# The Experiences of Parents of Children Who Are Deaf or Hard of Hearing in Vietnam: A Preliminary Study Focusing on Access to Education

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### Declaration

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

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## Acronyms

**Db:** Decibels

**IDEO:** Intergenerational Deaf Education Outreach

**PVEST:** Phenomenological Variant of Ecological Systems Theory

SBREC: Flinders University Social and Behavioural Research Ethics Committee

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

**WHO**: World Health Organisation

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#### Abstract

**Background**: The purpose of this research is to examine the experiences of parents of children who are deaf or hard of hearing in supporting their children to access education in Vietnam. Parents play a crucial role in supporting their children to gain full access to education. However, it was widely reported that parents of those children confront a range of problems to support their children to access education. Currently, there has been a lack of research exploring the experiences of those parents in literature. This research examines factors affecting those parents in supporting their children to access education, factors supporting them to overcome those challenges, and their expectations for their child's future education.

**Methodology**: A qualitative approach using a phenomenological research design was chosen to explore the central phenomena. Ten parents of children who were diagnosed as deaf or hard of hearing and aged 6 to 9 years were recruited through the support of the Association of Parents of Children with Hearing Impairment. Participants were interviewed via telephone with a mix of open and closed questions; interviews were audio recorded, transcribed and thematically analysed.

**Findings:** The research results show that there are nine main factors that affected the parents in this study in making decisions relating to education for their children including: lack of information resources, perspectives of those parents on communication approaches, the families' financial capacity, the psychological impact on the participants after their children' diagnosis, the attitude of family members, attitude of school administrators, lack of local schools and qualified teachers, and current education system for the Deaf in Vietnam. Apart from those factors, the lack of knowledge of the participants' partners about Deaf education and the partners'

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employment are considered to be barriers to educational access and successful communication with their child. Five main factors which are considered as facilitators for those parents: family support, social network, employers, the Intergenerational Deaf Education Outreach project, and the mother's characteristics. Self-determination of the mothers in this research plays a key role in decisions relating to education for their children at early ages. The majority of the parents expected their child to have better access to education for the Deaf and achieve higher levels of education in the future.

#### **Chapter One**

#### **Context and Aims of the Study**

#### **1.1 Introduction**

Hearing impairment is the most common sensory impairment (Mathers, Smith, & Concha, 2000) and predominant in individuals of all ages (Mackenzie, 2011). The World Health Organisation (WHO, 2017) estimated that there were 360 million people with hearing impairment throughout the world, accounting for 5 per cent of the world's population. In Vietnam, according to the United Nations Population Fund (UNFPA, 2011), 7.8 percent (6.1m individuals) of 78.5 million people aged five years or over had at least one functional disability such as hearing, mobility, visual or cognitive impairment. Among the population living with functional disability, it was reported that 3.13 per cent were people with hearing impairment.

The effort to promote equal access to education for people with disabilities in general and people with hearing impairment in particular has been recognised (Chataika, Mckenzie, Swart, & Lyner-Cleophas, 2012; Department of Human Services, n.d.). A range of policies and legislation at both national and international levels has been developed and enacted. For example, Article 26 of the Universal Declaration of Human Rights states that 'Everyone has the right to education' (United Nations, 1948). In addition, the United Nations Convention on the Rights of Persons with Disability (UNCRPD) (United Nations, 2007) includes a regulation that requires all parties who signed and ratified it to take responsibility for ensuring people with disabilities have the right to equal access to education. The ratification of this international human rights treaty in Vietnam in 2014 is expected to ensure and protect the rights for equal participation of people with disabilities in all aspects of life. Apart from the UNCRPD, the government of Vietnam also

enacted the Law on Persons with Disabilities in 2010 (The Vietnamese National Assembly, 2010). This legal document includes an emphasis on the right to equal access to education for individuals with disabilities and the responsibilities of the Ministry of Education and other ministries to implement this law.

Although the potential for improved access to education based on the above developments is acknowledged, the enrolment rate and literacy attainment of children with hearing impairment are currently much less than the average rate for the general population (World Federation of the Deaf, n.d). Rong and Shi (2001) referred to the Chinese Statistical Yearbook for enrolment statics of children with hearing impairment, stating that children with hearing impairment were restricted in terms of access to education in China. They found that only 4.2 individuals per 10,000 of all children with special needs had a chance to enroll in special programs, including opportunities for children with hearing impairment, to enroll in schools for people with hearing impairment. Liversidge (2003) reviewed the findings of previous studies of his colleagues. The results showed that an estimated 50 percent of people who are deaf or hard of hearing did not attend schools at the age of 17 and 18 years. In Vietnam, according to the United Nations Population Fund (UNFPA, 2011), it was estimated that 96.8 per cent of children without disabilities at the age of 6-10 years were enrolled in primary school, while this proportion among those with all disabilities dropped to 66.5 per cent. There was no reported school attendance rate among children who are deaf or hard of hearing. Furthermore, the literacy rate reported among those with disabilities was much lower than people without disabilities, 76.3 per cent and 95.2 per cent, respectively (UNFPA, 2011). The literacy rate among youth with hearing impairment (from 15 to 24 years old) was reported as about 42 per cent (UNFPA, 2011).

Parents play a vital role in supporting their children to have opportunities to gain full access to education. It has been widely reported that the development of a child is influenced strongly by a broad ecological context in which parents and families are fundamental participants in educating a child from birth (Karchmer, Mitchell, Marschark, & Spencer, 2003; Kuder, 2013). Each decision of parents impacts significantly all aspects of a child's life (Kuder, 2013). In education, the involvement of parents in children's education was proved as a positive factor facilitating the improvement of communication skills, social – emotional adjustment and academic achievement of children with hearing impairment (Calderon, 2000). Parents were considered as facilitators to educational inclusion for their children with hearing impairment. Eriks-Brophy, Durieux-Smith, Olds, and Fitzpatrick (2006) conducted research through 10 focus groups of children with hearing impairment, their parents and their teachers at school in order to examine facilitators and barriers to including those children in schools. The result showed that parents were advocates for issues associated with their children's education through understanding educational policies and procedures, and creating a cohesive relationship with teachers and administrators. Furthermore, home-school partnership in general education and special education was considered one of the key factors leading to successful education planning (Lo, 2008), affirming that opportunities should be created for parents to be involved in building educational activities for their children.

However, many parents of children with hearing impairment have to confront a range of problems to support their children to access education. Parents reported feeling stressed about meeting the demands relating to education support for their children (Marschark, 1997). Parents may struggle with communicating with their children (Eriks-Brophy et al., 2006). Those parents might not have skill or knowledge to build strategies to help their children develop language and

communication skills (Eriks-Brophy et al., 2006). It was also reported by those parents that the financial burden probably affects their decision-making about whether they stay at home to facilitate the development of their child's speech and language (Eriks-Brophy et al., 2006). In addition, several parents mentioned that their attempts to communicate with their children's teachers and administrators had not been successful (Eriks-Brophy et al., 2006; Reed, Antia, & Kreimeyer, 2008). The reasons identified included parents not being aware of educational policies and procedures (Eriks-Brophy et al., 2006).

Apart from the above issues, parents of children with hearing impairment lack options to choose an appropriate school for their children (Marschark, 1997). In Vietnam, there are few schools which can deliver teaching programs for children with hearing impairments. It has been the experience of the researcher that these schools are mainly located in big cities, such as Hanoi and Sai Gon. As a result, many children who are deaf or hard of hearing have to move to cities to study. Furthermore, anecdotally there appears to be an understanding that these schools do not have enough qualified teachers for the available special education programs. In Vietnam, although some universities provide a teaching qualification in special education, most of the graduates do not have adequate knowledge and professional skills specifically in teaching children who are deaf or hard of hearing (Nelson, 2015). Furthermore, there is no university in Vietnam offering a Master's course to train professionals or practitioners working with those children (Global Foundation for Children with Hearing Loss, 2013, as cited in Nelson, 2015). Although sign language is widely recognised in the field internationally as a specific community language, there is no standard test to examine the qualifications of learners. Furthermore, most of the teaching students have limited opportunities to practice sign language and have few chances to communicate with people with hearing impairment.

There has been a lack of research to date exploring the experiences of parents of children who are deaf or hard of hearing in supporting their children to access education in Vietnam, and research in teaching children with hearing impairment is limited. Meanwhile, it is understood that parents of children with hearing impairment have to confront many problems to help their children gain access to education. This research aims to provide valuable data on the experiences of parents of children who are deaf or hard of hearing in supporting their children to access education, with potential to reduce the gap in the literature and contribute to future education policy and practice.

#### **1.2 Research Aims**

This research aims to explore the experiences of parents of children who are deaf or hard of hearing in supporting their children to access education in the current educational context in Vietnam. The researcher anticipates that the outcomes of this research will provide more empirical evidence to help other researchers who intend to undertake related research. Furthermore, this research has potential to contribute to raising awareness of school administrators, teachers and policy makers about parental challenges in supporting children who are deaf or hard of hearing to access education.

In this research, participants will be invited to describe and discuss factors affecting them in supporting their children to access education. The researcher will explore both internal and external factors which are experienced by parents of those children such as response to diagnosis, their financial situation and available information resources. In addition, the experiences of those parents in coping with difficult situations when helping their children to access schools and parental expectations will also be investigated in this project.

#### **1.3 Structure of Dissertation**

This dissertation is structured as follows:

## **Chapter 2: Literature Review**

This chapter provides a general review of the previous literature. The research questions are presented in this chapter.

#### **Chapter 3: Methods**

This chapter describes the research design, participant selection and recruitment, ethical considerations, procedures for data collection and analysis, and rigour considerations. Demographic information of participants is also presented in this chapter.

#### **Chapter 4: Results**

This chapter presents the findings and analyses collected data. Themes and quotes which aim at answering the research questions are revealed in this part of the dissertation.

#### **Chapter 5: Discussion and Conclusion**

This chapter discusses and summarises the findings. In the discussion section, the findings of this research are compared and contrasted with previous studies. Recommendations for future studies, and the identification of limitations are also presented.

#### **Chapter Two**

#### **Literature Review**

#### 2.1 Definition, Types and Causes of Hearing Impairment

#### 2.1.1 Definition

Currently, researchers as well as organisations have adopted a range of definitions and terminologies to indicate 'deaf' and 'hard of hearing'. Kuder (2013) states that 'there is no "legal" definition of deafness' (p.230), meaning that there is also no fixed working definition of hearing impairment. For example, the World Health Organisation (WHO) uses two terms to describe individuals' experience of hearing impairment and they are 'hearing loss' and 'deafness' (WHO, 2017). WHO (2017) defines a person as having 'hearing loss' when he or she is not 'able to hear as well as someone with normal hearing – hearing thresholds of 25 dB or better in both ears'. 'Deafness' indicates the condition of having profound hearing impairment (WHO, 2017). People who are deaf can hear little or no sound. Many individuals with hearing impairment can utilise hearing aids or have a cochlear implant to improve their hearing ability (WHO, 2017). However, there are many factors affecting the extent of hearing recovery after having hearing aids or a cochlear implant fitted, such as background noise, negative side effects, and sound quality (Kochkin, 2000).

Deaf Australia (2010) uses several definitions to identify people with different grades and types of hearing impairments, including deaf (with a lower case d), hard of hearing, a hearing impairment, and the Deaf (with a capital D). Deaf Australia (2010) classified deaf (with a lower case d) as people who have difficulties with the physical condition of hearing impairment or as related to the most severe level of hearing impairment, as stated in the

Individuals with Disabilities Education Act (IDEA, 2004). Hard of hearing refers to people who acquire hearing impairment after birth and can communicate by speech (Deaf Australia, 2010), lip-reading and residual hearing (Aussie Deaf Kids, n.d.). 'Hearing impairment' is an alternative term for 'hard of hearing' which has been used by many professionals and practitioners (Aussie Deaf Kids, n.d.). Many people with hearing impairment, particularly people who have profound deafness from birth do not consider themselves as having a disability but as being a member of a cultural minority group (Mackenzie, 2011). 'Deaf' is a term used to illustrate individuals who use Australian Sign Language (or Auslan) and are involved in the signing Deaf community (Aussie Deaf Kids, n.d.). The Deaf community shares their own 'language, traditions, mores and values' (Mackenzie, 2011, p. 409).

In Vietnam, the Law on Persons with Disabilities (The Vietnamese National Assembly, 2010) did not adopt any specific definition for hearing impairment. Practitioners and professionals who work in the auditory field often apply definitions which have been used internationally. People who are living with deafness in Vietnam may also identify themselves as 'Deaf' with a capital 'D'. In common with the Deaf community in Australia and elsewhere, this population shares their typical culture and language among its members, as noted above, and sign language is considered to be the 'native language' of the Deaf. The Deaf who are living in each region (Northern, Central and Southern Vietnam) are using different sign language systems that have developed locally. Although many professionals in the field have tried to encourage people who are Deaf to reach an agreement on developing Vietnamese Sign Language, anecdotal evidence from the researcher's experience indicates that the Deaf community prefers using regional sign language dialects to Vietnamese Sign Language. However, people from different regions may still understand each other when they communicate using regional sign

language. Kyle, Woll, Pullen, and Maddix (1985) state that 'The most important feature which makes communication possible across different sign languages is the shared culture of deaf people' (p.172). The vocabulary could be learned through interaction between signers (Kyle et al., 1985) because of similarities based on its visual and iconic nature.

