thực hiện khảo sát và phỏng vấn cha mẹ tại bệnh viện (khảo sát tại địa điểm mà cha mẹ đề xuất cho phỏng vấn. Thời gian thực hiện đến 2/1

Tôi làm đơn này kính mong Ban Giám đốc bệnh viện Nhi Trung ương, Viện trưởng Viện Nghiên cứu, khoa/phòng .... Tâm bệnh cho phép tôi được tiến hành nghiên cứu (lấy số liệu) tại Bệnh viện Nhi Trung ương.

Tôi xin cam kết chấp hành đầy đủ các quy định, nội quy của Bệnh viện.

Tôi xin trân trọng cảm ơn./.

BAN GIÁM ĐỐC DUYỆT

K/ - HTQT
C - KHĐT
- TCCB

BỆNH VIỆN NHI TRUNG ƯƠNG

GIÁM ĐỐC

Lê Thanh Hải

Phòng Hợp tác quốc tế duyệt

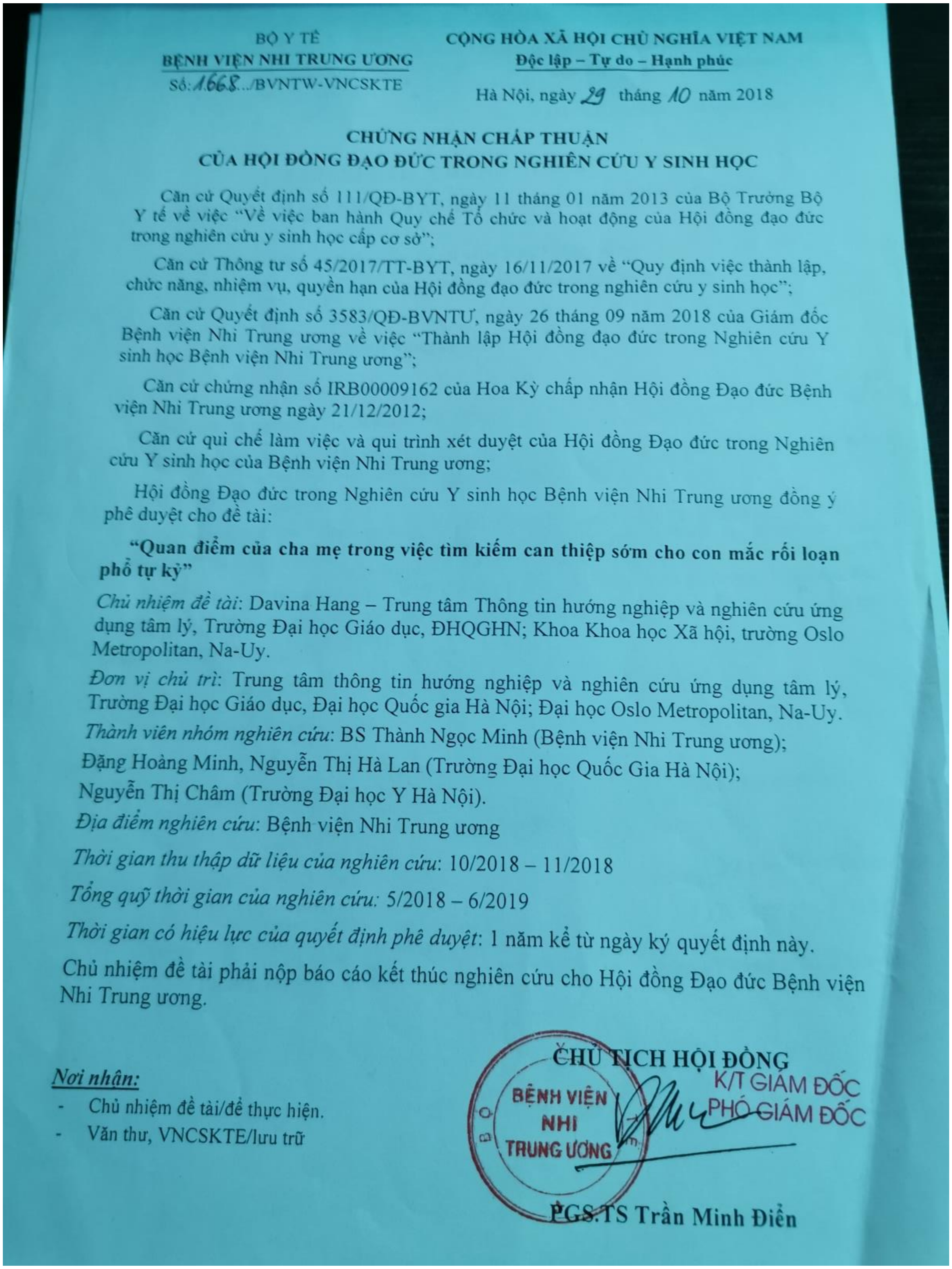
Chủ nhiệm đề tài

Davina Hang

Khoa/Phòng ...A7... duyệt

Thanh Ngọc Minh

Appendix C: HOSPITAL AGREEMENT



BỘ Y TẾ
BỆNH VIỆN NHI TRUNG ƯƠNG
Số: 1668.../BVNTW-VNCSKTE

CỘNG HÒA XÃ HỘI CHỦ NGHĨA VIỆT NAM
Độc lập – Tự do – Hạnh phúc

Hà Nội, ngày 29 tháng 10 năm 2018

CHỨNG NHẬN CHẤP THUẬN CỦA HỘI ĐỒNG ĐẠO ĐỨC TRONG NGHIÊN CỨU Y SINH HỌC

Căn cứ Quyết định số 111/QĐ-BYT, ngày 11 tháng 01 năm 2013 của Bộ Trưởng Bộ Y tế về việc "Về việc ban hành Quy chế Tổ chức và hoạt động của Hội đồng đạo đức trong nghiên cứu y sinh học cấp cơ sở";

Căn cứ Thông tư số 45/2017/TT-BYT, ngày 16/11/2017 về "Quy định việc thành lập, chức năng, nhiệm vụ, quyền hạn của Hội đồng đạo đức trong nghiên cứu y sinh học";

Căn cứ Quyết định số 3583/QĐ-BVNTƯ, ngày 26 tháng 09 năm 2018 của Giám đốc Bệnh viện Nhi Trung ương về việc "Thành lập Hội đồng đạo đức trong Nghiên cứu Y sinh học Bệnh viện Nhi Trung ương";

Căn cứ chứng nhận số IRB00009162 của Hoa Kỳ chấp nhận Hội đồng Đạo đức Bệnh viện Nhi Trung ương ngày 21/12/2012;

Căn cứ qui chế làm việc và qui trình xét duyệt của Hội đồng Đạo đức trong Nghiên cứu Y sinh học của Bệnh viện Nhi Trung ương;

Hội đồng Đạo đức trong Nghiên cứu Y sinh học Bệnh viện Nhi Trung ương đồng ý phê duyệt cho đề tài:

"Quan điểm của cha mẹ trong việc tìm kiếm can thiệp sớm cho con mắc rối loạn phổ tự kỷ"

Chủ nhiệm đề tài: Davina Hang – Trung tâm Thông tin hướng nghiệp và nghiên cứu ứng dụng tâm lý, Trường Đại học Giáo dục, ĐHQGHN; Khoa Khoa học Xã hội, trường Oslo Metropolitan, Na-Uy.

Đơn vị chủ trì: Trung tâm thông tin hướng nghiệp và nghiên cứu ứng dụng tâm lý, Trường Đại học Giáo dục, Đại học Quốc gia Hà Nội; Đại học Oslo Metropolitan, Na-Uy.

Thành viên nhóm nghiên cứu: BS Thành Ngọc Minh (Bệnh viện Nhi Trung ương);
Đặng Hoàng Minh, Nguyễn Thị Hà Lan (Trường Đại học Quốc Gia Hà Nội);
Nguyễn Thị Châm (Trường Đại học Y Hà Nội).

Địa điểm nghiên cứu: Bệnh viện Nhi Trung ương

Thời gian thu thập dữ liệu của nghiên cứu: 10/2018 – 11/2018

Tổng quỹ thời gian của nghiên cứu: 5/2018 – 6/2019

Thời gian có hiệu lực của quyết định phê duyệt: 1 năm kể từ ngày ký quyết định này.

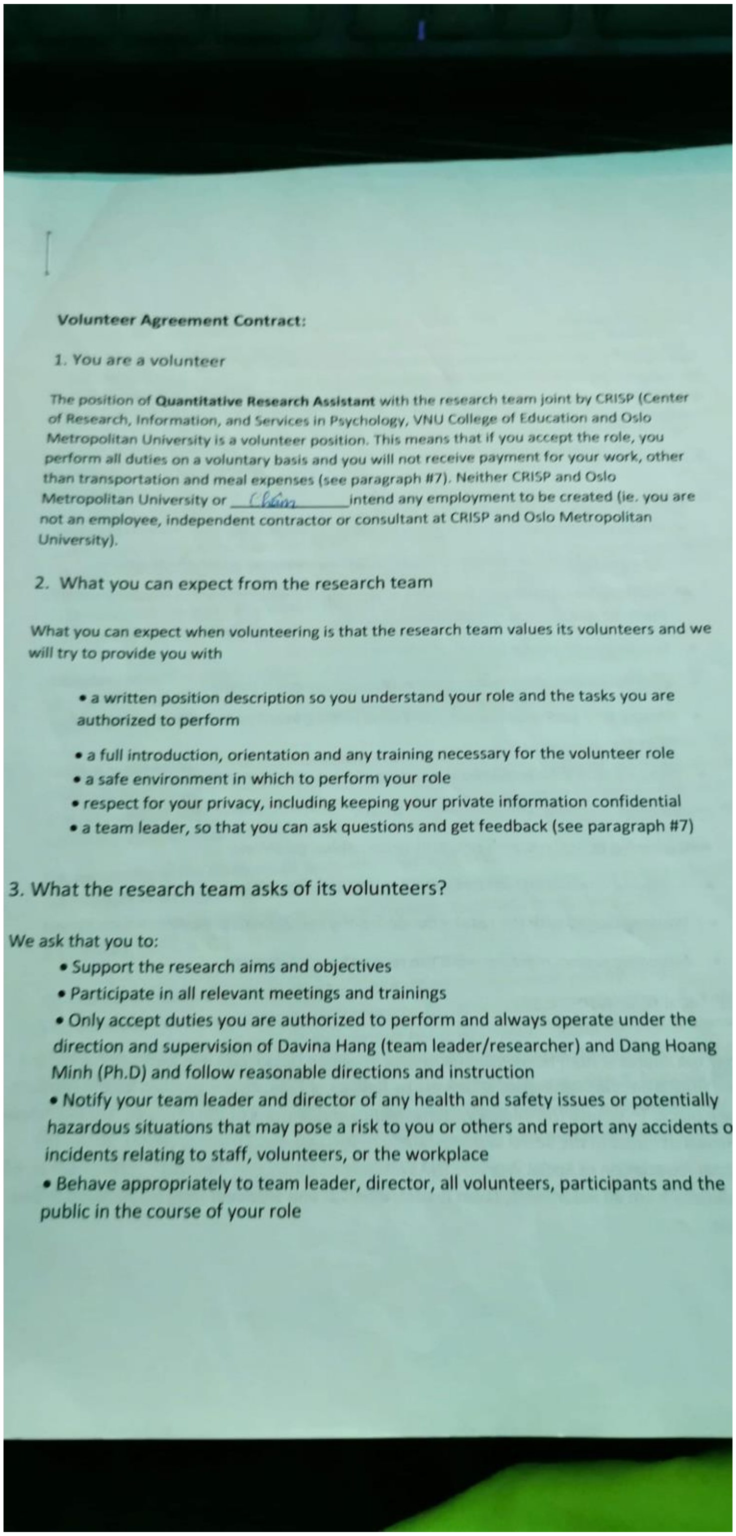
Chủ nhiệm đề tài phải nộp báo cáo kết thúc nghiên cứu cho Hội đồng Đạo đức Bệnh viện Nhi Trung ương.

