GROWING UP DEAF IN IPOH: PERSPECTIVES OF MALAYSIAN CHINESE PARENT AND DEAF ADULT CHILD

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DEDICATION

I dedicate this thesis to the cherished memory of my beloved late grandpa, Mr. Lee Seng Hock. His unwavering encouragement to pursue knowledge and embrace a lifelong journey of learning has profoundly impacted me.

ABSTRACT

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Lee Wan Ying

In Malaysia, 0.1% of the population has hearing impairment. Yet, due to its often unseen complexity, the needs of the deaf person are easily overlooked. Without proper interventions, deaf individuals may be left vulnerable to language deprivation, delayed development, and mental health issues. In Malaysia's multilingual context, communication interventions are crucial for the development of deaf children, and parents and support systems play an important role in mitigating the challenges they face. Therefore, this research aims to explore the experiences of the deaf person, their parents, and the accessibility to the support system in Malaysia. Bronfenbrenner's ecological system theory, Tajfel's social identity theory, and Glickman's deaf identity theory were used to frame this research to understand how the unique context of Ipoh impacted the deaf person and his identity. Through purposive and snowball sampling, six pairs of deaf adults (aged 20-37) and their parents were recruited as participants. An ethnographic approach was adopted, using participant observations and in-depth interviews to explore their experiences. The thematic analysis revealed key themes: deaf participants' navigation between hearing and deaf communities, highlighting a fluid identity (being as I am and connecting according to needs), parents' emotional coping, perception of normality, and roles in supporting their deaf child. Additionally, the analysis identified themes within the support system, including awareness of needs, deaf-friendly communication, support for financial independence, essential education, and the necessity for better policy implementations. Results also revealed that parents depended on the government’s resources, which were biased toward the welfare and medical models despite policies rooted in the social model approach. There was an apparent lack of Malaysian Sign Language (BIM) interventions across all sections. These findings emphasise the need for tailored interventions for deaf children and awareness campaigns about deafness and BIM to educate stakeholders and members of society. Future research is recommended to explore the urban Malaysian Deaf community and the educational system’s influence on deaf identity development.

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APPROVAL SHEET

This thesis entitled “**GROWING UP DEAF IN IPOH: PERSPECTIVES OF MALAYSIAN CHINESE PARENT AND CHILD**” was prepared by LEE WAN YING and submitted as partial fulfillment of the requirements for the degree of Doctor of Philosophy in Social Science at Universiti Tunku Abdul Rahman.

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SUBMISSION OF THESIS

It is hereby certified that Lee Wan Ying (ID No: 17AAD05222) has completed this thesis entitled “Growing Up Deaf in Ipoh: Perspectives of Malaysian Chinese Parent and Child” under the supervision of Associate Professor Dr. Kok Jin Kuan (Supervisor) from the Department of Psychology and Counselling, Faculty of Arts and Social Science, and Assistant Professor Dr. Joanna Tan Tjin Ai (Co-Supervisor) from the Department of Languages and Linguistics, Faculty of Arts and Social Science.

I understand that the University will upload a softcopy of my thesis in PDF format into UTAR Institutional Repository, which may be made accessible to UTAR community and public.

Yours truly,

Wan

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(*Lee Wan Ying*)

DECLARATION

I hereby declare that the thesis is based on my original work except for quotations and citations which have been duly acknowledged. I also declare that it has not been previously or concurrently submitted for any other degree at UTAR or other institutions.