#### 2.1.2 Types of Hearing Impairment

Hearing impairment is classified into two main types, conductive hearing loss and sensorineural hearing loss (Kuder, 2013; Mackenzie, 2011; Westwood, 2009). Conductive hearing loss happens when deformity, functional failure or objects inserted from outside the body occur or appear in the outer or middle ear area (Kuder, 2013; Westwood, 2009). When an individual has conductive hearing loss, their audibility will be affected considerably but they do not lose all of their hearing ability (Mackenzie, 2011). Those individuals can still hear if they have hearing aids which amplify sound or environmental conditions are conducive to facilitating hearing such as use of amplifiers (DiSarno, Schowalter, & Grassa, 2002; Sockalingam, Pinard, Caissie, & Green, 2007). In terms of sensorineural hearing loss, damage to hair cells in the cochlea or inner parts of the ear can lead to this type of hearing impairment (Kuder, 2013; Westwood, 2009). Individuals can acquire sensorineural hearing loss at any period of their life such as acquired sensorineural loss in neonates, or during the school-age period (Smith, Bale, & White, 2005). Apart from problems associated with audibility, people with sensorineural hearing loss struggle to hear sounds or cannot hear sounds at all because sounds which are audible are not clear or changed in form (Westwood, 2009). Speech, language and cognitive ability of those individuals with sensorineural hearing loss are influenced adversely because this type of hearing impairment may be permanent (Smith et al., 2005). People who present with mixed hearing loss

have both conductive and sensorineural hearing loss (Kobayashi, Koga, & Suzuki, 2004; Mackenzie, 2011).

#### 2.1.3 Causes

Two approaches to classifying causes leading to hearing impairment are by congenital causes and acquired causes, and by the type of hearing impairment. Congenital causes might include genetic or non-genetic factors such as maternal rubella and low birth weight, or incorrect use of medicines during pregnancy or during the perinatal period (WHO, 2017). There is also a range of acquired causes leading to hearing impairment such as infectious diseases (for instance meningitis and mumps), damage to the ear or head, aging, and occupational hearing impairment (WHO, 2017).

Mackenzie (2011) classified the causes based on the two types of hearing impairment identified above: conductive hearing impairment and sensorineural hearing impairment. In conductive hearing impairment, the impairments which occur in the outer ear and the middle ear can cause this type of hearing loss (Mackenzie, 2011). Cerumen (ear wax) or a foreign object were considered to be the most common causes of conductive hearing impairment (Olusanya, 2003). Impairment in the middle ear such as otitis media or cholesteatoma can also cause hearing impairment (Acuin & WHO, 2004). There has not been a fixed definition of otitis media (Bluestone & Klein, 2007) and cholesteatoma (Olszewska, Rutkowska, & Özgirgin, 2015). In general, otitis media is defined as 'a group of complex infective and inflammatory conditions affecting the middle ear, with a variety of subtypes differing in presentation, associated complications, and treatment' (Qureishi, Lee, Belfield, Birchall, & Daniel, 2014, p. 15). Cholesteatoma refers to 'a disease of an epidermal origin that most commonly occurs in the middle ear cleft' (Olszewska et al., 2015, p. 81).

In terms of sensorineural hearing impairment, congenital and hereditary factors such as aplasia, dysplasia or maternal rubella may affect audibility. The inner ear aplasia occurs when a failure of the otic placode develops in the first three weeks of gestation (Marsot-Dupuch, Dominguez-Brito, Ghasli, & Chouard, 1999). Dysplasia is 'a general term for the abnormal growth or development of cells or organs' (Fratila, 2012, p. 83). Mothers' illness and perinatal problems such as maternal rubella are common causes of hearing impairment (Cohen, Durstenfeld, & Roehm, 2014), resulting in up to 20 percent of pre-lingual hearing impairment (Smith, 2001). Robertson, Cutts, Samuel, and Diaz-Ortega (1997) reviewed rubella immunisation in developed and developing countries through the WHO Global Programme for Vaccines and Immunisation, and related articles. Robertson et al. (1997) reported that while the rate of using rubella vaccine in developed countries was 92 percent at that time, there was only 28 percent use in developing countries during the same time period. Lack of awareness by the general public and health workers about health issues and medicine may lead to serious consequences for mothers and their children in some countries (Smith, 2001). In Australia, the measles-mumps-rubella vaccine which has been available to all infants since 1989 has helped to successfully control the spread of rubella (Chan, Dey, Wang, Martin, & Beard, 2015; Chiu et al., 2010). Consequently more recent hospitalisation rates due to rubella are reportedly at very low levels (Chiu et al., 2010).

#### 2.1.4 Grades of Hearing Impairment

The degree of hearing impairment is measured by decibels (dB) which is based on the pressure exerted by a particular sound.

Threshold	Children	Description
26-40 dB	Mild	Struggle with hearing distant speech or in noisy
		environments
41-60 dB	Moderate	Difficulty following even close range conversational
		speech
61-80 dB	Severe	Can hear only loud speech
Over 81dB	Profound	May recognise sound as vibrations

Table 2.1: Grades of Hearing Impairment (WHO, n.d.)

#### 2.2 Hearing impairment and educational outcomes

The majority of children who are deaf or hard of hearing have poorer educational performance and less academic achievement than their peers without hearing impairment (Järvelin, Mäki–torkko, Sorri, & Rantakallio, 1997; Qi & Mitchell, 2012; Teasdale & Sorensen, 2007). Järvelin et al. (1997) conducted research in Finland to assess the relationship between hearing impairment and school performance. This study examined the phenomena based on a sample which included 395 children with hearing impairment who were born between 1966 and 1977 and randomly selected participants without hearing impairment. Academic performance was evaluated based on the average of all marks of the participants. The findings revealed that hearing impairment significantly reduced educational outcomes of individuals with hearing impairment, even those with mild hearing impairment. The study also points out that when the subjects had more severe hearing impairment, their results were noticeably poorer than their those of their peers (Järvelin et al., 1997, p. 174).

In line with the research of Järvelin et al. (1997), Qi and Mitchell (2012) conducted a review of school achievement of individuals who are deaf and hard of hearing in the United States. The study by Qi and Mitchell (2012) was based on data which was collected from five norming studies of the Stanford Achievement Test for Deaf and hard of hearing students (Stanford). The Stanford is the national academic achievement testing program which has been conducted since 1969. The norming studies were conducted by the Gallaudet Research Institute (Qi & Mitchell, 2012). The study sample was students who were aged from 8 to 18 years. The assessments were organised in five years 1974, 1983, 1990, 1996 and 2003 with different cohorts each time. The authors reviewed the reading comprehension, mathematics problem-solving, and mathematics procedures subtests. They found that the academic achievement of those who are deaf or hard of hearing was much lower than peers with hearing in the normal range. The results showed that individuals with hearing impairment performed poorly in reading comprehension tests, but better in mathematics problem-solving and mathematics procedures subtests over a period of 30 years. The authors emphasise that the average performance of reading skills among these students was just equivalent to the fourth-grade.

In contrast, several researchers point out that children with hearing impairment could achieve in education as well as other peers without hearing impairment when they were fostered by supportive environments including knowledgeable and skillful teachers and devoted parents (Eriks-Brophy et al., 2012; Hadjikakou, Petridou, & Stylianou, 2008; Richardson, 2015). Eriks-Brophy et al. (2012) investigated factors which supported children with hearing impairment to participate in mainstream school settings in Canada, and detractors which prevented them from studying effectively. The researchers used data from a larger study which had been conducted by Durieux-Smith et al. (unpublished data) (as cited in Eriks-Brophy et al., 2012, p. 58). The

participants in this research included 24 parents of young adults with hearing impairment, 16 young adults with hearing impairment and 14 itinerant teachers. After analysing the research data, Eriks-Brophy et al. (2012) found that most of the young adults with hearing impairment who had finished high school were enrolling in or had graduated from postsecondary education. The results of research by Richardson (2015) are consistent with the above findings. He examined the educational achievement of students who are deaf and hard of hearing and compared with other students without disability in distance learning programs. The results clearly showed that more children with hearing impairment, but who did not have any other disabilities, completed the course than their peers without disabilities. These children passed the course and got higher marks than others did. However, those with additional disabilities such as intellectual disability or restricted mobility seemed to have lower levels of achievement than those without disabilities and individuals with hearing impairment. The researcher concluded that hearing impairment did not result in poor educational outcomes, but additional disabilities probably affected academic achievement negatively.

Good communication skills may support children with hearing impairment to gain a better educational outcome. Hadjikakou et al. (2008) conducted research to investigate the perspectives of children who were deaf and hard of hearing (who used an auditory or oral approach), their parents, and their teachers on those students' academic and social inclusion. All of these parents expressed the view that their children communicated very well with teachers and their classmates. The teachers also stated that they could communicate effectively with those children. The parents also believed that efficient communication skills helped their children to obtain higher educational achievement and be included effectively in general secondary schools.

#### 2.3 Impact of hearing impairment on the family

### 2.3.1 Psychological impacts

A feeling of stigma was experienced widely among parents of children with hearing impairment. Ebrahimi et al. (2015) conducted a quantitative research study with 90 mothers with deaf children in order to explore to what extent they experienced discrimination when they had a child with hearing impairment. It was reported that most of participants had experienced discrimination because of their children's hearing impairment, and they also felt embarrassed for themselves. As a result, their social and psychological status was affected significantly.

Previous research conducted in western countries reported that parents of children with hearing impairment typically experienced feelings of shock, anger, panic, despair and bereavement (Bosteels, Van Hove, & Vandenbroeck, 2012; Eleweke, Gilbert, Bays, & Austin, 2013; Hintermair, 2006; Jackson, Traub, & Turnbull, 2008; Kurtzer-White & Luterman, 2003; Meinzen-Derr, Lim, Choo, Buyniski, & Wiley, 2008; Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2002; Thakre, Thakre, & Alone, 2012; Wathum-Ocama & Rose, 2002; Wesley, 2011). Meinzen-Derr et al. (2008) examined the stress of parents of children both with and without hearing impairment in the United States. The researchers recruited 152 caregivers of those children by using the 68-item paediatric hearing impairment questionnaire which is validated to measure caregiver experience of stress. The results showed that parents of children with hearing impairment were experiencing more stress than parents of children without hearing impairment. Although some kinds of parental stress around child rearing reduced over time, stress relating to educational problems of those with hearing impairment increased after diagnosis of hearing impairment. The results of qualitative research by Bosteels et al. (2012) are consistent with the above research. They also explored the experiences of parents of children who were diagnosed

with hearing impairment in Belgium. Using a phenomenological approach, the authors interviewed sixteen parents of children with hearing impairment aged from five to seven years. When their child was initially diagnosed with hearing impairment, all parents reported feeling overwhelmed and said that 'I was in a different world' (p.987).

#### 2.3.2 Impact on communication among members in family

The ability to communicate efficiently and effectively plays an important role in cognitive and social development of children, and building social relationships (Decker, Vallotton, & Johnson, 2012). However, hearing impairment significantly impacts children's developing communication skills, causing delay in the development of expressive and receptive communication (WHO, 2017). The most difficult challenge between hearing parents and their children with hearing impairment is communication (Kobel, 2009b). In most cases, a priority of early intervention for those children focuses on improving the acquisition of language and communication skills (Karchmer et al., 2003).

There are several communication options provided to individuals with disabilities which focus on improving language and communication skills. Kuder (2013) reviewed communication approaches used through history finding, for instance, that from 1817 to 1860 educational programs mainly concentrated on improving spoken language and sign language (manual language) for children with hearing impairment. Recently, total communication which includes both auditory-oral and manual modes has also been used widely (Kuder, 2013). This means that parents can choose auditory-oral, sign language or the total communication approach for their children with hearing impairment. The bilingual-bicultural approach is a new method which focuses on developing a good language foundation based on sign language which is considered as the first or native language of deaf children (Dammeyer & Marschark, 2016). For example,

children who are deaf or hard of hearing in the United States are taught American Sign Language before being taught English (Kuder, 2013). Gravel and O'Gara (2003) also introduced some communication options for families of children with hearing impairment in the United States including auditory-verbal, auditory-oral, Manually Coded English, and American Sign Language.

Parents of children with hearing impairment seem to prefer auditory-oral methods to manual options. Auditory-oral is a communication method which helps people with hearing impairment develop spoken language by using residual hearing and speechreading (Musselman, 2000). Kobel (2009b) states that the communication mode between family members and a child with hearing impairment depended on the experiences and beliefs of the parents, however, most parents preferred their children to learn how to speak. In line with the research of Kobel (2009b), a qualitative research study by Borum (2012) examined the perspectives of parents of children who were deaf and hard of hearing in choosing communication modes. He recruited 14 African American hearing parents who were living in Washington, DC, metropolitan area and Pennsylvania in the United States to participate in his research. The results revealed that most of those families oriented their children towards oral tradition modes through speech. This communication option was probably the major way to help family members make daily conversation.

Parental choices for approaches to their children's communication are influenced by several factors. Eleweke and Rodda (2000) used a case study design to conduct a study with two hearing families who had preschool-aged children with hearing impairment in England with the aim of exploring factors affecting those parents in choosing communication methods for their children. Four factors emerged in this study. The first factor is information that was provided to

parents, especially during the time following diagnosis of their children's hearing impairment status. The second factor is the parents' perceptions and understanding of hearing aids. Many of those parents had assumed that by using hearing aids their children could hear and communicate normally. The attitude of service professionals, teachers and educational administrators was the third factor identified as influencing the selection of communication methods by those parents. Generally, the parents stated that professional and educational officers did not appear to understand their feelings and provided limited information relating to the potential communication approaches for their children. Finally, counselling and other assistive services also contributed to the parents' decision. However, the parents emphasised that neither of those services was adequate. These findings are reflected in the research reported by Li, Bain, and Steinberg (2003) and Decker et al. (2012). Decker et al. (2012) noted in their research that parents of children with hearing impairment were strongly influenced by the perceptions of audiologists and speech pathologists in their selection of a communication approach. Li et al. (2003) also surveyed eighty-three parents of children with hearing impairment to examine factors contributing to their decision about a communication modality. The results revealed that parents chose a communication approach for their children with hearing impairment based on their beliefs and attitudes about hearing impairment, severity of their children's hearing loss, and anticipation of their children's ability to speak and sign in the future.