Nơi nhận:
- Chủ nhiệm đề tài/để thực hiện.
- Văn thư, VNCSKTE/lưu trữ

CHỦ TỊCH HỘI ĐỒNG
K/T GIÁM ĐỐC
PHÓ GIÁM ĐỐC

PGS.TS Trần Minh Điển

Appendix D: VOLUNTEER CONTRACT AGREEMENT



Volunteer Agreement Contract:

1. You are a volunteer

The position of **Quantitative Research Assistant** with the research team joint by CRISP (Center of Research, Information, and Services in Psychology, VNU College of Education and Oslo Metropolitan University is a volunteer position. This means that if you accept the role, you perform all duties on a voluntary basis and you will not receive payment for your work, other than transportation and meal expenses (see paragraph #7). Neither CRISP and Oslo Metropolitan University or __Châm__ intend any employment to be created (ie. you are not an employee, independent contractor or consultant at CRISP and Oslo Metropolitan University).

2. What you can expect from the research team

What you can expect when volunteering is that the research team values its volunteers and we will try to provide you with

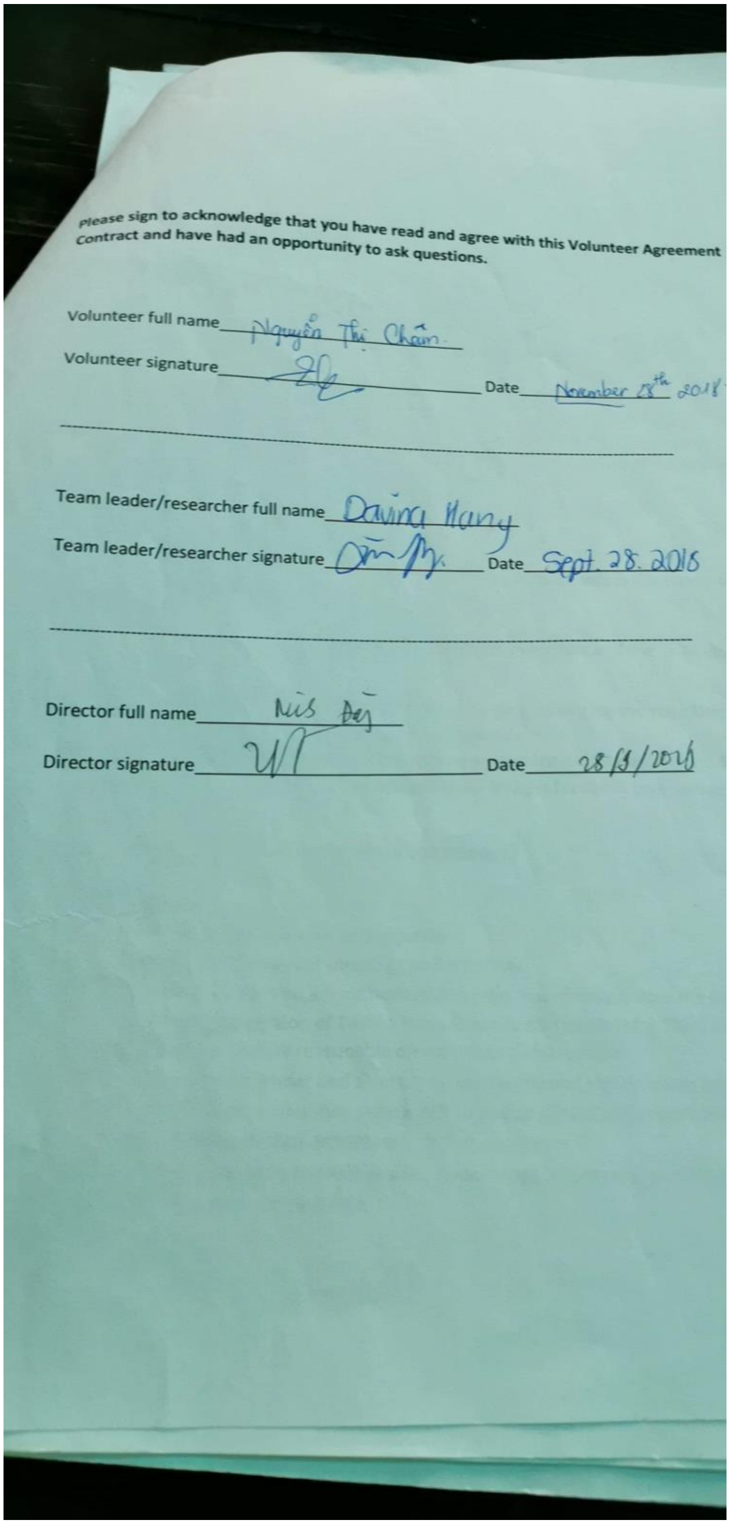
- a written position description so you understand your role and the tasks you are authorized to perform
- a full introduction, orientation and any training necessary for the volunteer role
- a safe environment in which to perform your role
- respect for your privacy, including keeping your private information confidential
- a team leader, so that you can ask questions and get feedback (see paragraph #7)

3. What the research team asks of its volunteers?

We ask that you to:

- *Support the research aims and objectives*
- *Participate in all relevant meetings and trainings*
- *Only accept duties you are authorized to perform and always operate under the direction and supervision of Davina Hang (team leader/researcher) and Dang Hoang Minh (Ph.D) and follow reasonable directions and instruction*
- *Notify your team leader and director of any health and safety issues or potentially hazardous situations that may pose a risk to you or others and report any accidents o*
incidents relating to staff, volunteers, or the workplace
- *Behave appropriately to team leader, director, all volunteers, participants and the public in the course of your role*

Appendix D: VOLUNTEER CONTRACT AGREEMENT



Please sign to acknowledge that you have read and agree with this Volunteer Agreement Contract and have had an opportunity to ask questions.

Volunteer full name Nguyễn Thị Chấm.

Volunteer signature ______ Date November 28th 2018

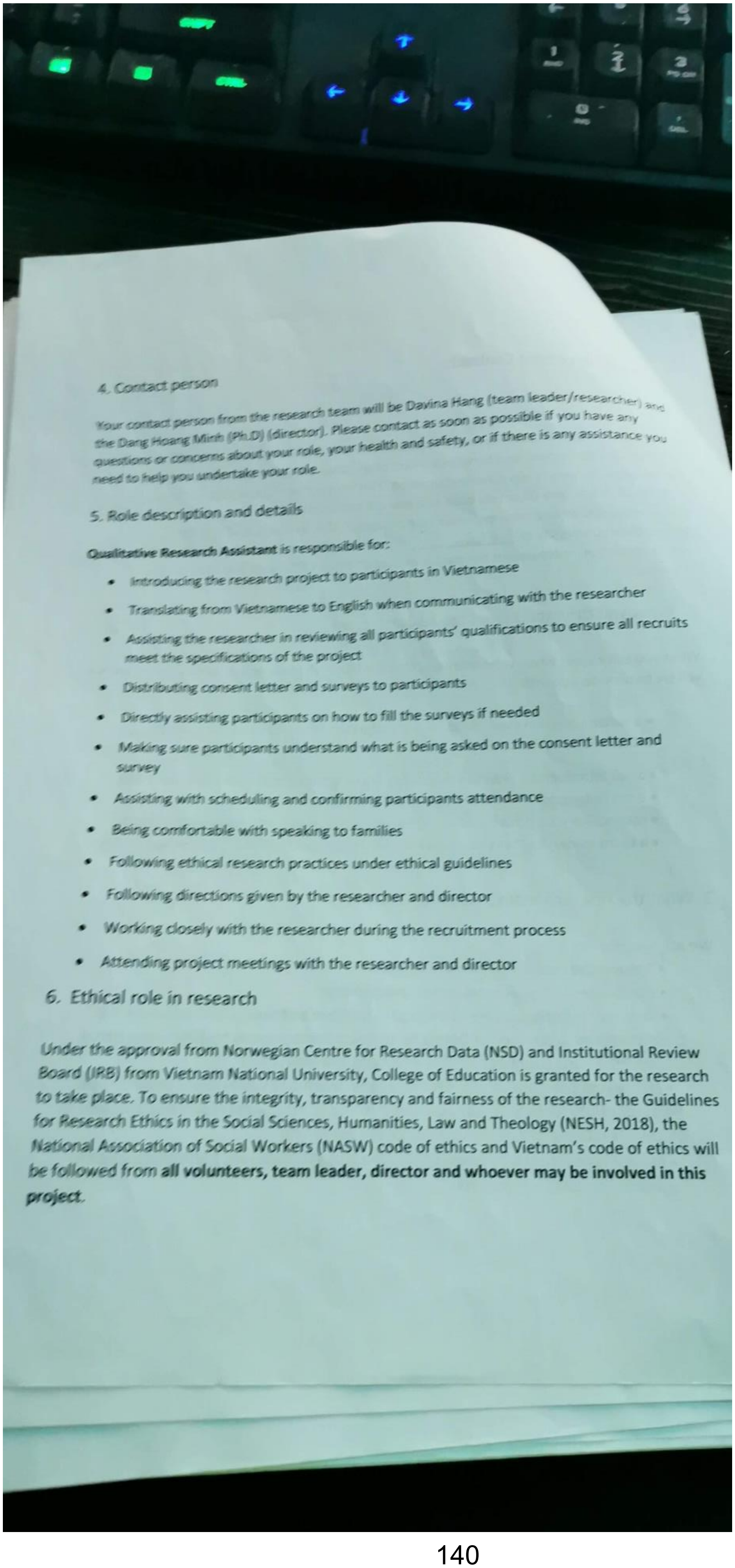
Team leader/researcher full name Davina Hany

Team leader/researcher signature ______ Date Sept. 28. 2018

Director full name Nis Đẹj

Director signature ______ Date 28/11/2018

Appendix D: VOLUNTEER CONTRACT AGREEMENT



4. Contact person

Your contact person from the research team will be Davina Hang (team leader/researcher) and the Dang Hoang Minh (Ph.D) (director). Please contact as soon as possible if you have any questions or concerns about your role, your health and safety, or if there is any assistance you need to help you undertake your role.