Name _____Lee Wan Ying____________

Date _____22 March 2024___________

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LIST OF ABBREVIATIONS

ASL	American Sign Language
BIK	Bahasa Isyarat Komunikasi (Sign Language for Communication)
BIM	Bahasa Isyarat Malaysia (Malaysian Sign Language)
BSL	British Sign Language
CBR	Community- based rehabilitation
dBHL	Decibles in Hearing Loss
DET	Disability Equality Training
DHH	Deaf and Hard of Hearing
DSM	Department of Statistics Malaysia
EHDI	Early Hearing Detection and Intervention
EMID	Enomenos Malaysian Interpreters for the Deaf
ENT	Deaf Nose Throat (Otolaryngology)
FCEI	Family Centered Early Intervention
IEP	Inclusive Education Program
JCIH	Joint Committee on Infant Hearing
JKM	Jabatan Kebajikan Malaysia (Social Welfare Department)
JPOKU	Jabatan Pembangunan Orang Kurang Upaya
KPM	Kementerian Pendidikan Malaysia
KPWKM	Kementerian Pembangunan Wanita, Keluarga, dan Masyarakat
KTBM	Kod Tangan Bahasa Melayu (Manual hand code Malay)
KTM	Keretapi Tanah Melayu (Malayan Railways Limited)
LLP	Limited Liability Partnership
LRT	Light Rail Transit System

MFD	Malaysia Federation of Deaf
MOH	Ministry of Health
MOHE	Ministry of Higher Education
MySTEP	Malaysian Short-Term Employment Program
NICU	Neonatal Intensive Care Unit
PDK	Pemulihan Dalam Komuniti
PESDEAF	Perak Sports Society of the Deaf
POPP	Persatuan Orang Perak Pekak (Perak Soceity of the Deaf)
PTA	Parent Teacher Association
PWD	People with Disability
SDG	Sustainable Development Goal
SEIP	Special Education Integrative Program
SLP	Speech-Language Pathologist
UK	United Kingdom
UNHS	Universal Newborn Hearing Screening
USA	United States of America
WFD	World Federation of Deaf
WHO	World Health Organization
YMCA	Young Men Christian Association

CHAPTER 1

INTRODUCTION

How do deaf people experience life in a multilingual country like Malaysia? How did parents raise their deaf children in Malaysia? What is the government's approach to improving the quality of deaf people's lives? This study explores the answers to these questions specifically in the context of Ipoh, Malaysia. Malaysia presents a unique context to this study – it is multilingual, it has resource constraints, and the view of deafness may be contrary to Western literature. The context of this study further narrows its focus on Ipoh, a city in Malaysia two hours north of capital city Kuala Lumpur and is less urbanized than Kuala Lumpur. This unique context of Ipoh raises the question of how similar or dissimilar deaf people's experiences would be compared to a more developed Western and possibly monolingual context.

This study is explored with the researchers' positionality as participatory observer and interviewer, where she adopts an active membership role to engage in the deaf community's activities but refrained from committing herself to the group's values, goals, and attitudes. She is a hearing individual who has been immersed and involved with one of the deaf communities in Ipoh for the past decade, first as a friend of the deaf and later as a community sign language interpreter. The ethnographic approach provided the opportunity to explore in depth the first-hand experiences of deaf people and their parents. This dissertation is written from the researcher's perspective of the findings but with careful noting of possible bias.

Before this study dives into the experiences of deaf people and their parents in Ipoh, this dissertation will provide a foundational understanding of deafness, deaf people, and the current global and national situation surrounding deaf issues. Hence, this chapter will begin with an overview of the prevalence of deafness globally and locally. It is followed by providing a general understanding of deafness and its impact on development. A historical background and progress of the different models of disability from the Western context will be presented to better understand the current global situation for deaf people and the current situation of deaf people in Malaysia.

The next part of the chapter narrows its focus on the Malaysian context – the currently implemented solutions to assist deaf people and the unique challenges that deaf people face in Malaysia. As this study is explicitly focused on the deaf people of Ipoh, comparisons will be made with Western and local literature. This background information serves as a platform to provide context to this study's problem statement, research questions, objectives, and significance.