# 2.4 Hindrance for children with hearing impairment to access education:

## experiences of parents

Research into the experiences of parents supporting access to education for their children who are deaf or hard of hearing is very limited. The majority of the studies explored the experiences of those parents in relation to early intervention, stress and using support services or

the experiences of children with hearing impairment in participating in education, higher education and inclusive education. Some researchers also explored how families of children with hearing impairment affected their children's education, but these researchers focused on views of other individuals such as teachers instead of parents.

Wathum-Ocama and Rose (2002) examined perspectives and experiences of Hmong parents of children who were deaf or hard of hearing in supporting their children to attend school in the United States. This research included six couples and one mother who had deaf or hard of hearing children studying in public schools. The results revealed that all of those parents had low educational expectations of their children with hearing impairment in comparison with other children. The given reason was that the parents might assume their children had learning difficulties due to hearing impairment. Wathum-Ocama and Rose (2002) explained that the parents' misunderstanding might originate from their cultural beliefs or they lacked knowledge about the impact of hearing impairment. The parents in this research were satisfied with the education services provided for their children. They said that teachers and other staff respected and encouraged them to participate in the school activities of their children. Another reported result is that although all participants agreed that education is very important for their child's future, they did not have any specific goals nor adequate knowledge to help themselves and their child to be more involved in education. The research findings revealed the biggest challenge that parents encountered in supporting their children's education was communication. Most of the parents were not fluent in English because of several factors. First, they had immigrated into the United States at least three years before this study was conducted. Secondly, most of these parents did not have any formal education. As a result, it was difficult for them to help their children study at school as well as at home.

Reed et al. (2008) explored facilitators and detractors of academic achievement of children who were deaf and hard of hearing in the United States. The researchers interviewed not only parents of those children but also teachers, principals, interpreters, and the children themselves. The results showed that the families of those children could play roles as facilitators but also detractors. Reed et al. (2008) said that some parents were concerned about how effectively their children studied at school. For instance, 52 percent of those parents could assist their children in doing homework. However, only 20 percent of them contacted schools for further information about their children's study. Many families also moved to the location which was more convenient for their children who are deaf or hearing impaired to go to school.

Kobel (2009b) did a survey with Ukrainian hearing mothers and fathers to examine their attitude towards services and/or programs for their children who are deaf or hard of hearing, the effect of the diagnosis on those parents, and their views about professionals. The author conducted a nationwide survey with 325 parents and a focus group with 17 of those families. In terms of challenges which those families encountered to support their children to attend school, the results showed that it was difficult for those families to afford expenses relating to hearing aids, weekly trips to residential schools which were far from their homes, and hiring speech pathologists. Furthermore, all parents whose children were at special boarding school five days per week reported being more stressed during those times as they did not have a chance to see their children more frequently.

Wesley (2011) also explored the experiences of 8 Hispanic families of children with hearing impairment in the United States, with 10 parents participating in the study. This research identified several themes including universal hearing screening, early intervention, school attendance, and transition of services. Regarding school attendance, the research results showed

that the majority of parents decided to let their children study in public instead of private schools due to costly tuition and long waiting lists for the latter. Furthermore, they preferred public schools because they expected their children to have more chances to communicate with peers without hearing impairment, and these schools have higher educational goals for their children. Some of the parents, however, also complained that their child was grouped with other children who had limited speech intelligibility. Those parents reported a belief that this affected their child's language development. Some parents chose private schools because they felt that these schools offered an environment that was very quiet. Furthermore, private schools often were equipped well. One important point which emerged in the research results is that the parents did not have strategies to help their children become more integrated into schools and achieve the educational goals that they set up for their child. In a related study in India, Thakre et al. (2012) collected data through conducting focus group discussion with 58 parents of children with hearing impairment, 10 school teachers and management personnel, and 10 junior doctors. The results show that parents who participated were satisfied with school services and their evaluation of school teachers and personnel was that they were very supportive.

Ghadim et al. (2013) investigated 'Mother's Perspective Toward al-Quran Education for Hearing Impaired Children in Malaysia'. This small study aimed at exploring the mothers' views on Islamic education of their children with hearing impairment. The researchers recruited four participants including two mothers of children with hearing impairment and two teachers. By using in-depth-interviews, the findings revealed several factors affecting access to education of children with hearing impairment in Malaysia. The first factor is that those families experienced lack of education support for their children. It was difficult for those mothers to help their children to study because they did not know formal sign language which was often used at

schools. Secondly, the Malaysian culture was also reported to affect education access of those children significantly. Many people believed that children with hearing impairment did not need to study and should not have the same education as other children. The parents also expressed some dissatisfaction with schools because the schools lacked technology support. Furthermore, some schools did not deliver education programs for children with hearing impairments reportedly because the teachers did not know how to teach the Quran to those children.

#### **2.5 Research Questions**

As stated in Flick (2009), 'Research questions are like a door to the research field under study' (p.103). These questions help to direct the data collection and to comprehend the research results (Creswell, 2012a). To investigate the experiences of parents of children who are deaf or hard of hearing in supporting their children to access education in Vietnam, the researcher posed the three following research questions:

(1) What are factors affecting parents of children who are deaf or hard of hearing in supporting their children to access education?

(2) How did parents confront barriers in supporting their children to access education?(3) What are parents' expectations?

#### 2.6 Summary

This chapter has provided an overview of the literature on hearing impairment, the impact of hearing impairment on educational outcomes and families, and the experiences of parents of children who are deaf or hard of hearing in supporting their children to access education in the United States, and developing countries other than Vietnam. Hearing impairment is categorised into mild, moderate, severe and profound grades. While some research reports that children who had more severe hearing impairment had significantly poorer

educational outcomes than those without hearing impairment, results of other studies show that children with hearing impairment can still achieve in education if they are fostered in a supportive environment. Hearing impairment may have remarkable effects on psychological health and communication among family members. Previous literature provided information about a wealth of factors affecting parents of children who are deaf or hard of hearing in seeking educational support for their child, including knowledge and skills about hearing impairment and education options, communication methods, financial capacity, location of schools, culture, and the quality of schools and teachers. This literature review helps the researcher link related knowledge from previous studies with the current research in order to explain the research phenomena and its importance. Literature relating to the hearing impairment field in general and in particular to the experiences of parents of children who are deaf or hard of hearing in supporting their child's education in Vietnam has been very limited to date. Three main research questions are also presented in this chapter.

#### **Chapter Three**

#### **Research Methodology**

#### 3.1 Study design

A qualitative approach was chosen to investigate the central phenomenon. Qualitative research is defined as 'empirical research where the data are not in the form of numbers.' (Punch, 2009, p. 3). This approach is 'best suited to address a research problem in which you do not know the variables and need to explore' (Creswell, 2012a, p. 16), and was used to understand more about the issue and to encourage research participants to share their stories (Creswell, 2007).

A phenomenological research design was selected to explore the experiences of parents of children who are deaf or hard of hearing in supporting their children to access education. This research design holds the science fundamental to philosophy (Creswell, 2007). Phenomenology was first described by Husserl (1982), a German mathematician, and a philosopher. In contrast with quantitative approaches, the fundamental concept of phenomenology is that individuals' views are reliable and valuable (Groenewald, 2004).

The researcher chose this method from a range of potential approaches for the following reasons:

(1) This method helps researchers to understand lived experiences which are provided by participants (Creswell, 2007). It emphasises personal perspectives and interpretation (Lester, 1999), and is used to explore subjective and objective experiences of those who share common phenomena.

(2) A few or many participants can be involved in the study when using this method (Aspers, 2009).

(3) The perspectives of participants are central in the data analysis (Aspers, 2009).

#### **3.2 Participant Selection and Recruitment**

This research focuses on parents of children who are deaf or hard of hearing impairment in Vietnam. The researcher chose these participants because there has been limited previous research exploring their experiences in supporting their children to access education. These parents play an important role in their child's developmental progress in general and educational decisions in particular. Potential participants were invited to take part in this study if they met the criteria as follows:

• Hearing parent

• They are parents of children with severe to profound hearing impairment currently aged under 18 years of age

• Their children are studying at special or mainstream schools

Potential participants were recruited through the support of the Association of Parents of Children with Hearing Impairment which is a not-for-profit organisation in Hanoi. The members of this organisation include parents of children who have varying levels of severity of hearing impairment and live in different provinces in Vietnam.

Prior to commencement, the researcher contacted the association to inform them about the study and sought their assistance in circulating the study introduction (Appendix A), information sheet (Appendix B) and consent form to its members (Appendix C). After receiving the approval of the request from the organisation (Appendix D), information about this study was posted on the organisation's Facebook page. Facebook was considered the preferred way for the organisation to disseminate the research information because the majority of its members have a

Facebook account and often visit the organisation's Facebook page. Potential participants who were interested in this project contacted the researcher through Facebook, enabling direct contact without involving the organisation. The researcher forwarded the letter of introduction, information sheet and consent form via email and their Facebook inbox, and sought and obtained the consent of participants verbally via telephone prior to the interviews.

#### **3.3 Participants**

This research recruited 10 parents of children who were diagnosed as deaf or hard of hearing and aged 6 to 9 years. Participants were living mainly in the north of Vietnam. One participant was living in the central region.

Participant information is described including demographics of the parents (Table 3.1) and child characteristics (Table 3.2). Respondents varied by career, education levels, place of residence and numbers of children. Children varied by gender, age, type of school, school grades and causes of hearing impairment.

#### **Demographic Information of Parents**

Participants who expressed their interest and participated in this research were mothers of children who are deaf or hard of hearing. The majority of participants (9 mothers) had a current job. One of the participants reported not working at the time of the interview, but also explained that she had previously worked in a company as an accountant. However, she had chosen not to work during the time of giving birth to a second child. The parents' educational levels ranged from secondary school to university, with half of them having a university degree. Most parents also revealed that they had more than one child. Interestingly, many of the participants' children who are deaf or hard of hearing are the first child in the family.

Name	Career	Education levels	Residential area	Numbers of children
Huong	Teacher	Bachelor	Hanoi	2
Vy	No job	High school	Da Nang	3
Thanh	Hairdresser	Secondary school	Hanoi	2
	Employee, chairperson of Association of Parents of Children with hearing			
Mai	impairment	High school	Hanoi	2
Trang	Employee	Bachelor	Hanoi	2
Tham	Teacher	Bachelor	Hanoi	2
Hien	Family business	Secondary school	Thai Nguyen	2
Thao	Cleaner	Secondary school	Hanoi	1
Hanh	Casual jobs	Bachelor	Hanoi	3
Nguyen	Teacher	Bachelor	Hanoi	2

# *Table 3.1*: Demographic Information of Parents

## Demographic information of children

All of the children in this research had been diagnosed as deaf or hard of hearing. One child also has vision impairment (Trinh, Hanh's daughter). Exposure to Rubella during the prenatal period affected the congenital development of the majority of the children, resulting in hearing impairment. Seventy percent of the children were studying at special schools; some children were studying at mainstream schools, and nearly half of the children were in primary school at the time of interview.

			Year			
Mathaw's name	Name of	Condon	of Diath	Causes of	Sahaala	School
Mother's name	child	Gender	Birth	impairment	Schools	Grade
				Congenital	Special	Primary
Huong	Huy	Male	2008	cause	school	school
				Acquired	Special	
Vy	Nguyet	Female	2011	cause	school	Preschool
				Congenital	Mainstream	
Thanh	Hung	Male	2011	cause	school	Preschool
				Congenital	Special	Primary
Mai	Duc	Male	2009	cause	school	school
				Congenital	Special	
Trang	An	Female	2011	cause	school	Preschool
					Mainstream	Primary
Tham	Hoang	Male	2009	Not known	school	school
				Congenital	Special	
Hien	Tuan	Female	2011	cause	school	Preschool
					Special	Primary
Thao	Vuong	Male	2010	Not known	school	school
				Congenital	Mainstream	
Hanh	Trinh	Female	2011	cause	school	Preschool
				Congenital	Special	
Nguyen	Hieu	Male	2011	cause	school	Preschool

Table 3.2: Demographic Information of Children

None of the above children have been offered an opportunity to receive a cochlear implant even though their grade of hearing impairment is severe or profound. While in Australia the opportunity exists for some children to access cochlear implants for hearing impairment remediation (Department of Health and Ageing, n.d.), limited opportunity exists in Vietnam because of costs and other access issues. Although the children of three participants are studying at mainstream schools, they cannot hear the instructions from their teachers nor communicate with classmates through speech or sign language.

## **3.4 Ethical Considerations**

Ethical issues should be considered carefully throughout the research implementation from the beginning to publishing a study (Creswell, 2013).

- Before commencing this study, ethics approval was obtained from Flinders University Social and Behavioural Research Ethics Committee (SBREC). Ethics Approval Number 7438 (Appendix E). The researcher also made initial contact with the Association of Parents of Children with Hearing Impairment and received their approval for supporting the research implementation.
- Detailed information about the research including a letter of introduction and an information sheet was provided to potential participants at the beginning of the study. The aim of the study and the interview procedure was clearly explained to the potential participants, as well as potential for any further contribution to the research process. The researcher also emphasised that participation was voluntary and participants did not have to answer the questions if they felt uncomfortable, and could withdraw at any time without any disadvantage.
- Consent was obtained from each participant prior to the interviews.
- During data collection, the researcher discussed the purpose of the study as outlined in information previously provided and reminded participants of the interview procedures prior to commencing interviewing. The researcher also provided information about a free counselling service for follow up if the participants experienced distress in relation to any aspect of subjects raised during the interviews.
- Identity of participants remained confidential at all times. Data were collected, transcribed and translated into Vietnamese by the researcher, and accuracy of the

translation was checked again by an independent translator. This translator is competent in both English and Vietnamese, and has experience in the disability field. The participation of the translator in checking the accuracy of translation of transcripts in this research helped the researcher reflect the participants' stories in English as they were told in Vietnamese. The recheck of translated transcripts will also help to increase triangulation of this research.