5. Role description and details

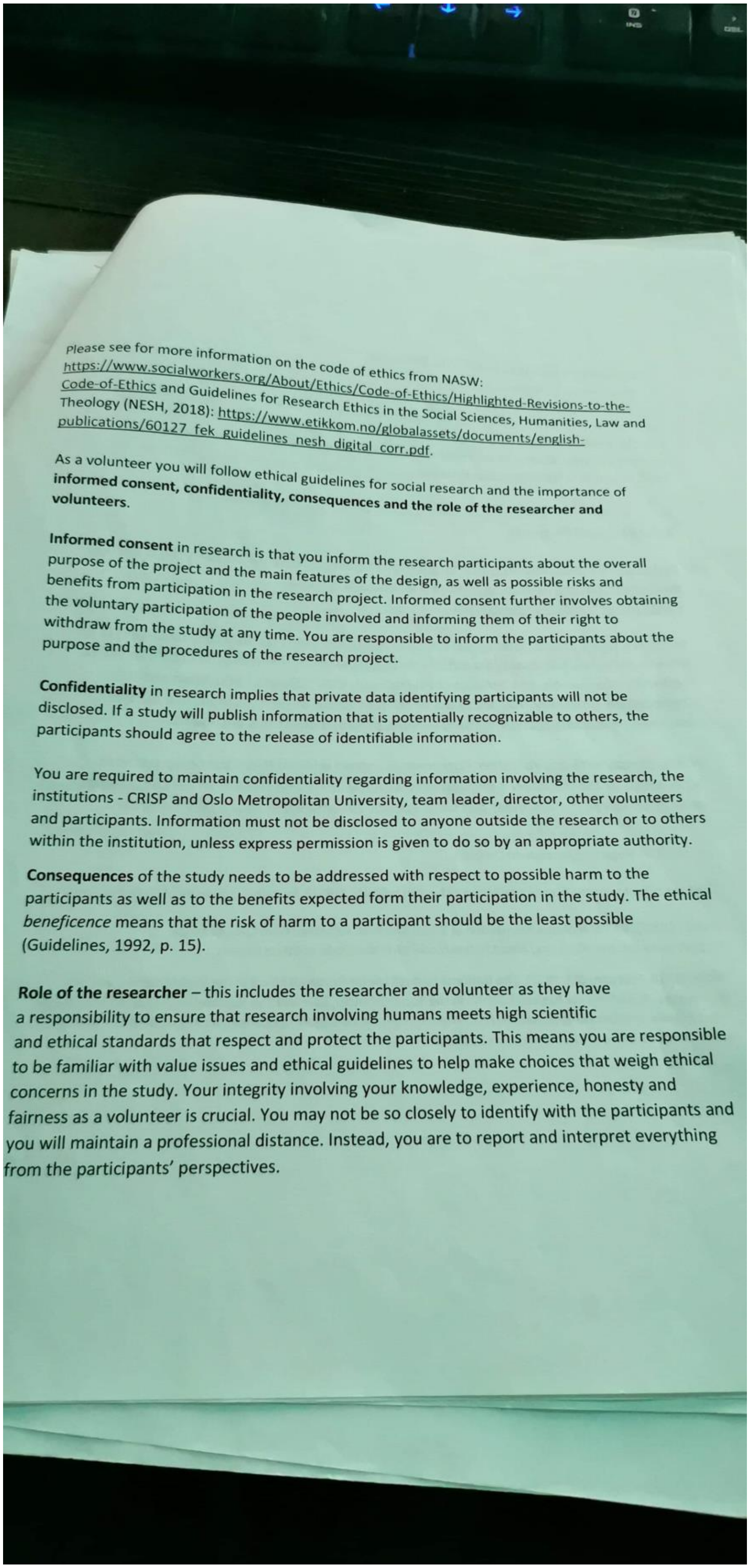
Qualitative Research Assistant is responsible for:

- Introducing the research project to participants in Vietnamese
- Translating from Vietnamese to English when communicating with the researcher
- Assisting the researcher in reviewing all participants' qualifications to ensure all recruits meet the specifications of the project
- Distributing consent letter and surveys to participants
- Directly assisting participants on how to fill the surveys if needed
- Making sure participants understand what is being asked on the consent letter and survey
- Assisting with scheduling and confirming participants attendance
- Being comfortable with speaking to families
- Following ethical research practices under ethical guidelines
- Following directions given by the researcher and director
- Working closely with the researcher during the recruitment process
- Attending project meetings with the researcher and director

6. Ethical role in research

Under the approval from Norwegian Centre for Research Data (NSD) and Institutional Review Board (IRB) from Vietnam National University, College of Education is granted for the research to take place. To ensure the integrity, transparency and fairness of the research- the Guidelines for Research Ethics in the Social Sciences, Humanities, Law and Theology (NESH, 2018), the National Association of Social Workers (NASW) code of ethics and Vietnam's code of ethics will be followed from **all volunteers, team leader, director and whoever may be involved in this project**.

Appendix D: VOLUNTEER CONTRACT AGREEMENT



Please see for more information on the code of ethics from NASW: https://www.socialworkers.org/About/Ethics/Code-of-Ethics/Highlighted-Revisions-to-the-Code-of-Ethics and Guidelines for Research Ethics in the Social Sciences, Humanities, Law and Theology (NESH, 2018): https://www.etikkom.no/globalassets/documents/english-publications/60127_fek_guidelines_nesh_digital_corr.pdf.

As a volunteer you will follow ethical guidelines for social research and the importance of **informed consent, confidentiality, consequences and the role of the researcher and volunteers**.

Informed consent in research is that you inform the research participants about the overall purpose of the project and the main features of the design, as well as possible risks and benefits from participation in the research project. Informed consent further involves obtaining the voluntary participation of the people involved and informing them of their right to withdraw from the study at any time. You are responsible to inform the participants about the purpose and the procedures of the research project.

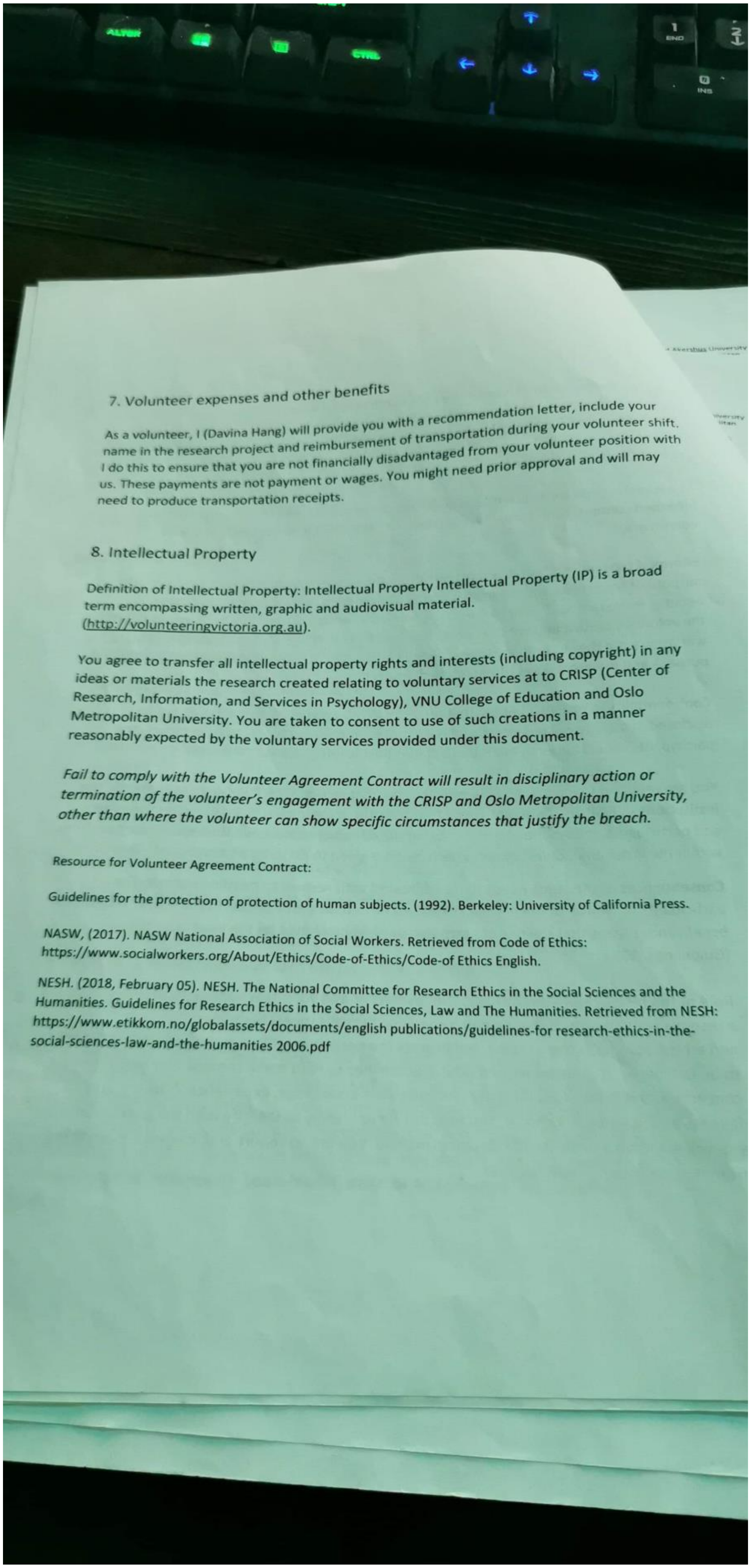
Confidentiality in research implies that private data identifying participants will not be disclosed. If a study will publish information that is potentially recognizable to others, the participants should agree to the release of identifiable information.