1.1 Background of Study

1.1.1. *Hearing loss/deafness*

When is a person considered to have a hearing impairment? Audiometry tests are used to diagnose and describe the individual's hearing loss level. Deafness is described based on the volume (dB) required to hear at frequencies, ranging from normal hearing, mild, moderate, severe to profound deafness. Table 1.1 below describes the grades of hearing loss (HL) of individuals according to WHO (Baines, 2007; *Grades of Hearing Impairment*, 2020) and the description of the functional difficulty (Baines, 2007).

Table 1.1

The Audiometry Descriptions of Hearing Loss

Type of hearing	dBHL	The norm	Functional difficulty
Normal hearing	0-25	A whisper at 15-25 dB is audible.	
Mild hearing loss	26-40	A quiet conversation is about 30 dB.	Difficulty in following conversations in noisy environments.
Moderate hearing loss	41-60	Conversational speech is 50-65 dB.	Difficulty following speech without hearing aids.
Severe hearing loss	61-80	Traffic noise is 75-85dB; hair dryer is 80 dB.	Hearing ability limited even with hearing aids.
Profound hearing loss	>81	Jackhammer at 100dB, Power lawn mower is 110dB, a jet plane 35m away at 140dB.	No auditory reception.

Note. dBHL refers to Decibels in hearing loss.

While the audiometry test provides information on the degree of hearing loss, different terms are used to categorize people according to the severity of hearing loss. H*earing impairment* is the overall term used to describe individuals with any degree of hearing loss (mild to profound). *Deaf* refers to severe hearing loss of a person to the point that there is very little or no functional hearing (e.g., severe and profound hearing loss). *Hard of hearing*, on the other hand, is when the individual has hearing loss where there is sufficient residual hearing that an auditory device can adequately assist in processing speech (e.g., moderate hearing loss) (World Health Organization [WHO], 2023).

It is also interesting to note that some individuals who lost their hearing later in life might regard themselves as *hard of hearing* or *deafened* rather than *partially deaf*, even though audiometrically, they may have the same level of hearing loss (Baines, 2007). These are different terms used by deaf people to express their self-perceived identity.

1.1.2. Prevalence of Hearing Loss

Research stated that the increase in hearing loss worldwide has been one of the concerns in the past decade (Mackenzie & Smith, 2009). World Health Organization reported that over 5% of the world's population (432 million adults and 34 million children) need rehabilitation to address their disabling hearing (WHO, 2023). WHO predicted that by 2050, 1 in 4 people (about 2.5 billion people worldwide) will have hearing loss. Unless action is taken now, about 700 million individuals will need access to ear and hearing care or rehabilitation (WHO, 2021).

In 2022, Malaysian statistics recorded 42,494 persons with hearing impairment on a national level. This is 6.71% of the overall persons with disabilities (PWD) of 633,653 persons (Department of Statistics Malaysia [DSM], 2022) and 0.13% of the Malaysian population of 32.7 million citizens (Jabatan Kebajikan Malaysia [JKM], 2023). In simple words, there are 13 persons living with hearing impairment in every 10,000 people.

Statistics for 2022 reported that 11.74% of the hearing-impaired population consists of children (age 18 years and below), 23.26% of young adults (age 19 – 35), 36.63% of middle adults (age 36 – 59), and 28.37%, older adults (above age 60) (Jabatan Kebajikan Malaysia [JKM], 2023). According to registration records, Selangor (8,682) has the highest number of persons with hearing impairment. Johor follows this with 4,623 persons, and Perak with 3,477 persons. These statistics are recorded according to the registration; however, the current number of deaf people residing in the states is unknown as, over the years, individuals are likely to relocate across states for education, employment, and marriage reasons. They are scattered across the country. With that said, it is worth noting that deaf adults often gather in cities and towns where they can secure employment and engage socially with other deaf people (*Deaf in Malaysia*, 2021).

To avoid the problems that derive from hearing loss, the best solution is prevention and early identification so appropriate interventions can be implemented. According to WHO (2019), about half of all cases of hearing loss can be prevented through public health measures. In children under 15 years old, 60% of hearing loss is caused by infections, birth-related causes, and ototoxic medicines, which are preventable through medical and educational interventions (e.g., immunization, good hygiene practices, improved maternal and child health practice, educating the younger generation about hearing loss).