- The researcher signed a Confidentiality Agreement (Appendix F) with the translator to ensure all research information was to be kept confidential. The names of participants were changed in transcripts, and in the draft as well as the final research report.
- Transcripts and the report draft were sent to the participants so that they would be able to check the accuracy as well as correct or request removal of any content.
- All electronic versions of data are stored on the researcher's computer that is protected by password, and on a Flinders University computer which requires authorised personal access details and password of the researcher or supervisor to log in. Data were stored in the Disability and Community Inclusion Unit, Flinders University, and will remain there for at least 5 years following the date of publication according to SBREC guidelines and requirements.
- After publication of the study, copies of the final report will be sent to participants via email and to the organisation's Facebook inbox to share the research results.

#### 3.5 Data Collection

Participants were interviewed via telephone for approximately 45 to 60 minutes. The interviews were conducted from a private room at Flinders University which ensured confidentiality and suitable conditions for a formal interview. Participants, who were located in

the geographical areas noted in Table 3.1, were able to choose an interview location suited to their needs and personal preferences. Prior to each interview, the researcher introduced herself and provided the participants with a brief review of information previously made available about the project and the interview procedures. The researcher then checked that each of the participants was willing to continue and whether they had any questions before commencing the interviews. The data collection process formally started when the researcher asked some demographic questions about each participant and their child (Table 3.1 and Table 3.2).

The research data were collected through semi-structured interviews using a mix of open and closed questions which may help to create an atmosphere in which participants are able to feel comfortable and relaxed when answering questions. All the interview questions were translated from English to Vietnamese by the researcher.

Kvale and Brinkmann (2009) suggested that the semi-structured interview approach might help the researcher explore the life experiences of participants and seek to understand their world. The interview questions were designed based on the three main research questions included in Chapter 2 (2.5), reviewed with the researcher's supervisors, and were adjusted where necessary to be suitable for each participant (Appendix G). Some interview questions were used as a guide in a changed order based on the responses of the participants to prior questions, or were expanded or restated if a participant did not clearly understand the initial question. The researcher then made note of these points to facilitate further explanations of those questions if applicable for other interviewees. At the end of each interview, the researcher always asked whether the participants wanted to add any further information to the interviews or to ask the researcher any questions.

The interviews were recorded using an audio digital recorder. Recordings were initially transcribed in Vietnamese and then translated into English by the researcher. As part of the research protocol previously described, each participant was sent a transcript in Vietnamese to check and if necessary correct information which they provided during their interview.

As part of maintaining the integrity of the research process, Seale and Silverman (1997) state that transcripts of recordings provide an excellent record of naturally occurring interactions. In comparison with field notes of observational data, recordings and transcripts can offer a highly reliable record to which researchers can return as they develop new hypotheses as data analysis evolves.

#### **3.6 Data Analysis**

Data analysis is a procedure to interpret and analyse research data (Creswell, 2012a). Interviews were transcribed verbatim, imported and analysed using a qualitative computer program named NVIVO. The researcher chose this program because it is quite straightforward to use. It can be used to import data from a range of types of documents such as Word, pdf and audio. This software can manage data and emergent themes professionally and efficiently and enable the researcher to readily track data. This program has helped researchers in coping with and visually mapping categories in their research (Welsh, 2002). Then the researcher applied inductive coding to the data, to draw meaning from text data developed from interviews. Inductive coding is an approach which allows research findings to appear from 'the frequent, dominant, or significant themes inherent in raw data' (Thomas, 2006, p. 238). This approach helps to summarise intensive raw data into a brief format and link collected data to research objectives and questions (Thomas, 2006). During this stage of the process, the researcher chose

data relevant to the research questions; similar codes were grouped and redundant codes were deleted.

#### **3.7 Rigour in Qualitative Research**

The establishing of strategies in order to ensure the accuracy and trustworthiness of qualitative research is very important (Creswell, 2012a). It makes sure that the researcher accurately reflects the phenomenon under investigation. Four criteria to assess the trustworthiness of qualitative research include truth value (credibility), applicability (transferability), consistency (dependability) and neutrality (confirmability). These criteria were established by Lincoln and Guba (1985) and researchers such as Krefting (1991), Shenton (2004), and Thomas and Magilvy (2011) have also used and further contributed to this model.

In terms of credibility, one form of triangulation is the involvement of a diversity of participants. This research explored the experiences of parents who lived in different regions of Vietnam. The variety of participants helped to provide rich stories for this research. Furthermore, triangulation of this study was substantiated by the supervision of two other researchers. Member checking is one of the criteria to evaluate credibility of research (Creswell, 2012a). In this research, in order to ensure trustworthiness, the researcher sent transcripts to each interviewee for review and comments. Shenton (2004) also emphasised that research credibility is facilitated through 'tactics to help ensure honesty in informants' (p.66). From the beginning of conducting this research, through provision of a Letter of Introduction, an Information Sheet and a Consent Form to participants the researcher aimed to ensure that participants were aware that they had the right to refuse to be involved in this research. Participants did not have to answer any questions they felt uncomfortable with or could withdraw from participation at any stage of the research

process. Information about ensuring confidentiality was also provided to participants before commencing the research.

Transferability of research refers to the ability to apply the research results to different contexts (Thomas & Magilvy, 2011). It means that when another researcher uses the same method but conducted in a different setting, the findings of that research could build on what is known (Shenton, 2004). One of the strategies to ensure transferability of research is for demographic information of the participants to be collected and analysed (Thomas & Magilvy, 2011). This research also provided readers with demographic descriptions which may help them understand further the results of this research through discerning participants' contexts.

Regarding dependability, Houghton, Casey, Shaw, and Murphy (2013) highlighted that in order to achieve rigour, an audit trail should be applied which provides reasonable evidence for method and interpretive judgements and also helps readers understand the processes within the research. For that reason, the purpose, research design, the recruitment of participants and the implementation process of this research were reported in detail. Thus, the reader may have opportunities to reflect on and assess the research processes (Thomas & Magilvy, 2011).

Confirmability also takes account of the audit trail which allows readers to trace collecting and analysing of data such as raw data and process notes (Baxter & Eyles, 1997). During the interview, the researcher noted emergent themes and used them during data analysis. These notes also helped the researcher increase the triangulation of data.

#### **3.8 Summary**

This chapter presented information about the research methodology and design used to explore the central phenomenon. A qualitative approach and phenomenological research design were chosen in order to help the researcher collect valuable data relating to the experiences of

parents of children who are deaf or hard of hearing in supporting their children to access education. The rationale for choosing a qualitative approach and phenomenological research design was also explained in this chapter. This research used semi-structured telephone interviews as the instrument for collecting data. Recruitment procedures and participants' demographic information were presented in this chapter, and data analysis using NVIVO was described.

### **Chapter Four**

## Findings

# 4.1 Introduction

In this chapter, data collected through semi-structured in-depth interviews with the participants is presented. After the data were transcribed and processed using NVIVO, the emergent themes were illustrated below including time of hearing impairment diagnosis, treatment journey, attitude of community and family to hearing impairment, psychological impacts for families, factors affecting parents in supporting their children to access education, parents' expectations for deaf education and for their child's future.

## 4.2 Diagnosis of hearing impairment

The majority of the participants' children were diagnosed with hearing impairment at ages from three months to one year.

Name of mother	Name of child	Time of diagnosis
Huong	Huy	9 months
Vy	Nguyet	1 year
Thanh	Hung	Few days, after giving birth
Mai	Duc	10 months
Trang	An	9 months
Tham	Hoang	3 months
Hien	Tuan	5 months
Thao	Vuong	2 years
Hanh	Trinh	6 months
Nguyen	Hieu	9 months

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Table 4 1.	Diagnosis	of Hearing	Impairment
<i>I u v v v v v v v v v v</i>	Diagnosis	or meaning	mpannen

The reason for the later diagnosis of hearing impairment in some children might be related to the lack of medical equipment for earlier hearing screening in local hospitals in Vietnam. Consequently, doctors may in some cases have produced incorrect or unreliable reports for hearing checks.

When my son was one year old, we recognised that he had some hearing problems. We brought him to a local hospital in Nam Dinh (a province located in the North). However, there was no technical equipment for hearing screening in the hospital. The doctor who was in charge that time checked my son's eardrums and said 'there is no abnormality with your son' ears. He looks wise. There is no problem with his hearing. Then, they gave us a supplement nutrition for the brain. Oh my god, I think my son's brain is normal. I did not give my son that medicine. (Thao, February 2017)

As mentioned in Chapter 1, the Newborn Hearing Screening program is not available for every newborn baby in Vietnam. The majority of the participants' children did not receive any hearing test until their parents recognised some apparent hearing difficulties. This leads to the relatively late diagnosis of hearing impairment among newborns, with only one of the mothers saying that her child's hearing status was checked after he was born.

We knew about my son's hearing problem when he was three or four days old. Before I was discharged from the hospital, they checked my son's hearing...They gave us paperwork for the newborns' hearing test. If any parents wanted to check their child's hearing, they just needed to sign in that paper. (Thanh, February 2017)

Most of the participants did not realise their child had a hearing problem until he or she barely reacted to sounds nor responded to communication with parents at a level comparative to other typically developing children of the same of age.

Because she is my first child, I do not have many experiences in raising a baby. Based on information provided by other mothers, at the age of three months, babies often turn their head back to react to their mothers' call when their mothers get back home. However, I did not have much chance to go far away from home at that time, so I did not recognise her

unusual symptom. When she was 4 or 5 months, people just asked me by accident 'She cannot hear us, can she? Why does she not turn her head back when we call?' I did not think much about their words at that time. Then, after I watched a TV program about children with hearing impairment, I suddenly realised that my daughter indeed had a hearing problem. (Hien, February 2017)

The mothers tried to test the hearing ability of their child before bringing them to a hospital for hearing screening.

I tested his hearing ability when he slept. I talked aloud and banged things, but he did not wake up. When he was awake, I made some noise from low to higher sound levels behind his back. He did not react to the sounds. However, I recognised that he had some reaction to loud sounds. (Mai, February 2017)

## 4.3 Long journey to 'fix' child's hearing

Most of the parents in this research searched for and tried a range of treatment methods for their child's hearing. After they had received the first result of their child's hearing ability, they went to other hospitals to check again once or many other times.

I brought her to the Vietnam National Hospital of Pediatrics. After I had got the results, we went to the Vietnam National Ear Nose Throat Hospital for the other check. The results were the same as the previous check. (Trang, February 2017)

The parents even tried many traditional treatment methods for their child.

I was so sad in the first three years when my child was diagnosed with hearing impairment. Every day I looked for information about rehabilitation centres or healers to fix my child's ears. I hoped he would not be deaf anymore and could speak like other children. I just focused on finding hearing aids and the centres that taught speaking and listening. I just focused on finding the places where they provided acupressure, both eastern and western approaches. After that, I had chances to meet other mothers who shared their experiences with me. I found the better way for my child's future. (Nguyen, February 2017)

## 4.4 Attitude of families and community

Interestingly, the majority of mothers reported that the other members of their family did not hold any negative attitudes to their child with hearing impairment. They even seemed to love this child more than they loved other children in their family. Mai answered the question about whether she recognised any negative attitude from her family towards her son as follows:

There is no adverse attitude towards my child. Because of his impairment, they love him more, even spoil him, and spoil him a lot. When other people know that he is deaf, they really sympathise with me.... On the other hand, they assume that because my child is vulnerable, he will not have any future. I understand they speak like that because of their sympathy with me. They did not have any prejudice to my child. (Mai, February 2017)

Some mothers reflected that they experienced some kinds of adverse attitude towards their deaf child.

... Some people made some rumours such as 'why is he deaf when there was no one else born with deafness in his mother's or father's family. Or the reason comes from his mother'. I have to say that there were many problems I needed to deal with at that time. (Tham, February 2017)

#### 4.5 Psychological impacts

The participants experienced a range of complex psychological impacts when they knew the diagnosis of deafness for their child. Some impacts and emotional responses which were expressed included sadness, embarrassment, guilt, depression, stress, anger, worry,

disappointment and shock. Among these effects, sadness was reported as the most common psychological impact affecting all the participants. For example, Thao revealed her difficult time when she and her family received the result of their son's hearing ability test as follows:

It is difficult to describe what I felt at that time. I was so sad. I could not believe what the doctor said about the deafness of my son. I was deeply disappointed about the ear check results. I said 'it is ridiculous'. I cried, cried a lot when I thought about my son. I completely collapsed. At that time, my husband and I often cried when we looked at our son.

The complex psychological impacts somehow shaped the way they nurtured their child. In the past, when I had to tell other people that my child wore hearing aids, I felt embarrassed. .... I felt guilty as well as ashamed for having such a baby. When everyone asked about him, I did not want to talk about his deafness. (Huong, February 2017) ....some people asked me 'how old is she?'. I said 'she is three now'. They asked 'why does she not say anything?'. I just answered 'her speaking is just delayed a bit'. I did not dare say the truth. Therefore, I did not often bring her to travel around with me. (Trang, February 2017)

The parents took several years to 'accept' and change their perception about the child's deafness. Currently, most of the participants seem to have overcome the psychological challenges. They became more open-minded about their child's situation by sharing their child's stories with other people. Furthermore, they tried to give their child more opportunities to have social interaction with others.

# **4.6** Factors affecting parents in supporting their children to access education *Attitude of other family members*

In general, the majority of the participants' family members disagreed, at the time they proposed them, with their decisions about schools or education programs for their child which are far from their home.

Other people in my family did not agree with me about the school which I chose for my son at the beginning. The reason is that they were afraid it was too early for Hoang to live independently. They advised me that I should not let him study at that school now. (Tham, February 2017)

Based on stories of the participants, it can be seen that the reason for their families' disagreement did not come from prejudice towards education for the Deaf. Their worries were mostly about the ability of the child to adapt to a new environment, financial situation of the family, the quality of the school and the long distance from their home to school. However, two participants revealed that their husbands and other family members expressed doubts about education for the Deaf and their child's future.