You are required to maintain confidentiality regarding information involving the research, the institutions - CRISP and Oslo Metropolitan University, team leader, director, other volunteers and participants. Information must not be disclosed to anyone outside the research or to others within the institution, unless express permission is given to do so by an appropriate authority.

Consequences of the study needs to be addressed with respect to possible harm to the participants as well as to the benefits expected form their participation in the study. The ethical *beneficence* means that the risk of harm to a participant should be the least possible (Guidelines, 1992, p. 15).

Role of the researcher – this includes the researcher and volunteer as they have a responsibility to ensure that research involving humans meets high scientific and ethical standards that respect and protect the participants. This means you are responsible to be familiar with value issues and ethical guidelines to help make choices that weigh ethical concerns in the study. Your integrity involving your knowledge, experience, honesty and fairness as a volunteer is crucial. You may not be so closely to identify with the participants and you will maintain a professional distance. Instead, you are to report and interpret everything from the participants' perspectives.

Appendix D: VOLUNTEER CONTRACT AGREEMENT



7. Volunteer expenses and other benefits

As a volunteer, I (Davina Hang) will provide you with a recommendation letter, include your name in the research project and reimbursement of transportation during your volunteer shift. I do this to ensure that you are not financially disadvantaged from your volunteer position with us. These payments are not payment or wages. You might need prior approval and will may need to produce transportation receipts.

8. Intellectual Property

Definition of Intellectual Property: Intellectual Property Intellectual Property (IP) is a broad term encompassing written, graphic and audiovisual material. (http://volunteeringvictoria.org.au).

You agree to transfer all intellectual property rights and interests (including copyright) in any ideas or materials the research created relating to voluntary services at to CRISP (Center of Research, Information, and Services in Psychology), VNU College of Education and Oslo Metropolitan University. You are taken to consent to use of such creations in a manner reasonably expected by the voluntary services provided under this document.

Fail to comply with the Volunteer Agreement Contract will result in disciplinary action or termination of the volunteer's engagement with the CRISP and Oslo Metropolitan University, other than where the volunteer can show specific circumstances that justify the breach.

Resource for Volunteer Agreement Contract:

Guidelines for the protection of protection of human subjects. (1992). Berkeley: University of California Press.

NASW, (2017). NASW National Association of Social Workers. Retrieved from Code of Ethics: https://www.socialworkers.org/About/Ethics/Code-of-Ethics/Code-of Ethics English.

NESH. (2018, February 05). NESH. The National Committee for Research Ethics in the Social Sciences and the Humanities. Guidelines for Research Ethics in the Social Sciences, Law and The Humanities. Retrieved from NESH: https://www.etikkom.no/globalassets/documents/english publications/guidelines-for research-ethics-in-the-social-sciences-law-and-the-humanities 2006.pdf

Appendix E: PARTICIPANT CONSENT LETTER.

English Version.

Request for participation in research project
"Perceptions of parents seeking early intervention strategies for their children with Autism Spectrum Disorder (ASD) in Hanoi, Vietnam"

What is the purpose of the research?
This research is a student project from the Oslo Metropolitan University in Oslo, Norway. The project is scheduled for completion by June 2019.This research's purpose is to understand parents seeking help for their children with autism spectrum disorder (ASD). We would like to hear your experiences in finding support for your child. Your information may help future researchers and students understand how families make health decisions for their children in Hanoi, Vietnam.You have been selected through the special need centre in Hanoi because you are citizen in Vietnam and have a child(s) diagnosed with autism spectrum disorder (ASD). This project is funded by the Oslo Metropolitan University's 2018 Scholarship for Master Students at the Faculty of Social Sciences.

What does participation in the project mean?
The study will have a short demographic questionnaire to gather information on you and your child's background such as age, gender, income, education, occupation and diagnosis.

Option A: A survey will be given to you that ask about how you find help for your child as well as your beliefs about the causes of autism. The questionnaire and survey will take 15 minutes.

Option B: A survey will be given to you that ask about how you find help for your child as well as your beliefs about the causes of autism. The questionnaire and survey will take 15 minutes. And also, you will participate in an in-person interview with the researcher at a time suitable for you. The interview will take approximately 90 minutes. The interview will have questions about your experiences on finding help for your child. The researcher will speak English and there will be an interpreter to translate from English to Vietnamese. Your information will be collected by written notes and audio recordings. You will be assigned a number code to ensure your name is not revealed during the data analysis.

***Note: For **Option B**, the interview will take place if the researcher invites you to the interview. It is NOT guaranteed that you will be part of the interview. If you are not part of the interview, this means you are ONLY part of the survey.

What will happen to the information about you and your child?
All personal data will be treated confidentially, and your name will remain anonymous. Your personal data will be processed based on your consent. The information given from you may be published in a report or in future publications regarding autism spectrum disorders. Any published or distributed materials will not contain information that could identify any individual parents, guardians, or children. Your participation will not affect your relationship with any health care providers or services. After the data collection, **the data will be secured in Norwegian Centre for Research Data for 364 days from June 2019**. Only the research team (researcher, supervisor, and co-supervisor) will have access to the data collected.

What are the risks and benefits?
This study may present minimal psychological and/or emotional stress during the caregiving questions in the interview. There is a small compensation for your time of participation and transportation. If you participate in only the survey you will receive $4 USD per parent. If you participate in both the survey and interview you will receive $8 USD per parent.

Voluntary participation:

It is voluntary to participate in the project, and you can at any time choose to withdraw your consent without stating any reason. If you decide to participate, you are free to skip any questions, and/or stop at any time. If you decide to withdraw, your information will be destroyed and not used in the publication. Your participation will be a valuable addition to our research and the findings could lead to greater public understanding of autism and family support in the field. These are your rights when you participate:

- You have the right to request access to the personal data that is being processed
- You have the right to request that the personal data is corrected or erased
- You have the right to request a copy of the personal data being processed
- You have the right to send a complaint to the Data Protection Officer or to the Norwegian Data Protection Authority regarding the processing of personal data.

Contact:
If you have any questions concerning the project, please contact: Davina Hang at: +47 93 98 33 07. Alternatively, you can reach co-supervisor (Vietnamese speaker): Dr. Minh at: +84 39 6941 115 or supervisor: Ragnhild Dybdahl, phone number: +47 67 23 84 44. The study has been notified to the Data Protection Official for Research, NSD - Norwegian Centre for Research Data. Contact details for Data Protection Services for Research at NSD – Norwegian Centre for Research Data AS: personvertjenester@nsd.no, +47 55 58 21 17 (NB: they are no longer called the Data Protection Official). Contact for Data Protection Officer at NTNU: Thomas Helgesen, email: thomas.helgesen@ntnu.no. +47 930 790 38.

Please Circle YES/NO.

Option A: I would like to participate in the survey NOT the interview. Yes No

Option B: I would like to participate in the survey AND the interview. Yes No

*If you selected **Option B**: I understand that it is not guaranteed that I will be selected for the interview and it is only when I will be contacted if I am needed for the interview. If I am not invited to the interview, this means I will only participate in the survey.*

Consent for participation in the study:

I have received information about the project and am willing to participate.

(Signed by participant)   (date: day/month/year)

Appendix E. PARTICIPANT CONSENT LETTER.

Vietnamese Version.

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GIẤY XÁC NHẬN ĐỒNG Ý THAM GIA NGHIÊN CỨU

QUAN ĐIỂM CỦA CHA MẸ TRONG VIỆC TÌM KIẾM CAN THIỆP SỚM CHO CON MẮC RỐI LOẠN PHỔ TỰ KỈ

Mục đích nghiên cứu:

Trung tâm Thông Tin Hướng Nghiệp, Nghiên Cứu và Ứng Dụng Tâm Lý (CRISP)

Nghiên cứu này nằm trong dự án liên kết của trường đại học Oslo Metropolitan thuộc Oslo, Na Uy. Dự án này dự kiến kết thúc trong tháng 6, 2019. Mục đích của nghiên cứu nhằm tìm hiểu quan điểm của cha mẹ có con mắc rối loạn phổ tự kỉ tham gia và nghiên cứu. Thông tin mà anh/chị cung cấp sẽ giúp những nhà nghiên cứu và cán bộ trợ giúp hiểu thêm về quá trình gia đình đưa ra những quyết định can thiệp cho trẻ tự kỉ hiện sống ở Hà Nội, Việt Nam. Chúng tôi xin mời anh/chị người có con đang được chẩn đoán mắc chứng rối loạn phổ tự kỉ tham gia nghiên cứu này.

Tham gia nghiên cứu là như thế nào?

Nếu đồng ý tham gia vào nghiên cứu, anh chị sẽ tham gia trả lời một số câu hỏi về thông tin cơ bản như: tuổi, giới, thu nhập, trình độ giáo dục, nghề nghiệp, và chẩn đoán của con. Sau đó anh chị sẽ lựa chọn một trong hai cách sau đây để tiếp tục tham gia nghiên cứu (anh chị sẽ đánh dấu vào lựa chọn của mình ở cuối thư mời này):

Lựa chọn A: một bảng hỏi nhằm tìm hiểu quan niệm về nguyên nhân gây ra chứng tự kỉ của anh chị cũng như cách anh chị đã và đang tìm kiếm trợ giúp cho con. Thời gian hoàn thành bảng hỏi này khoảng 15 phút.

Lựa chọn B: Ngoài việc tham gia trả lời một bảng hỏi như lựa chọn A, anh chị sẽ tham gia vào một cuộc phỏng vấn cá nhân về những kinh nghiệm tìm kiếm trợ giúp cho trẻ. Nghiên cứu viên sẽ nói bằng tiếng anh và có phiên dịch viên diễn giải sang tiếng Việt. Thông tin sẽ được thu thập bằng cách viết ghi chú lại và ghi âm. Anh/chị sẽ được gắn mã để đảm bảo rằng tên của anh/chị không được tiết lộ trong quá trình phân tích số liệu.

- **Lưu ý:** Đối với lựa chọn B, nghiên cứu chủ định lựa chọn những người tham gia phỏng vấn. Trong trường hợp, anh chị muốn tham gia phỏng vấn mà không được liên hệ, chúng tôi rất xin lỗi anh chị và cám ơn sự nhiệt tình ủng hộ của anh chị.

Điều gì sẽ xảy ra với thông tin về anh/chị và trẻ của anh/chị?