Developing countries such as Malaysia may be more affected by preventable hearing loss. The number of cases of preventable hearing loss is higher in low- and middle-income countries (75%) than in high-income countries (49%) (WHO, 2023). Difficulties of hearing loss are also magnified in developing countries, where there are generally limited services for people who are hard of hearing, a limited number of trained personnel to help those with hearing impairment, and little awareness of how to deal with the difficulties associated with such loss (Mackenzie & Smith, 2009). As a developing country, Malaysia may face similar challenges in managing hearing loss issues in its prevention and provision of holistic development for people with hearing impairment.

1.1.3. Understanding Deafness

The comprehensiveness of deafness should not be confined to the degree of hearing impairment, but it should consider other aspects that influence the deaf persons' development with deafness. To explain deafness deaf people better, Baines (2007) used four criteria to provide clarity. These four criteria to understand deafness are audiometry, onset of deafness, communication style, and identity. Each person with hearing impairment has a unique background based on a combination of these four criteria, contributing to the diverse experience of being deaf.

1.1.3.1 Audiometry. The first aspect of deafness is audiometry. As described in *Table 1.1 (in Section 1.1.1 Hearing loss)*, audiometry provides a diagnosis and description of the individual's hearing loss level. With the diagnosis, the medical professional then discusses the management of hearing loss with the caregiver of a deaf child. The management of hearing loss includes the consideration of conventional hearing aids, bone conduction devices, remote microphone systems, contralateral routing of signal aids, and cochlear implants, according to the child's and family's needs and desires (Porter et al., 2021)—all which focuses on restoring hearing.

Conceptualizing deafness from the medical point of view is commonly known as the "medical model of deafness". The medical model conceptualizes deafness as a pathological or disabling condition that professionals attempt to treat (Baines, 2007; Bingham et al., 2013). More about the impact of deafness will be described in *Section 1.3*. However, it is sufficient to say that if there is no early intervention of any kind, the effect of deafness is detrimental to a child's development in the different domains, such as language, emotional, behavioral, cognitive, and social development, which affects well-being. Hence, medical professionals would recommend hearing restoration or rehabilitation if possible.

1.1.3.2. Age of onset. The next aspect of understanding deafness is the age of onset, as it significantly affects language and literacy acquisition (Baines, 2007). Pre-lingual deafness is hearing loss that occurred before the child acquired speech and language skills, while post-lingual deafness refers to hearing loss that occurs after the development of speech and language skills. Language skills here refer to spoken language skills. Kitson and Fry (1990) suggested four categories of deafness that focus on the linguistic and developmental experience of deafness, as shown in Table 1.2 below.

Table 1.2

Four Types of Hearing Loss Onsets

Level of Deafness	**Onset of Hearing Loss**	
	Prelingual deafness	Post-lingual deafness
Profound	Prelingual profound deafness	Post-lingual profound deafness
Partial	Prelingual partial deafness	Post-lingual partial deafness

Language acquisition and linguistic development have been seen from the perspective of a spoken language, not a signed one. Recent research revealed that sign language acquisition does not hinder but instead helps the deaf person to learn a spoken language (Pontecorvo et al., 2023). Thus, acquiring sign language for those with pre-lingual deafness would be encouraged to reduce the risk of language deprivation. As this research's findings are relatively new, they may not have entirely been received or implemented among medical professionals and educators. Nonetheless, the onset of hearing loss is an essential aspect of deafness as it can help determine the assistance needed for spoken or signed language acquisition and development. The choice of language for expression and communication would later play a significant role in the deaf person's social life. The selection of communication mode is discussed next.