My family said 'I think he cannot do anything now. You know he is deaf. Let him be like this. We should save and earn more money. Then, we will give him all when he grows up. I think this is a better way'. I used to think about my family's words many times. However, I ultimately decided that my son should go to school whatever happens. Then I found more school information online. (Thao, February 2017)

This perception about the child's education might originate from the lack of information and knowledge about education for the Deaf. One of the participants reported that she was the only person in her family to participate in events or conferences relating to the Deaf.

## Shortage of finance

Most of the participants experienced some financial burden. The accumulation of not only school fees but also other expenses such as the fees for transportation and hearing aids sometimes exceeded the financial capacity of the families.

... to be honest, we are struggling with the school expenses for my son. We can afford some months or one year. However, I think it may be difficult for us to send him to school for further study. (Tham, February 2017)

The majority of parents expressed a desire for their child to receive a cochlear implant. However, they could not afford it because it is too expensive to have cochlear implants in Vietnam, especially when they were not able to receive any funding support from the government.

There is a financial support program for customers who want to get a cochlear implant. They can pay a certain amount of money in each period until they can pay all the fee. However, parents still need to have VND300 million (equivalent to about AUD18,000). That amount of money exceeds our capacity. Based on my family's annual income, we do not have that amount of money. I am working as a hairdresser and my husband is working as Xe om (a kind of transportation service similar to taxis, but drivers use a motorbike instead of a car). How can we afford the expense for a cochlear implant? (Thanh, February 2017)

In some families involved in this research, the fathers of the children were mainly in charge of earning money. Some mothers had to stay at home or work part-time in order to have time to take care of the child. As a result, their income was reduced and was not enough for the better educations options for their child.

The financial situation is one of the factors affecting the choice of school type. Some participants reported that they felt it was difficult to afford the education fee at private schools. Therefore, they chose public schools or even learning centres which had a cheaper fee for their child.

...When I choose a school for my child, I wanted to choose a good one. Public school is really good. Teachers take care of my child carefully... The quality of private schools is better than public schools such as a higher quality of teacher. However, the school fee is really expensive. I want to send my son to this kind of school but I cannot afford it. (Thanh, February 2017)

Some other families felt lucky because they were supported for a part of the tuition fee from schools which were under the management of the government. As a result, they did not need to worry as much about school fees.

When my child studied at the Vietnamese – Korean Centre, he received some financial support from the government. (Huong, February 2017)

## **Communication**

The majority of participants preferred to use auditory-oral method rather than sign language after their child was diagnosed with hearing impairment.

When he was 6 years old, he started wearing hearing aids. At that time, I hoped that he could speak as other children. Therefore, I brought him to several speech and language rehabilitation centres to get early intervention. (Tham, February 2017)

Currently, most of the participants in this research oriented their child to learn sign language or followed learning programs which were taught by sign language. To be honest, my son has profound hearing impairment. He cannot hear sound. Therefore, my family lets him learn sign language. We wish that sign language would optimise his development. (Nguyen, February 2017)

Some mothers decided to orient their child to study using a total communication approach (both auditory – oral method and sign language). It means that those participants wanted to develop their child's speech by lip-reading, residual hearing and sign language.

We speak to him and also use sign language. Now, he can be lip-reading and understand what I say to him. (Nguyen, February 2017)

One of the participants wanted her child to follow the auditory – oral communication method.

My daughter is currently learning to speak. She is using hearing aids to hear sounds and speak at school. Honestly, I do not want to try any other communication methods for her at moment. I expect that she can hear sounds. (Trang, February 2017)

Trang also revealed how her family could communicate with her daughter at home. *I still speak to her. If she does not understand, I will sign. However, I do not learn sign language. I have not let her study sign language.* (Trang, February 2017)

Although each family had their own communication method for their children, communication breakdown between a child who is deaf or hard of hearing with other family members sometimes seems inevitable.

My husband does not have much time to learn sign language because he has to go to work. I attend most of the lessons. My husband and my son do not often communicate with each other. For me, I can almost understand what Huy wants to say.... If my husband and Huy want to talk about something with each other, I will become a translator. My husband does not get his points. (Huong, February 2017)

The second reason that leads to communication difficulties was that the children of participants in this research were still very young. Therefore, their sign language vocabulary was not yet advanced enough to communicate effectively with their parents.

Now he is just 6 years old. He is studying at Nhan Chinh school. Teachers still teach him speaking instead of sign language. He creates sign language by himself to communicate with others. ... As a result, we still find it difficult to communicate with each other. I do not completely understand him. (Nguyen, February 2017)

They also tried to communicate by guessing what their child wanted to do before the child made a request or indicated their wishes. Communication between the parents and child was minimal and rarely happened. The researcher asked how they could communicate with their child before they learned sign language.

We rarely had conversations with each other. The normal communication method between us: he screamed out, I talked out loud and guessed his thoughts through his behaviour and gestures.... (Mai, February 2017)

Many parents bought hearing aids for their child with the hope to increase the quality of communication. They used normal conversation with their child by talking but not signing.

When he was 5, we bought him hearing aids. We hoped that he could learn how to speak as others' children did. We brought him to several rehabilitation centres. However, the results were not as we expected.... He is studying Grade 1 now. I taught him most of the lessons in grade 1 before he went to school. He is going to enter Grade 2. Based on his language and

*communication ability, I am afraid that it might be difficult for him to follow Grade 2.* (Tham, February 2017)

#### Perspectives of the participants on learning sign language

Regarding options to improve communication ability for children who were diagnosed as deaf or hard of hearing, all of the participants revealed that they were not provided with any information about sign language at the time of diagnosis.

At that time, the doctors said that the best way to help my daughter communicate with others is to wear hearing aids. (Hien, February 2017)

Some participants later realised the potential role of sign language in their child's development. Although this family tried to direct their child to developing the auditory - oral method, they noticed that their child could not follow learning programs in higher classes at school because they did not hear clearly what the teachers said.

... He can understand simple words such as grandmother and grandfather. When we have meals, I teach him many times to say 'let's have a meal'. Then he can say it. However, listeners need to focus serious attention on what he says in order to understand his spoken words.... I taught him all lessons in Grade 1. He could complete Grade 1. Now he is studying Grade 2. I feel that it is difficult for him to follow lessons when his speech and language are restricted. Therefore, we made a decision that he should learn sign language. (Tham, February 2017)

#### Lack of information

The mothers experienced some difficulties relating to seeking school information for their child. Inadequate information was provided, leading to dissatisfaction for the parents.

When I looked for school information, I just could see and hear basic information or positive sides. I could not find answers for some of my questions. I doubted the reliability of information. (Tham, February 2017)

If parents do not have a smart phone or computer, it may be more difficult for them to access information relating to hearing impairment.

To be honest, I did not know much information about deafness because I did not have a smart phone. I felt my life was so difficult. Then, I tried to buy one to access the internet for finding information. (Trang, February 2017)

Complex psychological aspects of some participants' responses at the time of diagnosis prevented them from sharing stories about their child with other people. As a result, this created more difficulties for them to approach schools for information for their child.

When I started searching for information, I felt it was so difficult because I did not ask my friends. I tried to find information by myself. (Nguyen, February 2017)

Websites of schools did not provide much information about special education in general and education programs specifically for children with hearing impairment (mainstream school).

When I visited the website of the school, the site provided only basic information. It just had some introductory sentences about a mainstream class organised in that school. It did not provide information that there were students with many types of disabilities studying with other peers without disabilities learning in the same class. I thought that children with disabilities were organised in a separate class because they had special needs. Then, when I visited the school I knew that every student with different types of disabilities and without disabilities studied in the same class. (Nguyen, February 2017)

#### Education system for the Deaf

The participants reported that although they wanted to orient their child to learn sign language and followed learning programs that were taught by sign language, the current education system in Vietnam did not let them do that. The reason is that sign language is not taught before grade 4.

I have not heard from school but I know that the children who are studying at Nhan Chinh School learn auditory – oral method learning program before grade 4. Then, they will start education programs which are taught by sign language from grade 4. Both preschool and grade 1 have two – year learning programs instead of one year as usual. (Nguyen, February 2017)

Therefore, there are several solutions chosen by the parents to deal with this problem. First, the mothers learned sign language and taught their child and other members in the family. *There is only me to learn sign language. I am the teacher of every member in my family. I learn signing, and then I teach Hoang. His father is too busy with his job.* (Tham, February 2017)

Secondly, parents of children who are deaf or hard of hearing established and organised a class by themselves, which taught sign language and education programs through sign language. Deaf teachers were hired to teach deaf children in this class. According to Trang, there are two main reasons that led to the establishment of this class. Initially it was found that no class which taught sign language by deaf teachers from Grade 1 had been organised in Vietnam. Parents then recognised the important roles of sign language in deaf education and communication.

I see sign language is a great communication method for deaf children. The Deaf learn sign language as others learn how to talk. This is an instinct and very natural characteristic... As

I know there is no class like that in Hanoi...in Vietnam. Now, many deaf children are being taught how to read lips. I think this method reflects a common concept which considers the Deaf as slow learners. However, the problems relating to deaf education do not originate from their learning ability, but from the teaching method. When they are taught by sign language, they can learn as effectively as others students. (Mai, February 2017)

## Attitude of school administrators

Interestingly, most of the participants reported that school administrators in special schools, mainstream schools and regular public schools were very helpful and willing to receive children who are deaf or hard of hearing. The teachers also treated those children well and took care of them at school.

However, one of the participants revealed that the school's administrator held a negative attitude towards her daughter when she came to school to discuss her child's enrollment.

I want to cry when I think about that moment. Initially, the principal did not let my daughter enroll in school. She had never seen my daughter. She might think that it was difficult to take care of my daughter because of her hearing impairment and low vision. She said 'No, your daughter should learn in a special school. (Hanh, February 2017)

#### Lack of local schools and qualified teachers

A common issue relating to deaf education which is mentioned by all participants in this research is the shortage of local schools therefore it was difficult to find an appropriate school near their home. Consequently, they had to bring their child to schools in the big city or central areas which were approximately 30 kilometers from their house. Their main transport means were buses or motobikes. It took a longer time with these kinds of vehicles to get to school. Furthermore, most of these schools did not provide accommodation for the children, therefore

parents also had to pick their child up after school, with much accumulated time of parents and other members in the family being used in providing transport.

The distance from my house to school is about 20 to 30 kilometres. .... It takes us four hours on the bus. If we drive a motorbike, it takes us about 2 hours. (Trang, February 2017)

However, there were a few good schools for the deaf in Hanoi, the capital of Vietnam. *I also tried to find school information for my son. However, there are not many schools for the deaf children in Hanoi. There is only a public school named Xa Dan. There is another private school named Nhan Chinh. In my experience, these two schools are the best in Hanoi and near my living place. ... There are schools for the deaf children but they are located far from my house, in suburban areas. Furthermore, their quality is not as good as Xa Dan. Therefore, I did not find more information about other schools.* (Mai, February 2017)

Although there were special schools in local areas, their quality was not good enough to meet the parents' expectations for their children's education.

There is a special school for children with disabilities in each district. However, this kind of school gathers not only children who are deaf or hard of hearing but with all types of disabilities. Therefore, I do not want to let my child study there. (Trang, February 2017) .... there are also children with autism and hyperactivity. I think the educational environment here is quite good. However, they do not provide services focusing on deaf children. (Nguyen, February 2017)

As reported by some participants, there was no school for deaf children near the area in which they lived. This meant parents needed to send their child to regular public schools, however, these schools did not provide accessible services and learning programs for deaf children. This meant that deaf children had to study with other peers without any technical

support such as teachers who knew sign language or sign language interpreters. These children just went to class and could not hear anything.

Because we live far from special schools, I just let my daughter enroll in a normal public school (Hanh, February 2017)

Tu Nhien School is a public school for children without disabilities... When I came to ask school principals for my child's enrollment, they were willing to receive my son. However, they also said that the school did not have teachers who were experienced to work with children who are deaf or hard of hearing. (Tham, February 2017)

At preschool, she cannot make many friends because of language barriers. If other friends talk with long sentences, she cannot understand. She often plays alone or with teachers. She does not often play with her classmates. (Thao, February 2017)

Some participants emphasised the roles of teachers who are deaf with deaf education. They realised that their children experienced some positive changes when they are taught by a deaf teacher. The researcher asked them whether they saw any improvement when their child was taught by learning programs using sign language.

I saw a lot of improvement. Plenty. The first time when I sent him to that class, I was afraid that he could not integrate into the class environment ... However, it surprised me when he could adjust to the new environment quickly.

... When he comes back home from school, he often uses sign language to communicate with me. He seems to be more open-minded. (Mai, February 2017)

Those children understand quickly. They see deaf teachers as super heroes. They love their teacher very much. Other members in my family and I also like my child's teacher. We also

*joined a sign language class for parents. We can see that the teacher is really helpful.* (Nguyen, February 2017)

However, there was a lack of qualified teachers who know sign language and had experience working with children who are deaf or hard of hearing.

... Currently, children with hearing impairment are taught by the oral method instead of sign language. Sign language of teachers at Nhan Chinh is not as good as deaf teachers. They may have good sign language vocabulary, however, their grammar probably needs to be improved. (Thao, February 2017)

#### 4.7 Support

#### Family support

Most of the mothers said that they received some kind of support from their extended family. For example, their parents often helped them take and pick up their children to and from school. Nguyen replied to the question about whether she received any support from the other members in her family to support her son to access education as follows:

The most active support comes from the parents of my husband. They always encourage us to overcome life difficulties. ... Because I was busy, I did not go to the school to ask the school administrators for my sons' enrollment. At that time, my husband's parents helped us discuss with the school principal about my son's situation. ... My husband's father is running his own business. He brings my son to school. Then, he comes back home to open his shop after that. ... In addition, he also helped us participate in a parents' meeting that was organised by my son's teacher. (Nguyen, February 2017)

It is an interesting finding that the participants did not usually receive any support from their extended family to find information. To be honest, no one helps me to find school information for children with hearing impairment. I did it myself. (Huong, February 2017)

Most participants, however, had financial independence therefore the majority of them did not rely on financial support from their extended family.