Tất cả những thông tin cá nhân sẽ được đảm bảo bí mật, và tên của anh/chị sẽ để dưới dạng ẩn danh. Thông tin mà anh/chị cung cấp có thể được ghi trong báo cáo hoặc có thể được nằm trong phần xuất bản liên quan đến chứng rối loại phổ tự kỉ. Bất kể tài liệu được xuất bản hay phân phát nào cũng sẽ không bao gồm thông tin có thể xác định từng cá nhân cha/ mẹ, người bảo lãnh hay bản thân trẻ. Sự tham gia của anh/chị sẽ không ảnh hưởng đến mối quan hệ giữa anh/chị và người chăm sóc hay nhân

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viên y tế. Sau khi thu thập số liệu, dữ liệu sẽ được bảo vệ tại trung tâm dữ liệu nghiên cứu Na Uy trong 364 ngày từ tháng 7, 2019. Chỉ có thành viên tham gia nghiên cứu (nghiên cứu viên, giám sát, đồng giám sát) mới có thể truy cập những dữ liệu thu thập.

Nguy cơ và lợi ích khi tham gia nghiên cứu là gì?

Khi chia sẻ về những trải nghiệm của mình, anh/chị có thể nhớ lại một số kỉ niệm không vui trong quá khứ và điều đó có thể làm phiền anh chị một thời gian.

Để cám ơn sự tham gia của anh/chị chúng tôi xin gửi chi phí 100,000 VND cho việc trả lời phiếu khảo sát. Nếu tham gia cả khảo sát và phỏng vấn anh/chị sẽ nhận được 200,000 VND cho mỗi người.

Tình nguyện tham gia nghiên cứu

Sự tham gia này là tình nguyện, anh/chị có thể từ chối tham gia nghiên cứu mà không cần đưa ra bất kỳ lý do nào. Nếu tham gia, chúng tôi khuyến khích anh/chị trả lời tất cả các câu hỏi trong quá trình phỏng vấn. Tuy nhiên, anh/chị có quyền bỏ qua bất cứ câu hỏi nào, hoặc dừng phỏng vấn bất kì thời điểm nào. Nếu anh/chị quyết định dừng tham gia nghiên cứu, thông tin của anh/chị cung cấp sẽ được hủy bỏ và không được tiếp tục sử dụng trong phần xuất bản nghiên cứu. Sự tham gia của anh/chị rất có giá trị trong nghiên cứu của chúng tôi và kết quả nghiên cứu sẽ góp phần hiểu tốt hơn về trải nghiệm của bố mẹ trong quá trình tìm kiếm các biện pháp can thiệp cho con.

Nếu anh/chị có bất cứ câu hỏi gì quan tâm đến dự án, vui lòng liên hệ : Davina Hang qua số điện thoại: 0 528 113 117, hoặc giám sát nghiên cứu: Ts. Đặng Hoàng Minh. Số điện thoại 035 5689 136. Nghiên cứu được sự cho phép của Cơ Quan Bảo Mật Dữ Liệu Cho Nghiên Cứu, trung tâm Dữ Liệu Nghiên Cứu Na Uy (NSD)

Lựa chọn một trong hai phương án sau:

Lựa chọn A: Tôi muốn tham gia vào khảo sát mà không tham gia phỏng vấn. ☐

Lựa chọn B: Tôi muốn tham gia khảo sát và tham gia phỏng vấn. ☐

- Nếu lựa chọn Lựa chọn B: Nghiên cứu chủ định lựa chọn những người tham gia phỏng vấn. Trong trường hợp, anh chị muốn tham gia phỏng vấn mà không được liên hệ, chúng tôi rất xin lỗi anh chị và cám ơn sự nhiệt tình ủng hộ của anh chị.

Giấy đồng ý cho việc tham gia nghiên cứu:

Tôi đã nhận những thông tin về dự án và sẵn sàng tham gia.

Chữ kí của người tham gia …………………………… Ngày……/tháng……/năm 20…

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Số điện thoại:…………………………………………….

Chữ kí người làm chứng……………………………… Ngày……/tháng……/năm 20…

Liên hệ : Nguyễn Thị Hà Lan #037 6534 774 (Trợ lý nghiên cứu)
Nguyễn Thị Châm #035 5689 136 (Trợ lý nghiên cứu)

Appendix F: DEMOGRAPHIC AND SURVEY QUESTIONNAIRE

Demographic Questionnaire

Parent Information:

1. What is your age?

2. What is your sex?

3. What is your marital status?
    a. Single (never married)
    b. Married, or in a domestic partnership
    c. Widowed
    d. Divorced
    e. Separated

Child(s) information:

4. What is your child's age?
5. What is the gender of your child?
6. When was your child diagnosed with Autism?

    _____, _____
    (month, year)

7. Who diagnosed your child?

8. How many children do you have?

9. Are there any other children in your household diagnosed with a disability or disorder? Please explain.

Parent education and family income level:

10. What type of school/professional training have you received? How many years of it?

11. What type of school/professional training have your partner received? How many years of it?

12. What do you do? Where do you work?

13. What is your current employment status?
    a. Employed full time, how many hours? ____
    b. Employed part time, how many hours? ____
    c. Unemployed and currently looking for work
    d. Unemployed and not currently looking for work
    e. Student
    f. Retired
    g. Homemaker
    h. Self-employed
    i. Unable to work

14. What does your partner do? Where does your partner work?

Thank you for your time.

Appendix F: DEMOGRAPHIC AND SURVEY QUESTIONNAIRE

#	Questionnaire							
1	People with autism can be helped to improve their behaviour through one-to-one therapy.	1	2	3	4	5	6	7
2	A chemical imbalance is the main cause of autism.	1	2	3	4	5	6	7
3	Autism is most often caused by illness during pregnancy.	1	2	3	4	5	6	7
4	Brain abnormalities are the main cause of autism.	1	2	3	4	5	6	7
5	Traumatic experiences very early in life can cause autism.	1	2	3	4	5	6	7
6	Autism can be best helped by encouraging people with autism to interact with others who are ‘normal.	1	2	3	4	5	6	7
7	Providing a warm and loving environment can help people overcome autism.	1	2	3	4	5	6	7
8	Having emotionally cold parents often causes autism.	1	2	3	4	5	6	7
9	Having a ‘bad upbringing’ causes autism.	1	2	3	4	5	6	7
10	The best way to treat autism is using appropriately prescribed drugs.	1	2	3	4	5	6	7
11	Autism is caused essentially by genetic factors.	1	2	3	4	5	6	7
12	Changes in diet can be very effective in treating autism.	1	2	3	4	5	6	7
13	Eating certain types of food can worsen autistic behaviour.	1	2	3	4	5	6	7
14	Whether a person with autism gets better may simply depend on luck.	1	2	3	4	5	6	7
15	Giving ‘rewards’ for ‘normal’ behaviour can reduce autistic behaviour.	1	2	3	4	5	6	7
16	Cold and unloving homes are a frequent cause of autism.	1	2	3	4	5	6	7
17	Punishing ‘strange’ and inappropriate behaviour can reduce autistic behaviour.	1	2	3	4	5	6	7
18	Drugs are an effective way of treating autism.	1	2	3	4	5	6	7
19	A belief in God can help a person overcome autism.	1	2	3	4	5	6	7
20	Complications during pregnancy can cause autism.	1	2	3	4	5	6	7

21	Autism is passed to children through genes.	1	2	3	4	5	6	7
22	The main cause of autism is brain abnormality.	1	2	3	4	5	6	7
23	Allergies to some foods can cause autism.	1	2	3	4	5	6	7
24	Treatment of autism is easier if the sufferer really wants to get better.	1	2	3	4	5	6	7
25	I go to professionals to find help for my child.	1	2	3	4	5	6	7
26	I go to a friend to find help for my child.	1	2	3	4	5	6	7
27	I go to family to find help for my child.	1	2	3	4	5	6	7
28	The strategies I currently use for my child are useful.	1	2	3	4	5	6	7
29	I go to my wife/husband to seek help for my child.	1	2	3	4	5	6	7
30	I go on the internet to seek help for my child.	1	2	3	4	5	6	7
31	I go to other parents to seek help for my child.	1	2	3	4	5	6	7
32	I go to religious leaders to seek help for my child.	1	2	3	4	5	6	7
33	I go to schools/teachers to seek help for my child.	1	2	3	4	5	6	7
34	When I am not around, there will be someone helping my child.	1	2	3	4	5	6	7
35	I need to make sacrifices when taking care of my child.	1	2	3	4	5	6	7
36	I would like more help for my child.	1	2	3	4	5	6	7
37	I am confused as to why my child acquired this condition.	1	2	3	4	5	6	7
38	I am afraid others may think my child has autism.	1	2	3	4	5	6	7

Strongly Disagree = 1	Disagree = 2	Somewhat Disagree = 3	Neutral = 4	Somewhat Agree = 5	Agree = 6	Strongly Agree = 7

Appendix F: DEMOGRAPHIC AND SURVEY QUESTIONNAIRE.
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BỘ CÂU HỎI

I. Thông tin chung

Thông tin trẻ

1. Trẻ bao nhiêu tháng tuổi? ______________________________

2. Giới tính: Nam ☐ Nữ ☐

3. Trẻ được chẩn đoán tự kỉ khi nào? Tháng__________, năm__________

4. Ai là người chẩn đoán bệnh của trẻ? _______________________________

5. Anh/chị có bao nhiêu đứa con? _______________________________

6. Có trẻ nào khác trong gia đình cũng được chẩn đoán có khuyết tật hay có rối loạn nào không? Có ☐ Không ☐

   a. Nếu có, anh chị vui lòng kể chi tiết. _________________________________

Thông tin cha mẹ

7. Anh/chị bao nhiêu tuổi? ________________________________

8. Giới tính của anh/ chị? Nam ☐ Nữ ☐

9. Tình trạng hôn nhân:

   a. Độc thân
   b. Kết hôn hoặc chung sống như gia đình
   c. Góa
   d. Đã ly hôn

Appendix F: DEMOGRAPHIC AND SURVEY QUESTIONNAIRE. Vietnamese Version.

e. Ly thân

10. Trình độ học vấn:
   a. Sau đại học
   b. Đại học
   c. Cao đẳng
   d. Trung cấp
   e. Cấp 3
   f. Cấp 2
   g. Cấp 1
   h. Không đi học

11. Trình độ học vấn của vợ/chồng:

   a. Sau đại học
   b. Đại học
   c. Cao đẳng
   d. Trung cấp
   e. Cấp 3
   f. Cấp 2
   g. Cấp 1
   h. Không đi học

12. Tình trạng công việc của anh/chị hiện tại là (có thể lựa chọn nhiều phương án)?

   a. Làm công việc bán thời gian, khoảng ____________ giờ/ ngày
   b. Thất nghiệp và đang tìm kiếm việc làm
   c. Thất nghiệp và hiện tại không tìm kiếm việc làm
   d. Sinh viên
   e. Nghỉ hưu
   f. Làm việc tại nhà
   g. Làm công việc tự do

h. Không có khả năng làm việc

13. Nếu đang làm việc, anh/chị làm việc ở đâu? ________________________________

14. Nếu đang làm việc, vợ/chồng của anh chị đang làm việc ở đâu? _______________

II. Niềm tin của cha mẹ về bệnh tự kỉ, cách điều trị tự kỉ và sự tìm kiếm trợ giúp cho trẻ tự kỉ Cho biết mức độ đồng ý của anh/chị với những khẳng định dưới đây về chứng tự kỉ, cách điều trị tự kỉ và sự tìm kiếm trợ giúp cho trẻ tự kỉ của anh/chị. Các mức độ đồng ý được đánh số thứ tự từ 1 đến 7 như sau.

1- Anh/chị **hoàn toàn không đồng ý** với ý kiến này.
2- Anh/chị **không đồng ý** với ý kiến này.
3- Anh/chị **không đồng ý một phần** với ý kiến này, tuy nhiên ý kiến này vẫn có ý đúng.
4- Anh chị **trung lập** với ý kiến này, không nghiêng về đồng ý hay không đồng ý.
5- Anh/chị **đồng ý** một phần với ý kiến này, tuy nhiên ý kiến này vẫn có ý sai.
6- Anh/chị **đồng ý** với ý kiến này.
7- Anh/chị **hoàn toàn đồng ý** với ý kiến này.

	Câu hỏi	Hoàn toàn không đồng ý	Không đồng ý	Không đồng ý một phần	Trung lập	Đồng ý một phấn	Đồng ý	Hoàn toàn đồng ý
1	Tổn thương trong những năm đầu đời là nguyên nhân chính dẫn đến tự kỉ.	1	2	3	4	5	6	7
2	Cách tốt nhất để điều trị tự kỉ là sử dụng thuốc phù hợp.	1	2	3	4	5	6	7
3	'Thưởng' cho những hành vi 'bình thường' có thể làm giảm những hành vi tự kỉ.	1	2	3	4	5	6	7

Appendix F: DEMOGRAPHIC AND SURVEY QUESTIONNAIRE.
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	Câu hỏi	Hoàn toàn không đồng ý	Không đồng ý	Không đồng ý một phần	Trung lập	Đồng ý một phần	Đồng ý	Hoàn toàn đồng ý
4	Những biến chứng trong quá trình mang thai có thể gây ra tự kỉ.	1	2	3	4	5	6	7
5	Tôi trao đổi chuyên gia để tìm cách can thiệp cho con tôi.	1	2	3	4	5	6	7
6	Tôi lên mạng Internet để tìm kiếm sự giúp đỡ cho con của tôi.	1	2	3	4	5	6	7
7	Tôi cần hi sinh nhiều thứ khi tôi chăm sóc con của mình.	1	2	3	4	5	6	7
8	Có thể cải thiện hành vi của người tự kỉ bằng liệu pháp hỗ trợ một người một.	1	2	3	4	5	6	7
9	Cách tốt nhất để giúp đỡ người tự kỉ là khuyến khích họ tiếp xúc với người bình thường.	1	2	3	4	5	6	7
10	Tự kỉ chủ yếu là do yếu tố gen gây ra.	1	2	3	4	5	6	7
11	Một gia đình lạnh nhạt và thiếu tình cảm là nguyên nhân thường gặp của chứng tự kỉ.	1	2	3	4	5	6	7
12	Tự kỉ là bệnh di truyền qua gen.	1	2	3	4	5	6	7

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	Câu hỏi	Hoàn toàn không đồng ý	Không đồng ý	Không đồng ý một phần	Trung lập	Đồng ý một phần	Đồng ý	Hoàn toàn đồng ý
13	Tôi hỏi bạn bè để tìm cách giúp đỡ cho con tôi.	1	2	3	4	5	6	7
14	Tôi gặp gỡ, trao đổi với những phụ huynh khác để tìm kiếm sự giúp đỡ cho con của tôi.	1	2	3	4	5	6	7
15	Tôi thấy cần được giúp đỡ nhiều hơn để giúp con mình.	1	2	3	4	5	6	7
16	Sự mất cân bằng hóa học là nguyên nhân chính dẫn đến tự kỉ.	1	2	3	4	5	6	7
17	Tạo môi trường thân thiện và yêu thương có thể giúp người tự kỉ vượt qua chứng bệnh này.	1	2	3	4	5	6	7
18	Sự thay đổi chế độ ăn có thể là cách hiệu quả trong điều trị tự kỉ.	1	2	3	4	5	6	7
19	Phạt đối với những hành vi 'kì lạ' và không phù hợp có thể làm giảm những hành vi tự kỉ.	1	2	3	4	5	6	7
20	Nguyên nhân chính của tự kỉ là bất thường của não.	1	2	3	4	5	6	7
21	Tôi trao đổi trong gia đình để tìm cách giúp đỡ cho con của tôi..	1	2	3	4	5	6	7

Appendix F: DEMOGRAPHIC AND SURVEY QUESTIONNAIRE. Vietnamese Version.

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	Câu hỏi	Hoàn toàn không đồng ý	Không đồng ý	Không đồng ý một phần	Trung lập	Đồng ý một phần	Đồng ý	Hoàn toàn đồng ý
22	Tôi gặp, trao đổi với những nhà sư/linh mục để tìm kiếm sự giúp đỡ cho con của tôi.	1	2	3	4	5	6	7
23	Tôi không hiểu tại sao con tôi lại mắc chứng bệnh này.	1	2	3	4	5	6	7
24	Tôi không hiểu tại sao con tôi lại mắc chứng bệnh này.	1	2	3	4	5	6	7
25	Cha mẹ lạnh lùng thường gây ra chứng tự kỉ của trẻ.	1	2	3	4	5	6	7
26	Một số loại thức ăn có thể khiến hành vi tự kỉ trở nên nặng hơn. Một số loại thức ăn có thể khiến hành vi tự kỉ trở nên nặng hơn.	1	2	3	4	5	6	7
27	Dùng thuốc là cách điều trị tự kỉ hiệu quả.	1	2	3	4	5	6	7
28	Dị ứng với một số loại thực phẩm có thể gây ra tự kỉ	1	2	3	4	5	6	7
29	Các biện pháp hiện tại tôi đang sử dụng cho con tôi rất hiệu quả.	1	2	3	4	5	6	7
30	Tôi đến gặp, trao đổi với giáo viên để tìm kiếm sự giúp đỡ cho con của tôi.	1	2	3	4	5	6	7

Appendix F: DEMOGRAPHIC AND SURVEY QUESTIONNAIRE.
Vietnamese Version.

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	Câu hỏi	Hoàn toàn không đồng ý	Không đồng ý	Không đồng ý một phần	Trung lập	Đồng ý một phấn	Đồng ý	Hoàn toàn đồng ý
31	Tôi sợ người khác nghĩ rằng con tôi bị tự kỉ.	1	2	3	4	5	6	7
32	Não phát triển bất thường là nguyên nhân chính của chứng tự kỉ.	1	2	3	4	5	6	7
33	Trẻ không được nuôi dưỡng và giáo dục tốt là nguyên nhân dẫn đến tự kỉ.	1	2	3	4	5	6	7
34	Tình trạng tư kỉ có tiến triển tốt hay không phụ thuộc đôi khi chỉ đơn giản là do may mắn.	1	2	3	4	5	6	7
35	Niềm tin vào chúa/đức phật có thể giúp người tự kỉ khỏi bệnh.	1	2	3	4	5	6	7
36	Điều trị tự kỉ sẽ dễ dàng hơn nếu bản thân người mắc thực sự có mong muốn cải thiện.	1	2	3	4	5	6	7
37	Tôi trao đổi với vợ/ chồng tôi để tìm kiếm sự giúp đỡ cho con của tôi.	1	2	3	4	5	6	7
38	Khi không có tôi ở bên, sẽ có người khác thay tôi giúp đỡ cho con của tôi.	1	2	3	4	5	6	7

Appendix G: INTERVIEW GUIDELINE. English Version.

Interview Guide

Purpose of this interview is to understand the diagnosis of your child, understand how and why you make health decisions for your child.

Family situation/coping/psychological well-bring

1. Can you tell me a little about your child?
2. When was s(he) diagnosed? By whom? Where? to understand how the parent made decisions in that period after diagnosis.
3. In what ways have your life changed after the diagnosis? In what ways have your life not changed?
4. What is it like to raise a child with autism?
5. How do people react to your child?
    a. What do they think/know about autism?

Help/support

6. Tell me in detail about the things you have done to help your child **before** you have found out.
7. Tell me in detail about the things you have done to help your child after you have found out.
8. How did you choose this support?
    a. Why did you choose this/those type of supports?
    b. What is useful/less useful?
        i. How did you know they were (or not) useful?
9. If you suspect someone you know has autism, where should they go for help first?

Knowledge/education

10. What do you know about autism?
    a. Did you know what autism is before/after diagnosis?
11. What do you think autism does to the person who has it?
    a. How does it work? (leading question)
12. Where do you find information about autism for his/her diagnosis?
13. Who do you talk to about your child?
14. Did anyone influence your actions? Tell me about how they influenced you.
15. Tell me about your interactions with your health care provider.
16. Tell me about your interactions with others (your family members, community members, alternative helpers, friends)
17. What do you do with the information from: a) doctors b) families c) friends d) associations e) otheri.e. training sessions, media?

Other – Empowerment, overcoming challenges

18. Are there any challenges? If challenges not mentioned***
19. How do you cope with these challenges (barriers)? How did you manage … what strategies have been useful?
20. Tell me about a time when something you have learned had a positive impact on you and your child?
21. How can people you've mentioned ________ help you make decisions on seeking treatment/support?

22. After having these experiences, what advice would you give to someone whose child has just been diagnosed with an ASD?
23. Is there anything you think I should know to understand how you seek help for your child?

Appendix G: INTERVIEW GUIDELINE. Vietnamese Version

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BẢN NHÁP

HƯỚNG DẪN PHỎNG VẤN

Mục đích của phỏng vấn này để hiểu về sự chẩn đoán của con anh/chị, hiểu lí do và cách thức mà anh/chị đưa ra quyết định sức khỏe đó cho con mình.