#### Social network

Most of the participants found information about schools on sites on the internet or through groups of parents of children with hearing impairment or the deaf community. They did not often meet other families to exchange information. The reason is that seeking information via a social network on the internet probably saved their time and money for travelling, and gave them more information. One of the participants, Trang, answered as follows when she was asked whether she participated in meetings for parents of children who are deaf or hard of hearing:

I often search for information and consult other parents via sites on the internet. It is difficult for parents to have a meeting together because everyone is so busy. (Trang, February 2017)

A few of the mothers found school information through participating actively in conferences and meetings relating to deaf education (Mai, Tham, Thao).

... I found information by asking people who I met in centres, and hospitals. When they told me some information, I wrote it down to remember. I also asked teachers for information that I needed or attended a conference of Duong Phuong Hanh (a deaf facilitator). ... I also joined the Vietnam Deaf Association or IDEO and consult other members on a forum for my child's school. (Tham, February 2017)

Some other participants found valuable information about deaf education through their networks of friends including people without disabilities and people who are deaf or hard of hearing. Mai described how she came to know information about sign language.

...I have a friend working with children with autism. She introduced me to another teacher working at the National Education College. This teacher is teaching children with hearing impairment. When I, and my husband, met her, she asked whether we knew a communication method for deaf children named sign language. That is the first time I heard about that. (Mai, February 2017)

## Employers

The participants also stated that they received great support from their employer and colleagues. Therefore, they had more spare time to bring their child to school or hospital for a health check.

... The school board and my colleagues permit me go to school late or take a day off when I have to bring my kid to hospital for health checks. Thanks to everyone's help at my workplace, I can bring my son to school every morning. If I worked at another school, I would neither have a job nor help my child access school. If I did not have the chance to bring my son to school, he would not be better. (Tham, February 2017)

#### Intergenerational Deaf Education Outreach project (IDEO) and its impact

Intergenerational Deaf Education Outreach (IDEO) is a project implemented from 2012 to 2015 aimed at improving communicative ability between deaf children and their families, building and training sign language interpreters, and developing professional human resource for the Deaf. This project was funded by the Japanese government, implemented with the cooperation of World Concern Vietnam and the Ministry of Education and Training. There were four provinces participating in this project including Hanoi, Thai Nguyen, Quang Binh and Ho Chi Minh city. One of the components of this project was to teach sign language to the deaf children and their families. 150 beneficiaries including Deaf children and their family members,

were supported through the project funding. Some of the participants in this research were beneficiaries from the project.

IDEO created a great place for the parents to share experiences not only about how to care and nurture those children but also school information. Huong told the researcher about how she could find information about the school at which her child was studying.

*I knew it through the IDEO project. Other parents of children who are deaf or hard of hearing recommended that project.* (Huong, February 2017)

The evaluation of parents who participated in this project was that IDEO was successful in introducing and training about a communication method, sign language, to them as well as their children. Mai and Nguyen answered as follows when the researcher asked where they learned sign language.

First, I and my husband learned sign language from a class which was organised by IDEO. Then, when the project finished, we and other parents hired Deaf teachers and organised a new class. Now, we are still joining that class. (Mai, February 2017)

*I love the IDEO project because it is really practical and helpful for my child.* (Nguyen, February 2017)

In addition, the parents commented positively that IDEO supported teachers at special schools to enhance their teaching skills:

... Apart from my son, teachers at his school also joined in the project. They strengthened their skills and knowledge in teaching Deaf. (Tham, February 2017)

Because of the effect of this training model, the parents tried to arrange their time to participate actively in the class, even if their house was far from the venue where the classes were organised. Most of the parents living in my area still work and do not seem to take care about studying things to help with rehabilitation for their children. They are too busy, and the project center is too far from our house. Therefore, most of them do not join the classes. For me, once I knew about the project, I was not absent from any class. (Huong, February 2017) It is about 40 - 50 km from my house to the centre (the place where the sign language classes were organised), though I tried to go to the class every week. The government and IDEO provide that great opportunity to us, so there is no reason we should not join the classes. (Hanh, February 2017)

Some mothers regretted not knowing about the project sooner. Huong repeated 6 times 'I felt regretful' when she was asked about her late participation in the IDEO project. Hanh also felt regretful when she found out about the project in its last two months.

My daughter also learns at the classes of IDEO. I found the project too late. I felt regretful. I knew when the class had only two months left. The Deaf teachers taught my daughter at my house. Then, I had to go to the project centre for two months. (Hanh, February 2017)

## 4.8 Mothers' traits and their determination

Neither fathers nor other members in the family other than mothers made important decisions relating to education for their children. Although they had to face many difficulties and disagreement from other family members about their child's schooling, the mothers were always determined that their children should have the same right to participate in schools as other children without disabilities.

... My husband did not agree with me to change my kid's school to Truc Son. He told me that this school is too far and we do not know about the quality of the school. My mother had the same opinion as my husband. However, I understand that Truc Son has a better education environment for the Deaf. I knew this because I have more chances to participate in the classes for parents who have the same situation than my husband does. Because I knew this school is better, then I made a decision to move my kid to that school. When my kid has studied in the new school for only a month, he knows how to write alphabets now. If he still learned at Viet Han (his previous special school), he would not know how to write. They did not teach him to write. (Huong, February 2017)

When I discussed with my family letting my son attend school, my family refused my proposal. They told me that I should let him stay at home until he is more mature. However, I still persuaded my family. I said 'Everyone grows up and becomes more mature because of nurturing environments. We should not protect him too much'. (Tham, February 2017)

The mothers also became active advocates to persuade school administrators to allow their children to enroll in school. The researcher asked Hanh about difficulties which she had to deal with when she asked the school administrator to let her child to study there. She replied that

...When I met the school principal, she did not permit my daughter to study at that school because of her disability. She did not know how my daughter is. She just presumed that it is difficult for a girl who has low vision and hearing impairment to study there. 'She said ...no. Your child should study in a special school that is designed for her'. I felt angry and sad. I cried. ...Then I said, according to the Vietnamese Law on disability, my daughter has a right to study in mainstream schools. When I talked about the law, she must know about it because she is a principal... After that, she said she agreed. (Hanh, February 2017)

Some mothers tried to give their child opportunities to meet the Deaf community and learn sign language very early.

My family let my daughter participate in the IDEO project from one-year old. She had chances to meet the older Deaf people. We recognised that these Deaf adults could use sign language very well. I thought if I orient my daughter to learn sign language like these Deaf people, it would be a better option for the future of my child. Therefore, I registered for her to learn two classes. The first class was to support her to use hearing aids. The second one is sign language which helped her communicate by sign language early. Now she communicates with others by both speaking and signing. (Hien, February 2017)

The parents also participated in sign language classes that were organised for them. Most of these classes were far from their homes, but they tried to attend. The researcher asked Nguyen whether she learned sign language.

Yes, I did. I learned a lot. I used to learn sign language directly from the IDEO project. They taught me at home. ... I also participated in programs for parents of deaf children. However, I was not able to attend all the sessions. I joined in these activities whenever I had spare time. (Nguyen, February 2017)

To gain access to better education for their child, some mothers decided to leave their current job and find another job which was located nearer the preferred school.

... A teacher whose house is near the place I live taught my daughter, however I felt that my child did not have much positive change. ... She could not say any words. ... I left my work, and then brought her to Hanoi to study. I found a new job there. (Trang, February 2017)

In most families, the mother was the first person or even the only person to learn sign language to communicate with the child and to participate in events regarding the Deaf and Deaf education. When asked about whether other members in the family learn sign language, Hien answered that

*There is only me to join in sign language classes. Then, I teach other members in my family.* (Hien, February 2017)

Trang also states that

...Generally, I am in charge of all tasks relating to my daughter's education. I bring her to school and pick her up. I instruct her to do homework. I also find information about learning methods for the Deaf and consult other mothers about deaf education. (Trang, February 2017)

**4.9 Education expectations** 

A third of the parents expressed their desire for a good local school for the Deaf that was located in their residential area. For example, Tham said that

*My expectation is that each commune or district should have a centre for children with disabilities in general and deaf children in particular.* 

Half of the participants were concerned about the quality of teaching as well as the shortage of human resources in deaf education. They expected that teachers not only in special schools but also mainstream schools would focus time and attention on children who are deaf or hard or hearing (Thanh, Trang).

Honestly, I wish those children who are deaf or hard of hearing would have equal opportunities to learn at schools as other children without disabilities. The most important thing at school is that teachers need to cherish those children. They should be more warmhearted and patient with those children than others. (Thanh, February 2017) In addition, the participants emphasised that it is necessary to train more qualified teachers for special schools and mainstream schools to teach deaf children, especially teachers who are deaf (Tham, Hien, and Thao).

If I had power, I would focus on increasing the quality and quantity of human resources working in deaf education, then, this trained group would train those with disabilities and Deafness. (Hien, February 2017)

The participants expected that schools which received students with hearing impairment would arrange classes based on the cognitive and hearing ability of each student.

... Schools need to classify classes for students with hearing impairment based on their hearing ability or whether they have additional disabilities. If a child is deaf and does not have cognitive impairment, he or she should be given a chance to study the same curriculum and exact school terms as others without disabilities. It means that students who are deaf without additional disabilities learn in different classes from students who are deaf and with multiple disabilities. (Vy, February 2017)

One of the participants emphasised that the information system relating to hearing impairment should be changed. The reason is that most of the families were not given adequate advice about opportunities and challenges that they may encounter in terms of education, communication methods and hearing aids for their child.

Firstly, I want to change the ways that information relating to hearing impairment is delivered to parents and how parents are given advice in relation to their child's hearing issues. I think the vulnerability of those children does not originate from their hearing ability, but comes from the lack of information and wrong decisions. This leads to adverse consequences affecting the entire life of those children. The reason is that when their child is deaf, they do not have the opportunity to access adequate information, are not counselled about existing chances and challenges regarding support programs. Provided information is often distorted or affected by powerful bodies. (Mai, February 2017)

The parents also wanted to receive financial support from schools and the government.

When deaf children study at mainstream schools, they should still receive a subsidy from the government as other people with disabilities have. ... Learning in centres seems better, but education fees are more expensive. As a result, poor families cannot let their children study there. (Tham, February 2017)

Sign language should be taught from preschool. Furthermore, local special schools should organise sign language classes for parents of children with hearing impairment.

I talked to the school principal of my son and said that 'I wish your school was able to run a sign language class for parents who are living in the local area...First of all, I just have a little dream that there is that kind of class at the school where my son is learning now. (Huong, February 2017)

*I hope that deaf children and my son are trained in sign language from pre-school.* (Nguyen, February 2017)

#### **4.10 Hope for the future**

Opportunities for deaf children to study in higher education were also a concern of the participants.

... I have a strong desire for my child's future and the Deaf in general, which currently is stuck somewhere. That desire is the opportunity for them to get a higher education and live independently. Currently, it is rare to see this kind of opportunity for deaf children, and deaf adults in Vietnam. Currently, in the educational environment it is very tough for them to get a better education. (Mai, February 2017)

Nguyen raised an interesting issue about communication and its relationship to inclusion when she stated that she wanted her child to develop in an educational and work environment with only Deaf people. She said that

After my child finishes the school and the course in a vocational learning centre, I hope that there is a specific workplace for only those with hearing impairment. (Nguyen, February 2017)

#### 4.11 Summary

This chapter presented an analysis of the findings from data collected through interviews with the parents of children who are deaf or hard of hearing. The themes which emerged to answer the research questions included diagnosis of hearing impairment, long journey to 'fix' child's hearing, attitude of families and community to the child's diagnosis, psychological impacts, factors affecting and facilitating parents in supporting their children to access education, education expectations, and hope for the future.

Chapter Five will concentrate on discussion of the research results. It will compare and contrast these research findings with previous studies. Chapter Five also presents limitations of the current study and recommendations for future research.

#### **Chapter Five**

#### Discussion

#### **5.1 Introduction**

The purpose of this research was to investigate the experiences of parents of children who are deaf and hard of hearing in supporting their children to access education. This research explored and described parents' reports of factors affecting them in supporting their children's access to school and overcoming challenges, and their expectations for their child's future education. Outcomes of this preliminary investigation include responses from 10 participants which were analysed and reported in Chapter 4, and which it is hoped may inform other parents' experiences in the future. The findings may also provide initial information to assist the government in further developing and implementing effective laws and policies regarding educational services for this population. This chapter will summarise and discuss the findings, outline limitations of the research, and make recommendations for future research.

#### 5.2 Factors affecting parents in supporting their children to access education

Based on the shared views of parents in the study, this research identified nine frequent factors that affected the participants in making decisions relating to education for their children who are deaf or hard of hearing. These factors include attitude of family members, shortage of finance, communication method, perspectives of the mothers on learning sign language, lack of information, current education system for the Deaf, attitude of school administrators, and lack of local schools and qualified teachers. These nine factors are considered and divided into different areas based on Ecological Systems Theory (Figure 1). Ecological Systems Theory was developed by Bronfenbrenner (1985, cited in Spencer, 2006a) and used to examine phenomena in the disability field such as mainstream school entry (Llewellyn & Hogan, 2000), or

maltreament of children with developmental disabilities (Algood, Hong, Gourdine, & Williams, 2011). Bronfenbrenner (1977) introduced the ecological environment with four components: a microsystem (a direct setting containing the person), mesosystem (the link between the settings of the person's microsystem), exosystem (factors affecting the person indirectly), and macrosystem (larger social principles).

The conceptual combination of phenomenology with ecological systems perspectives helps to explain clearly 'the phenomenological quality of individual-context interactions' (Spencer, 2006b, p. 698). This combination was developed by Spencer (1995, as cited in Spencer, Fegley, & Harpalani, 2003), and is known as the phenomenological variant of ecological systems theory (PVEST). PVEST provides further understanding about phenomena through examining two directions: social experience-based cognitions and individual-context interactions (Spencer, 2006b).