Bối cảnh gia đình/ sự đối mặt/ tình trạng khỏe mạnh tâm trí

1. Anh/chị có thể chia sẻ một chút về con của anh/chị?
2. Con anh/chị được chẩn đoán khi nào? Bởi ai? Ở đâu? Để hiểu cách cha mẹ đưa ra quyết định trong giai đoạn sau khi chẩn đoán.
3. Sau kết quả chẩn đoán, cuộc sống của anh/chị thay đổi như thế nào? Không thay đổi ở những khía cạnh nào?
4. Cuộc sống nuôi dạy trẻ có tự kỷ của anh/chị như thế nào?
5. Mọi người phản ứng với con của anh/chị ra sao?
    a. Họ nghĩ/biết gì về tự kỷ?

Sự trợ giúp/hỗ trợ

6. Anh/chị hãy chia sẻ chi tiết về những việc anh/chị đã làm để giúp con mình **trước** khi biết con mình có hội chứng tự kỷ.
7. Anh/chị hãy chia sẻ chi tiết về những việc anh/chị đã làm để giúp con mình **sau** khi biết con mình có hội chứng tự kỷ.
8. Anh/chị lựa chọn sự trợ giúp này như thế nào?
    a. Tại sao anh/chị chọn cách trợ giúp này?
    b. Nó hiệu quả/không hiệu quả ở điểm nào?
        i. Làm sao anh/chị biết cách trợ giúp này hiệu quả/không hiệu quả?
9. Nếu anh/chị cho rằng một ai đó mà anh/chị biết là tự kỷ, đâu sẽ là nơi đầu tiên họ nên tìm đến nhờ giúp đỡ?

Kiến thức/ giáo dục

10. Anh/chị biết gì về tự kỷ?

Appendix G: INTERVIEW GUIDELINE. Vietnamese Version

   a. Anh/chị biết về tự kỷ trước hay sau khi chẩn đoán?

11. Theo anh/chị, tự kỷ tác động như thế nào đến người có chứng tự kỷ?

   a. Nó hoạt động như thế nào?

12. Anh/chị tìm kiếm thông tin về tự kỷ để chẩn đoán cho con mình từ nguồn nào?

13. Ai là người anh/chị chia sẻ về đứa con của mình?

14. Có bất cứ ai tác động đến hành vi/hành động của anh/chị không? Xin mời anh/chị kể về cách họ tác động đến anh/chị.

15. Anh/chị chia sẻ về tương tác của anh/chị với đơn vị cung cấp dịch vụ sức khỏe đó.

16. Anh/chị chia sẻ về tương tác của mình với những người khác (thành viên trong gia đình, cộng đồng, những người giúp đỡ khác, bạn bè)

17. Anh/chị làm gì khi có các thông tin từ: a) bác sĩ b) gia đình c) bạn bè d) hiệp hội e) khác, ví dụ như buổi tập huấn, truyền thông?

Khác – Trở nên mạnh mẽ hơn, vượt qua khó khăn

18. Anh/chị có gặp khó khăn gì không? Nếu khó khăn không được đề cập ***

19. Anh/chị đối mặt với những khó khăn (rào cản) đó bằng cách nào? Cách anh/chị quản lý…? Cách thức nào hữu ích?

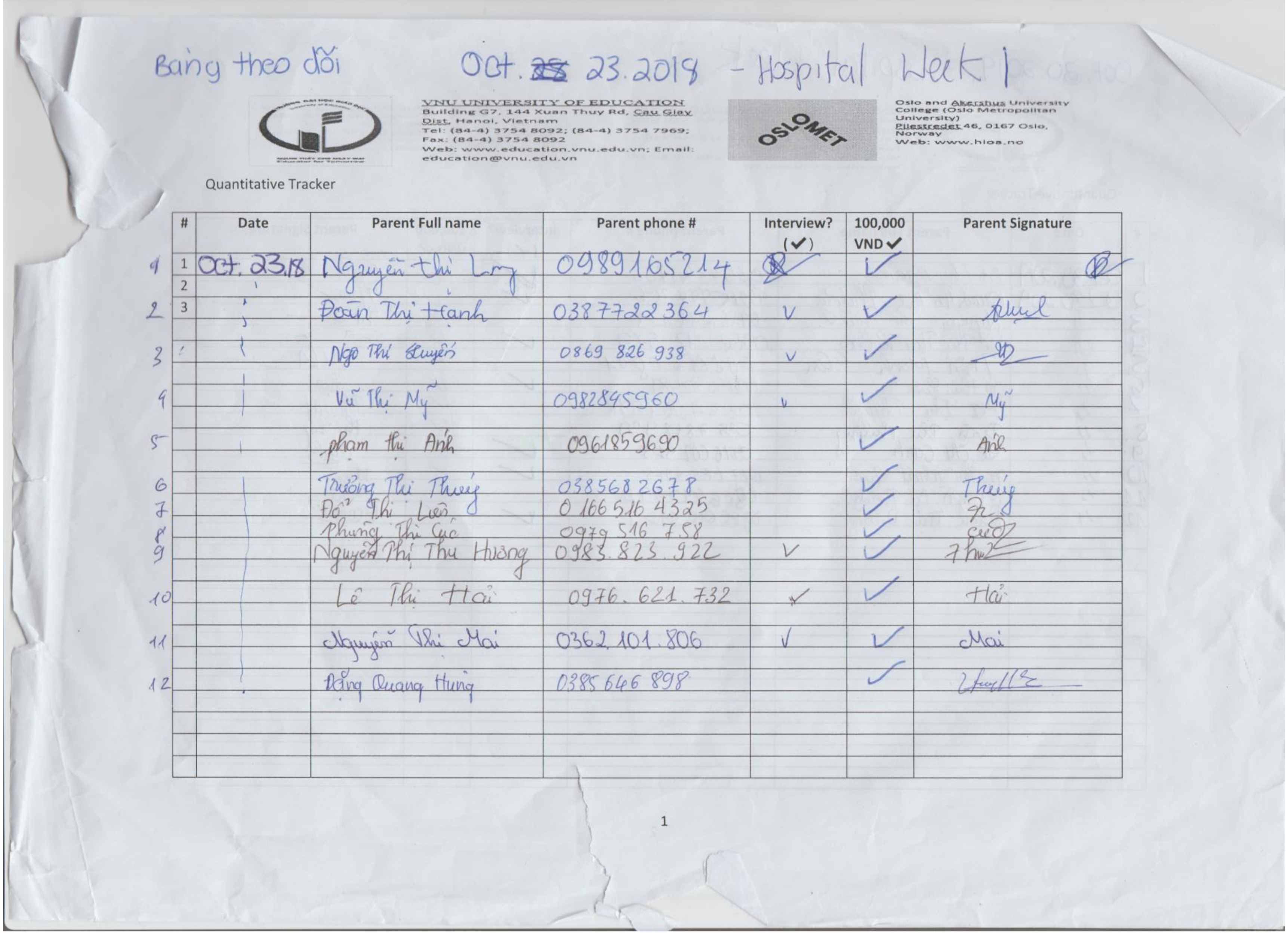
20. Anh/chị hãy kể về một lần khi anh/chị học được một điều gì đó có tác động tích cực lên chính bản thân mình và con của anh/chị.

21. Bằng cách nào người anh/chị vừa đề cập ___________ đã giúp anh/chị đưa ra quyết định tìm kiếm sự trợ giúp/điều trị?

22. Sau khi đã có một số kinh nghiệm như vậy, anh/chị sẽ đưa lời khuyên gì cho người cũng có con có chẩn đoán là tự kỷ?

23. Có bất cứ điều gì anh/chị nghĩ tôi nên biết để hiểu hơn về cách anh/chị tìm kiếm sự giúp đỡ cho con của mình?

Appendix H: COMPENSATION TRACKER



Bảng theo dõi Oct. ~~25~~ 23.2018 - Hospital Week 1

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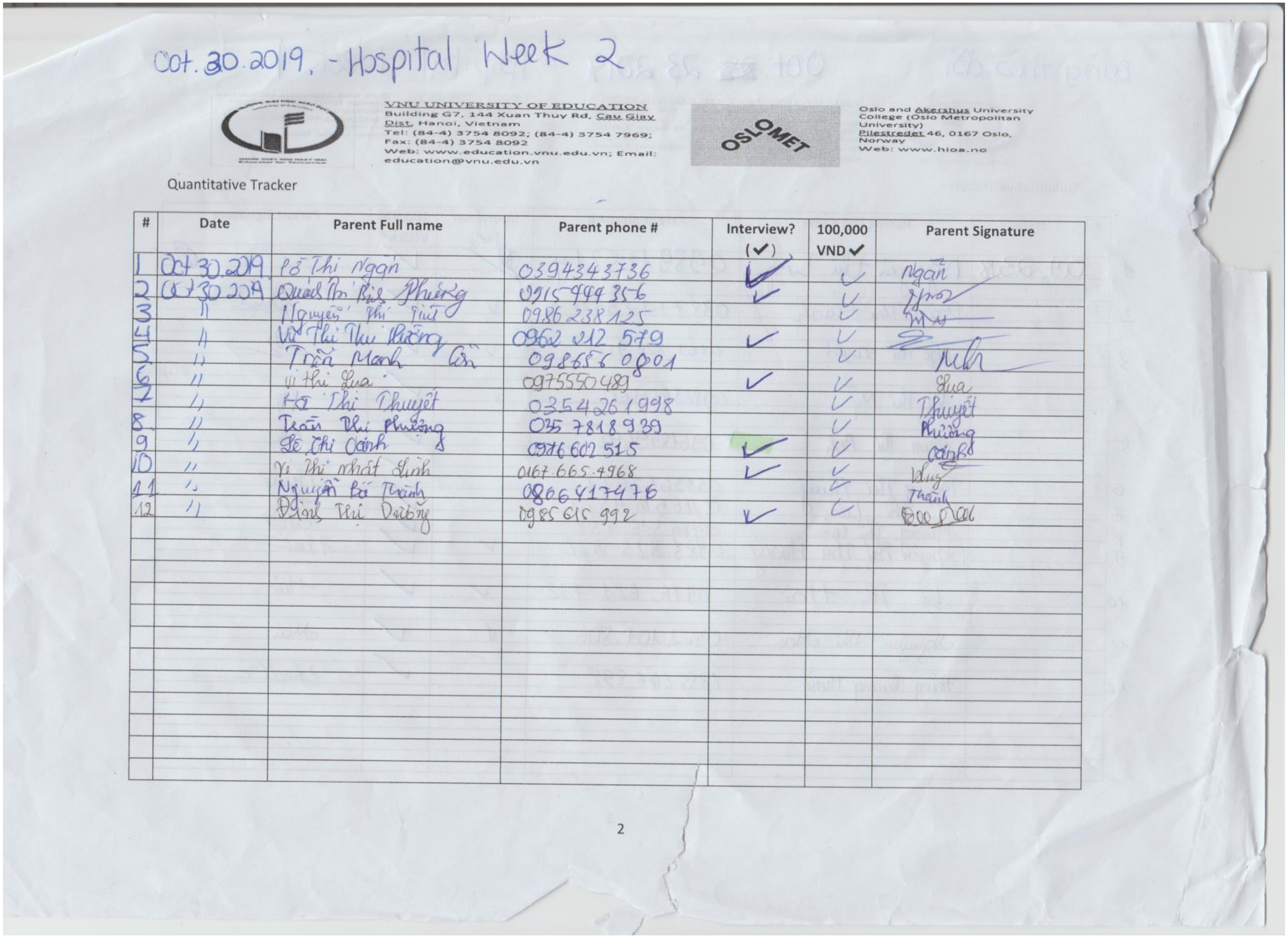
Quantitative Tracker