This theory helps practitioners 'explain and describe situations' of their clients (Rothery, Lehmann, & Coady, 2001, p. 66). The system was built on a basis of the belief that individuals were affected by their surrounding environment (Spencer, 2006a). The conceptual combination of phenomenology with ecological systems helps to explain and describe clearly individual-context interactions (Spencer, 2006a). Based on the participants' reports, the Ecological Systems Theory, and phenomenological approach, the research will be arranged and analysed with the nine factors situated within four systems: Individual, Microsystem, Exosystem and Macrosystem (Bronfenbrenner, 1977).

#### Macrosvstem

Vietnamese education system for the Deaf

#### Exosystem

• The participants' husbands knowledge about deaf education The participants' husbands' employment

# Microsystem

- Family members
- Information resources
- Local schools
- Administrators & Teachers

# Individual

- Perspectives on
- communication approaches
- *Finance*
- Psychological impacts

Figure 5.1: The Parents' Ecological System

In terms of Individual factors, parents spoke during the interview process of varying beliefs and perceptions about their children's communication methods. Originally, all of the parents in this study chose listening and spoken language as their communication option with their child. The reason is that they would like their child to function well in hearing society. Later, the majority of the participants have shifted from this communication method to sign language. One of the reasons for this change was that the parents recognised the low possibility of recovering or developing their child's hearing and speaking skills. Furthermore, the available information about another communication method, sign language, which is often provided by other parents, helped the parents have more choices. They also found out through social networks and conferences on hearing impairment education the benefits of sign language in helping their child develop language and communication skills.

The result is supported by similar findings in previous studies. Specifically, this finding is consistent with the research of Wesley (2011). The parents in Wesley's research revealed that they oriented their child to study sign language when their child could not improve their spoken language after many efforts. The perspectives of the parents in this research on three common communication methods: auditory-oral method, sign language or mixed method was one of the factors which influenced their child to develop the auditory-oral method usually registered their child to study in mainstream schools. Meanwhile, the families who recognised sign language as a language of the Deaf often chose study in special schools or mainstream schools which organised sign language classes for students, and taught popular educational programs based on sign language.

Financial difficulties also affected educational decisions of the parents (Hintermair, 2006; Kobel, 2009b). The financial burdens could come from school fees. Many private schools had more expensive educational fees than other types of schools. The expensive fees of private schools prevented some of the parents from achieving their educational expectations for their child (Kobel, 2009b). Transportation expenses, which the parents had to meet to enable their child to get to school and be picked up, were considered as a factor causing the increase of these families' financial difficulties. Furthermore, most of the families in this research reported that they found it very difficult to afford expenses regarding hearing aids and cochlear implants for their child. Interestingly, the majority of the participants stated that they received almost no

financial support from their extended family for expenses relating to their child's educational fees, but were otherwise financially independent. The participants' husband was the main person in the family to be responsible for the remaining financial resources of the whole family.

The parents in the current research experienced a range of complex psychological impacts, including sadness, embarrassment, guilt, depression, stress, anger, worry, disappointment and shock. These impacts were reported widely by other parents of children who are deaf or hard of hearing in other countries throughout the world (Bosteels et al., 2012; Eleweke et al., 2013; Hintermair, 2006; Kurtzer-White & Luterman, 2003; Meinzen-Derr et al., 2008; Pipp-Siegel et al., 2002; Thakre et al., 2012; Wathum-Ocama & Rose, 2002; Wesley, 2011). While most of the above research listed broad psychological impacts for those parents, the current research found that sadness was the most common emotional response reported by the parents. These negative psychological effects did not reduce in one month or even one year, but often continued for years. During the early stages of the child's life, the parents' sensitivity toward their child's hearing problem significantly affected their openness to share stories with others. Therefore, some parents did not let their child participate in social activities as they did with their other child or children. However, this attitude and behaviour of the parents changed after they adjusted to their child's disability and had more chances to meet other families who had similar situations. Currently, they are more open-minded when asked about their child's hearing problem.

In terms of factors relating to the microsystem, many of the participants' family members had negative attitudes towards their child's education. Interestingly, the negative attitude of the family members which was reported by most of the mothers in this research did not come from their adverse attitude towards their child's deafness. It originated instead from their worries with

the child's ability to adapt within a school environment and the inadequate quality of educational programs at schools for children with hearing impairment.

The research findings also show that all mothers experienced a lack of access to educational information resources. It is reported that their extended family only provided minimal support for seeking information about schools and deaf education. This finding is in line with previous studies (Jackson, 2011; Kobel, 2009b; Wolfe, 2001). This issue was reported to originate from two main reasons: the psychological impact experienced by the participants, and inadequate educational services which came from the microsystem. It is probable that many parents had not overcome psychological effects and barriers before they started finding information about education for their child. Therefore, they were reluctant to talk openly with other people about their child's educational issues in order to seek more information. Jamieson, Zaidman-Zait, and Poon (2011) revealed that about a quarter of the parents in their research reported that they were in need of emotional support from a counsellor or their extended family to deal with stress associated with effects of their child's hearing impairment.

Information relating to services for people with hearing impairment, especially education is not provided sufficiently. It has previously been found that information about educational options for parents of children with hearing impairment has not been adequately provided by service providers (Wolfe, 2001). In the current context, with increased options available, the inadequacy of advertising on websites and in mass media about available educational programs and schools for deaf and hard of hearing children caused many difficulties with access to information for the parents. Although some schools notified the parents that they provided classes for students who are deaf or hard of hearing, the information provided was sketchy, and they probably did not pay much attention to circulating detailed information about these classes.

As a result, reflecting what Kobel (2009b) states in his research, the parents did not find many reliable information resources, except information about available hearing tests and purchase of hearing aids. The parents in the research of Jamieson et al. (2011) expressed the need for clear information about intervention programs and services for their child. Findings from the current study suggest that counselling and disability support centres in Vietnam should pay more attention to networking with parents of children with disabilities in general and children with hearing problems in particular.

Educational system deficits seem to commonly impact the experience of children with hearing problems. In this study, a lack of quantity and quality of local schools and educational programs for children with hearing impairment was reported by most of the parents. One of the mothers in this research decided to cease her child's learning programs at one of the mainstream schools because she was not satisfied with the program provided. Another participant could not find a school with learning programs for the Deaf in her residential area. Therefore, she registered her child to study at a school which was far from their family's house. This research finding is in line with previous studies (Hintermair, 2006; Kobel, 2009b; Lytle, Johnson, & Hui, 2005; Reed et al., 2008). Hintermair (2006) revealed that some parents in his research had to travel 2.5 hours to have access to adequate services for their child. Furthermore, it was more difficult for families who are living in rural areas to access intervention programs and education (Lytle et al., 2005). Many parents had to move to live in other regions to help their child gain more suitable educational access (Reed et al., 2008).

Both positive and negative attitudes of school administrators toward education for the Deaf were reported by the participants. The negative attitude of the staff might come from the lack of knowledge of the disability field in general and hearing impairment in particular. In this

case, the parents became advocates for their child and persuaded the school administrators to accept their child to study at the school. This research finding is consistent with the research results of Izzo (1999). Izzo (1999) emphasised that this lack of knowledge might lead to inadequate services and insufficient placements in the education system for children with hearing impairment.

A lack of quantity and quality of teachers who had experiences in special education and in working with children who are deaf or hard of hearing were revealed in the research findings. This result is consistent with the research of Lytle et al. (2005) and Wolfe (2001). The shortage of teachers might originate from educational policies and systems regarding Deaf education (Macrosystem). The parents in this research also emphasised the important role of Deaf teachers in their child's education. These parents recognised that their child's language and the ability to adapt to and within the environment would be better if they were taught by a Deaf teacher.

The factors affecting the mothers in this current research in supporting their children to access education in the Exosystem were also reported. There are two factors in the Exosystem revealed by the participants in the interviews including their husbands' employment and knowledge about deaf education. The participants reported that their husbands were often busy at work, so they did not have time to learn sign language. Consequently, communication breakdown occurred between the children and their fathers. One of the participants in this research stated that her husband did not want to let their child study at school. This opinion might originate from a lack of knowledge about the Deaf and deaf education. This research implies that there is a need to develop services to provide basic knowledge about the Deaf and deaf education for parents of children with hearing impairment as well as services to learn sign language at a distance for people who cannot participate in sign language classes at school.

Currently, the educational system in Vietnam is preventing children with hearing impairment from learning sign language from early ages. Many parents in this research reported that while they wanted their child to learn sign language from Grade 1, the current learning program not only at mainstream schools but also special schools which followed the learning curriculum of the Ministry of Education and Training did not allow their child to access sign language until Grade 4. This research result recognises the importance of access to and development of language in the first few years of the child's life, within families as well as within schools and communities.

#### **5.3 Facilitators supporting parents to overcome barriers**

The results of this study show that there are five main factors which are considered as facilitators in supporting the parents to deal with their child's educational barriers: family support, social networks, employers, IDEO and the participants' characteristics. After analysing data, it seems that in this context the mothers' characteristics are the most important factor determining their child's access to suitable education. Although the mothers in this research experienced sadness and shock when they knew of their child's hearing impairment and there was disagreement with their husband and family member about their child's education, they became advocates for their child's rights for equal education.

Most of the parents in this research reported that they received some support from other members in their immediate and extended family. The support might include help to take their child to school and pick them up, and participation in parental meetings at school in cases when the child's parents were busy. This is a consistent finding with the research of Nybo, Scherman, and Freeman (1998). Nybo et al. (1998) revealed that the grandparents of children who are deaf

or hard of hearing were willing to provide a range of supports for their child and their grandchildren, or even 'waited to be asked for help or volunteered' (p.266).

Contact with other families of children who are deaf or hard of hearing was the most preferable way for the participants in this research to access information and resources. The participants reported that the information that was shared by other parents via social network websites was very valuable. While they could not find detailed information about schools and educational programs for the Deaf and hard of hearing children directly, other families provided them with information about both advantages and disadvantages of each school. As a result, the parents had a multi-dimensional view about available educational options for their child. Thus, a group of parents participating in a social network online can be evaluated as having positive effects in circulating educational information in a field which had limited details available on formal websites of schools. The results of this research are consistent with findings of other previous studies (Hintermair, 2000; Jackson, 2011). Jackson (2011) revealed in her study that the parents highly appreciated social networking with other parents because they valued personal interaction with people who experienced the same situation as them. Although the social network of parents of children who are deaf or hard of hearing is smaller than that of other parents who do not have a child with hearing impairment, these parents are satisfied with the support that they have received from social networks (Lederberg & Golbach, 2002).

IDEO is an effective new model in deaf education. Some of the parents in this study had a chance to participate in this project which was reported to have brought positive effects for the beneficiaries. This project initially solved some current issues regarding the educational system in Vietnam. First, the project provided deaf teachers instead of teachers who are hearing. It has been recognised among the Deaf that deaf teachers are more competent in delivering grammar,

sentence structure and vocabulary of sign language than hearing teachers (Shantie & Hoffmeister, 2000; Smith, 2013). Secondly, an interpreter (a hearing person) also accompanied deaf teachers to participate in sign language lessons. Therefore, the parents of the child could also learn the same sign language as their child. This means that if the parents are able to use sign language, the possibility of communication breakdown among family members will decrease. Thirdly, the deaf teacher and interpreter taught sign language directly at the child's house. Thus, it solved the issue of a lack of schools and qualified teachers in local areas. Fourthly, a group of interpreters were trained to increase their ability in sign language. This contributed to the increase of human resources for special education schools or programs.

Self-determination of the mothers in this research plays a key role in decisions relating to education for their children at early ages. As with other mothers, the mothers in this study sacrificed their energy, and time for their child. Although these mothers experienced complex psychological impacts after their child was diagnosed with hearing impairment, they were pioneers in learning sign language, contacting professionals in the field and actively finding available service options for their child. They became the interpreter for other family members. The participants in this research sometimes prioritised their child's education beyond other benefits for the family. For example, they left previous jobs and moved to another company closer to their child's school. Furthermore, in some situations, the whole family moved to other regions, often to big cities, so that their child with hearing impairment had more opportunities to study in a good quality school. Izzo (1999) points out in his research that while fathers are often the main person in the family to make the final decisions regarding some family concerns, the mothers are considered as 'leaders' in decision-making processes regarding their child's education. They

fought for their child's right to obtain access to education equal to that of hearing children. These findings are in line with the research results of Wolfe (2001), who revealed that the majority of the mothers counselled other families about needing to be more active in the planning of their children's education, and became advocates for their children's educational issues.

#### 5.4 Parents' expectation for child's education

The majority of the parents expected their child to have better access to education for the deaf. In order to obtain that goal, the participants wanted positive changes in the educational system for the Deaf in Vietnam. These changes may include more qualified teachers, more local schools, financial support and earlier educating with sign language at school for the child.

Although the parents in this research had not set longer term educational goals clearly for their child, they expressed hope that their child would have chances to achieve higher education. This result is in line with the research of Wathum-Ocama and Rose (2002), Kobel (2009a) and Wesley (2011). Long-term goals for their child such as 'successful future', 'a better life' and 'living independently' were revealed by the majority of the parents (Wathum-Ocama & Rose, 2002, p. 47), all of which are influenced by access to effective education.

#### **5.5 Limitations**

This research has several limitations because of cost, time, and geographical issues. Limitations and recommendations to solve the limitations are listed as follows.

- The first limitation is regarding the relatively small number of research participants, as the researcher recruited only ten parents of children who are deaf or hard-of-hearing for interviewing, and all were contacted through the support of the Association of Parents of Children with Hearing Impairment. This is a small percentage of the total number of parents of those children in Vietnam, and may mean that many other valuable stories from both fathers and

mothers in this context have not been included in this research. The experiences of participants in this preliminary study therefore will not necessarily be representative of every parent who has deaf children and children who are hard of hearing in Vietnam.

- The residential areas of the research participants are located in big cities in Vietnam which have more schools for children who are deaf or hard of hearing and better services than other rural or mountainous areas. Therefore, the findings in this research may not reflect the experiences of those parents living in other geographical areas.

- Due to the location of the researcher in Australia during data collection, this research used telephone interview as a research method. As mentioned in the book by Creswell (2012b), in this type of interview, the researcher does not have direct contact with the participants. As a result, this might impact negatively on how the researcher interprets data due to limited communication between the researcher and participants. Using member checking of interview transcripts was one of the critical strategies to reduce this potential impact.

#### **5.6 Recommendations for Future Research**

As mentioned in Chapter 2, studies reporting parents' experiences play an important role in supporting the government to develop and implement more effective laws, policies and regulations relating to education for children who are deaf or hard of hearing. However, the research in this field is still limited in Vietnam and other countries across the world. Further research related to the experiences of parents in supporting access to education for their children who are deaf or hard or hearing should be implemented. Building on this preliminary study through research conducted with parents in other regions in Vietnam is recommended. Recruitment of greater numbers of participants, with support and encouragement for involvement of both fathers and mothers, will enable opportunities to gain further insight into and sharing of

these lived experiences and their potential to influence availability of effective educational options.

#### **5.7 Conclusion**

This chapter discussed the findings based on three research questions: factors affecting parents of children who are deaf or hard of hearing in supporting their children to access education, factors supporting those parents to overcome barriers, and parents' expectations for their child's education. The findings revealed that the participants' experiences were affected mainly by factors which are divided into three ecological systems: Microsystem (including factors relating to the Individual), Exosystem and Macrosystem. Although the factors in these systems significantly affected the participants in supporting their children to access education, their determination as, in this case, mothers play a crucial role in decisions relating to education for children with hearing impairment. The participants in this research expect that their children can obtain future access to higher education. To conclude this Chapter and the dissertation, some limitations of the current research and recommendations for future research to extend the findings of this preliminary study were also discussed.

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# Appendix A: Letter of Introduction



School of Health Sciences Disability & Community Inclusion Sturt South Wing (S271) GPO Box 2100 Adelaide SA 5001 Tel: 08 82012576 Fax: 08 82013646 ruth.crocker@flinders.edu.au http://www.flinders.edu.au/sohs/sites/disability-studies/ CRICOS Provider No. 00114A

#### **LETTER OF INTRODUCTION**

(for parents)

Dear Sir/Madam,

This letter is to introduce Ms Thi My Hanh Nguyen who is studying Master of Disability Policy and Practice in the Faculty of Medicine, Nursing and Health Sciences at Flinders University.

She is undertaking research leading to the production of a thesis on the subject named 'The Experiences of Parents of Children Who Are Deaf or Hard of Hearing in Vietnam: A Preliminary Study Focusing on Access to Education'.

She would like to invite you to assist with this project by agreeing to be involved in an interview which covers certain aspects of this topic. The interview will last in 45 to 60 minutes.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Since she intends to make an audio-recording of the interview, she will seek your consent to record the interview, to use the recording or a transcription in preparing report or other publications, on condition that your name or identity is not revealed. The consent form will be sent to you via your email address. If you do not have an email, you will be asked to give your consent verbally at the beginning of the interview, which will be recorded.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on +61 8 82013423, fax +61 08 8201 3646 or e-mail (ruth.crocker@flinders.edu.au)

Thank you for your attention and assistance. Yours sincerely

Ret Condes

Ruth Crocker Lecturer Disability & Community Inclusion

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 7438). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au Appendix B: Information Sheet



Ms Thi My Hanh Nguyen Faculty of Medicine, Nursing and Health Sciences School of Health Sciences **Disability and Community Inclusion Unit** Sturt South Wing (S271) GPO Box 2100 Adelaide SA 5001 Tel: + 61 8 8201 2576+ 61 8201 3646 Fax: nguy0747@flinders.edu.au http://www.flinders.edu.au/mnhs/ CRICOS Provider No. 00114A

# **INFORMATION SHEET**

(for parents)

# Title: 'The Experiences of Parents of Children Who Are Deaf or Hard of Hearing in Vietnam: A Preliminary Study Focusing on Access to Education'

#### **Researchers:**

Ms Thi My Hanh Nguyen Faculty of Medicine, Nursing and Health Sciences Flinders University Ph: +61 8 8201 2576 Email: nguy0747@flinders.edu.au

#### **Supervisors:**

Ms. Ruth Crocker School of Health Sciences Disability & Community Inclusion Flinders University Phone: 08 82013423 Email: ruth.crocker@flinders.edu.au

Dr Paul Jewell School of Health Sciences Disability & Community Inclusion Flinders University Ph: +61 8 8201 2576 Email: paul.jewell@flinders.edu.au

# **Description of the study:**

This study is part of the project entitled '*The Experiences of Parents of Children Who Are Deaf* or Hard of Hearing in Vietnam: A Preliminary Study Focusing on Access to Education'. This project will investigate the experiences of parents of children who are deaf or hard of hearing in supporting their children to access education. This project is supported by Faculty of Medicine, Nursing and Health Sciences, Flinders University

# **Purpose of the study:**

This project aims to explore the experience of parents of children who are deaf or hard of hearing in supporting their children to access education in Vietnam.

## What will I be asked to do?

You are invited to attend a telephone interview with a researcher who will ask you a few questions about your experiences in supporting your children to access education. Participation is entirely voluntary. The interview will take about 45 - 60 minutes. The interview will be recorded using a digital voice recorder to help with looking at the results. Once recorded, the interview will be transcribed (typed-up) and stored as a file in a computer protected by password for five years as required by research ethics at Flinders University.

# What benefit will I gain from being involved in this study?

It is expected that policy makers and administrators in schools will be raised awareness of issues which parents of children who are deaf or hard of hearing have to cope with in supporting their children to access education. The sharing of your experiences will contribute to the improvement of the quality of education for children with hearing impairment in future.

# Will I be identifiable by being involved in this study?

We do not need your name and you will be anonymous. Once the interview has been typed-up and saved as a file, the voice file will then be destroyed. The typed-up file will be stored on a password protected computer that only the researcher will have access to.

# Are there any risks or discomforts if I am involved?

The researcher anticipates no risk from your involvement in this study; however, given the nature of the project some participants could experience emotional discomfort. If any emotional discomfort is experienced, you can contact Flinders University Counselling Service as the following address: .

# Tel: 8201 2118

Email: <u>counselling@flinders.edu.au</u> (please provide your full name, phone number, in the email and a counsellor will contact you by phone)

Appointment-Monday to Friday; 8:45am to 5:00pm

# How do I agree to participate?

Participation is voluntary. You may answer 'no comment' or refuse to answer any questions and you are free to withdraw from the interview at any time without effect or consequences. A consent form accompanies this information sheet. If you agree to participate please read and sign the form and send it back to me via email: nguy0747@flinders.edu.au. If you do not have email, you will be asked to confirm whether you agree to participate at the beginning of the interview, which will be recorded.

# How will I receive feedback?

On project completion outcomes of the project will be given to all participants. Your organisation will be asked to help the researcher circulate the final report.

# Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 7438). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au Appendix C: Consent Form



# CONSENT FORM FOR PARTICIPATION IN RESEARCH (by interview)

The Experiences of Parents of Children Who Are Deaf or Hard of Hearing in Vietnam: A Preliminary Study Focusing on Access to Education

I .....

being over the age of 18 years hereby consent to participate as requested in the Letter of Introduction for the research project named 'The Experiences of Parents of Children Who Are Deaf or Hard of Hearing in Vietnam: A Preliminary Study Focusing on Access to Education'

- 1. I have read the information provided.
- 2. Details of procedures and any risks have been explained to my satisfaction.
- 3. I agree to audio recording of my information and participation.
- 4. I understand that:
  - I may not directly benefit from taking part in this research.
  - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
  - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
  - I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

Participant's signature.......Date......

Appendix D: Consent from the Association of Parents of Children with Hearing Impairment

Re: Request for permission to conduct research Nguyệt Hà <ha.artex@gmail.com> Fri 8/26Thi My Hanh Nguyen

Dear Hanh,

Thanks for your caring about Deaf and education for Deaf children. I highly appreciate your research and do our best to support you.

Please do not hesitate to contact us for the interview at any your convenient time.

Best regards,

Nguyet Ha.

2016-08-22 14:07 GMT+07:00 Thi My Hanh Nguyen <<u>nguy0747@uni.flinders.edu.au</u>>:

Dear Madam,

Let's me introduce myself first, my name is Nguyen Thi My Hanh, studying Master of Disability Policy and Practice at Flinders University in South Australia, Australia. My student ID is 2155913.

I am doing a research topic in my university course named Dissertation. The research I wish to conduct is *'The Experiences of Parents of Children Who Are Deaf or Hard of Hearing: A Preliminary Study Focusing on Access to Education'*. The project outcomes will be expected to not only fill the gaps among research literature but also help to raise awareness of policy makers and educational administrators of related issues in supporting those family to help their children

to access education. This project will be conducted under the supervision of Dr Paul Jewell, Senior Lecturer and Ms Ruth Crocker, Lecturer of Disability and Community Inclusion Unit at Flinders University.

Currently, I am finding participants who are parents of children who are deaf or hard of hearing to involve in this project. I know that Association of Parents of Children with Hearing Impairment, is a not-for-profit organisation which gathers parents of children who are deaf or hearing impairment together for sharing their experiences as well as participating other social activities. Thus, I believe that the members of your organisation will probably provide their lived experiences which fit in this research topic.

I am hereby seeking your consent to approach a number of your organisation's members, parents whose children are deaf or hard of hearing. Then, I will conduct interview with those who are interested in this project via telephone by Vietnamese. Each interview will last no longer than 60 minutes. All information provided by interviewees will be guaranteed confidentiality.

Your cooperation in this project will be highly appreciated and contribute significantly to the success of this project. If you have any further question, please do not hesitate to contact me via email <u>nguy0747@flinders.edu.au</u>.

Yours sincerely,

Nguyen, Thi My Hanh Flinders University Faculty of Medicine, Nursing and Health Sciences School of Health Sciences

Disability and Community Inclusion Unit

Appendix E: Ethics Approval

# FINAL APPROVAL NOTICE

Project No.: 74	438
Project Title:	The Experiences of Parents of Children who are Deaf or Hard of Hearing in Vietnam: A Preliminary Study Focusing on Access to Education
Principal Researcher:	Ms Thi My Hanh Nguyen
Email:	nguy0747@flinders.edu.au
Approval Date:	2 November 2016Ethics Approval Expiry Date:1 June 2019

The above proposed project has been approved on the basis of the information contained in the application, its attachments and the information subsequently provided.

# RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

 $\cdot$  all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.

• the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.

•the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email

human.researchethics@flinders.edu.au.

# 2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the <u>National Statement</u> on <u>Ethical Conduct in Human Research (March 2007)</u> an annual progress report must be submitted each year on the 2 November (approval anniversary date) for the duration of the ethics approval using the report template available from the <u>Managing Your Ethics Approval</u> SBREC web page. Please retain this notice for reference when completing annual progress or final reports.

If the project is completed before ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request <u>and</u> an annual report.

# Student Projects

The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your first report is due on 2 November 2017 or on completion of the project, whichever is the earliest.

# 3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

• change of project title;

•change to research team (e.g., additions, removals, principal researcher or supervisor change); • changes to research objectives;

• changes to research protocol;

·changes to participant recruitment methods;

·changes / additions to source(s) of participants;

changes of procedures used to seek informed consent; provided to participants;
changes / additions to information and/or documentation to be provided to potential participants;
changes to research tools (e.g., questionnaire, interview questions, focus group questions); extensions of time.

To notify the Committee of any proposed modifications to the project please complete and submit the Modification Request Form which is available from the <u>Managing Your Ethics Approval</u> SBREC web page. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted <u>prior</u> to the Ethics Approval Expiry Date listed on this notice.

# Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

# 4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or <u>human.researchethics@flinders.edu.au</u> immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Appendix F: Confidentiality Agreement with the Translator

# **CONFIDENTIALITY AGREEMENT**

# **Transcription Services**

The Experiences of Parents of Children who are Deaf or Hard of Hearing in

Vietnam: A Preliminary Study Focusing on Access to Education

I, \_\_\_\_Phuong Thi Thu Dinh\_, transcriptionist, agree to maintain full confidentiality in regards to any document received from Hanh Thi My Nguyen related to her research on 'The Experiences of Parents of Children who are Deaf or Hard of Hearing in Vietnam: A Preliminary Study Focusing on Access to Education'. Furthermore, I agree:

- 1. To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the transcription of audio-taped interviews, or in any associated documents;
- 2. To not make copies of any computerized files of the transcribed interview texts, unless specifically requested to do so by Hanh Thi My Nguyen;
- 3. To store all study-related materials in a safe, secure location as long as they are in my possession;
- 4. To return all study-related documents to Hanh Thi My Nguyen in a complete and timely manner.
- 5. To delete all electronic files containing study-related documents from my computer hard drive and any backup devices.

I am aware that I can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the files to which I will have access.

Transcriber's name (printed) Phuong Thi Thu Dinh

Transcriber's signature

Date: 25 May 2017

# Appendix G: Interview Guide

- 1. Could you tell me about your child?
- How old is he/she?
- What are causes of his/her hearing impairment?
- Which kind of communication method is he/she using now?
- Which grade is he/she studying now?
- Which school type is he/she studying?
- 2. Let's talk about factors affecting yourself in supporting your child to access education.
- What are advantages when you found a school for your child?
- + Yourself
- + Support from family and others
- + School
- What difficulties did you have to cope with when finding a school for your child?
- + Finance
- + Information
- + Available school near living area
- + Social stigma
- + Supporting resources
- + Psycho-emotional experiences
- How did you overcome those problems?
- As you mentioned several factors above, what are your biggest concerns?
- How is your satisfaction to your child's education?
- 3. Let's talk about your expectation. What goals do you have for your child's future education?

- If you had power to change current education system, what would you think of your child's education so far?