	#	Date	Parent Full name	Parent phone #	Interview? (✓)	100,000 VND ✓	Parent Signature
1	1	Oct. 23.18	Nguyễn thị Lung	0989165214	✓	✓	
	2						
2	3		Đoàn Thị Hạnh	0387722364	✓	✓	
3			Ngô Thị Luyến	0869 826 938	✓	✓	
4			Vũ Thị Mỹ	0982845960	✓	✓	Mỹ
5			phạm thị Anh	0961859690		✓	Anh
6			Trương Thị Thuỷ	0385682678		✓	Thuỷ
7			Đỗ Thị Liên	0 166 516 4325		✓	
8			Phùng Thị Cúc	0979 516 7.58		✓	Cúc
9			Nguyễn Thị Thu Hương	0983.823.922	✓	✓	
10			Lê Thị Hải	0976.621.732	✓	✓	Hải
11			Nguyễn Thị Mai	0362.101.806	✓	✓	Mai
12			Đặng Quang Hưng	0385 646 898		✓	

1



Oct. 30.2019, - Hospital Week 2

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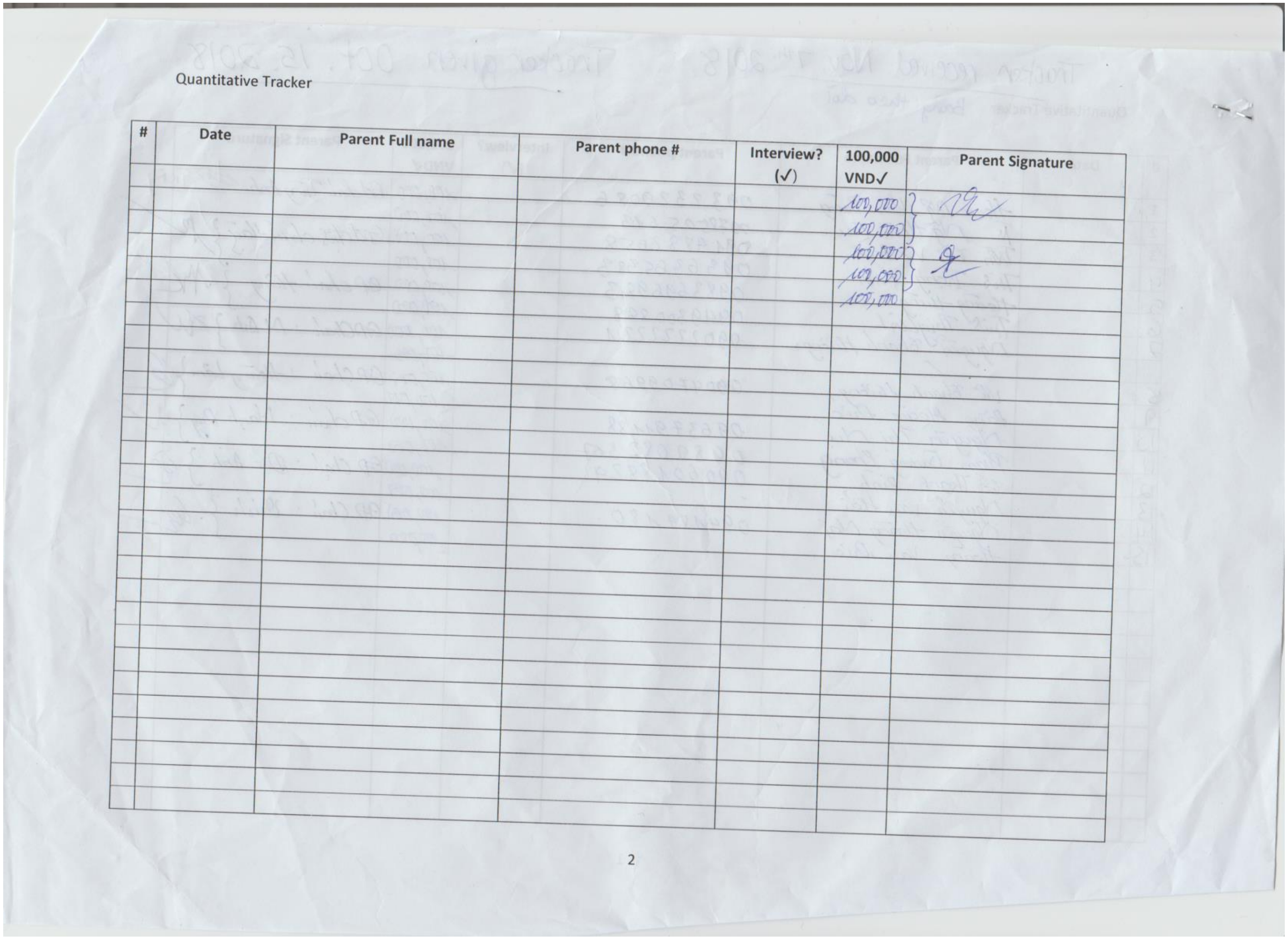
Quantitative Tracker

#	Date	Parent Full name	Parent phone #	Interview? (✓)	100,000 VND ✓	Parent Signature
1	Oct 30.2019	Lô Thị Ngân	0394343736	✓	✓	Ngân
2	Oct 30.2019	Quách Thị Bích Phượng	0915 444 356	✓	✓	
3	〃	Nguyễn Thị Tuất	0986 238125		✓	
4	〃	Vũ Thị Thu Hường	0962 212 579	✓	✓	
5	〃	Trần Mạnh Cần	098656 0801		✓	Mh
6	〃	Vi thị Lua	0975550489	✓	✓	Lua
7	〃	Hà Thị Thuyết	0354261998		✓	Thuyết
8.	〃	Trần Thị Phượng	035 7818939		✓	Phường
9	〃	Lê Thị Oanh	0976 602 515	✓	✓	Oanh
10	〃	Vi Thị nhất Linh	0167.665.4968	✓	✓	Dung
11	〃	Nguyễn Bá Thành	0806417476		✓	Thành
12	〃	Đinh Thị Dường	0985 615 992	✓	✓	

2



Quantitative Tracker

#	Date	Parent Full name	Parent phone #	Interview? (✓)	100,000 VND✓	Parent Signature
					100,000	
					100,000	
					100,000	
					100,000	
					100,000	

2

Tracker received. Nov. 7th. 2018. Tracker given. Oct. 15. 2018

Quantitative Tracker Bảng theo dõi

#	Date	Parent Full name	Parent phone #	Interview? (✓)	100,000 VND✓	Parent Signature
1		~~Hoàn~~ Ng. Yến Trang	0932329086		100,000	Gđ cháu Tùng Anh. Tùng
2		~~Tr~~ Ng Hoài Thu.	0978505613		100,000	
3		Trần Thị Vũ Bình	0914882058.		100,000	Gđ chị cháu Hoài
4		Triệu Trọng Anh.	0936365383		100,000	
5		Hoàng Hưng	0983696983		100,000	GĐ cháu Hưng
6		Triệu Thùy Linh	0949300888.		100,000	
7		Nguyễn Thanh Hường.	0902222221		100,000	GĐ Cháu : M Anh
		/			~~100,000~~	
8		Vũ Thanh Hường,	0904709968		100,000	GĐ Cháu : Hoàng Lâm
9		Đặng Hoàng Đức			100,000	
10		Nguyễn Thị Nụ	0963791188		100,000	GĐ cháu : Mạnh Duy
11		Phạm Quang Phong	0989082367		100,000	
12		Tô Thanh Bình	0906018824		100,000	GĐ Cháu : Đức Anh
13		Nguyễn Văn Hải	-		100,000	
14		Nguyễn Hoàng Nai	094184180.		100,000	GĐ Cháu : Vinh
15		Hoàng Văn Đức			100,000	

Qualitative Tracker – Interview

#	Date	Parent Full name	Parent Phone #	100,000VND VND✓	Signature
1	29 Oct.2018	Nguyễn Thị Thảo	0379907276	✓	Thao
2	29 Oct. 2018	Nguyễn Hồng Phượng		✓	Phuong
3.	5 ~~Oct~~ Nov 2018	Vũ Thị Thu Hường.		✓	Hường.
4	5 Nov. 2018	vi thị Lua		✓	Lua
5.	5 Nov. 2018	vi thị nhật Linh		✓	
6	8 Nov. 2018	Nguyễn Thị Thu Hà	0974. 827. 781	✓	
7	8 Nov 2018	TRỊNH THỊ LAN ANH	0973641709	✓	Anh
8	8 Nov. 2018	Hà Bích Phượng	0963211828	✓	
9	16 Nov. 2018	Đinh Quang Bằng	0934.674.366	✓	

Appendix I: BUDGET FOR ADMINISTRATIVE FEES

Money used for:	**Reason**	**Value $ (USD) (total S1750 USD = 15,000 NOK)**
Compensation for parents (survey-100 parents and interview-9-13 parents)	-Survey: We pay $4 to each parent for their time/transportation. -Survey+ time: We pay $8 for parents for time/transportation. $4 X 100 (# parents for surveys) = **$400.00** $8x13 (# parents for interviews + surveys) = $104.00 $104 - $52 ($4X13 overlap)= **$52.00** $400+52= $452.00	$452.00
Plan A: Full-time interpreter	Usually professional full-time interpreter (used for interviews, translations of research tools) cost $200.00usd/month X2 months= $400.00usd.	$400.00
Plan B: Recruit Volunteers – travel $	Support volunteer with transportation/gratitude for contribution	$50.00
Travel	Oslo -Hanoi (round trip)	$800.00
Administrative: paper and print	Administration	$100.00