1.1.3.3 Communication Mode. The following criterion of Baine's (2007) perspective of deafness and deaf people is communication mode. This topic has been much discussed and debated as policymakers and practitioners aim to provide early, ready, and meaningful linguistic access (Kauffman et al., 2023). Would the spoken and/or signed language be the chosen mode of communication for the deaf person by the family or school system? But more importantly, which mode of communication would deaf people prefer to use in their social interactions?

Research showed that multiple factors contributed to the communication mode adopted by deaf people. These factors include the type and level of deafness, age of onset, cognitive abilities, language skills, geographical area, availability of various types of communication, kind of schooling, the sociopolitical climate of the time, audiological status and identity choice of individual’s parents, presence or absence of Deaf role models, and the subjective views of the individual, their family, and their audiological/educational advisers (Baines, 2007; Chong & Hussain, 2022). All these factors influence the communication choice of the deaf person.

Deaf people may communicate using sign language, manually coded signs (e.g., sign exact English), home signs, and oral communication. Sign language is a visual-spatial system based on hand movements and facial expressions that deaf people use as a native language. It has unique grammatical rules and structure; it is not a visual representation of a spoken language. It is a fully functional and expressive language, using handshapes, facial expressions, gestures, and body language to convey meaning (Baines, 2007). On the other hand, oral communication maximizes residual hearing by using aids (e.g., hearing aids or cochlear implants), lip-reading, speech, and written communication (Baines, 2007).

When deaf individuals have limited access to signed or spoken linguistic input or were raised in social isolation, these deaf individuals with minimal language develop and use systems of manual gestures called “home signs” to communicate with their hearing family members. The home sign is systematic and productive and functions as a linguistic system (Day et al., 2018). These home signs are not widely understood outside the immediate social groupings (Baines, 2007).

The actual method used to communicate is complex. For example, in America, communication varies across individuals – signing according to the ASL grammar rules, signing in English word order, or using regional or home signs (Day et al., 2018). Depending on the situation or upbringing of the deaf individual, he may adopt one or more communication methods in different contexts. To keep the focus on conceptualizing deafness, the situation in Malaysia relating to communication will be discussed in a separate section (*Section 1.5.1 The Language Situation for Deaf People*).

1.1.3.4 Identity. Self-expression in communication mode – signed or spoken language- is closely linked to identity. How deaf individuals view their deafness, and their choice of communication mode relates to which group of people they identify themselves with. The primary distinguishing factor of deaf individuals is their adoption of a pathological or cultural identification with their hearing status (Day et al., 2018). Pathological identification views deafness as a disability that needs rehabilitation, while cultural identification views deafness as a cultural and linguistic lifestyle choice (Baines, 2007). These are the two main deaf identity groups that will be discussed in this section. The history of how these identities emerged (*Section 1.4.1 Deaf History*) and the progress of the deaf identities (*Section 2.4.1 Identity Constructs of Deaf People*) will be discussed in later sections as this dissertation progresses.

The term “deaf” (lowercase ‘d’) is then given to individuals who view deafness as a disability that needs rehabilitation (Baines, 2007). Deafness is primarily an audiological experience. They may have lost some or all of their hearing early or late. They prefer to communicate in a spoken language and will focus their efforts on hearing and speech rehabilitation. Hence, the choice of communication is also likely skewed to using spoken languages. In short, they communicate, function, and identify with the “hearing world” that depends on sound. They do not embrace the Deaf cultural norms and values (Day et al., 2018) nor use sign language (Baines, 2007). In other instances, they usually do not wish to have contact with the signing Deaf communities and prefer to retain their membership in the majority society (hearing dominant) where they socialise Ladd (2005b).

Deaf people who view themselves as a distinct linguistic and cultural group are given the term “Deaf” (capital ‘D’) (Day et al., 2018). Generally, the Deaf identity is defined as individuals who communicate using sign language (e.g., American Sign Language) and ascribe to Deaf cultural values and norms, regardless of their hearing status and use of assistive listening devices (Day et al., 2018).

The term “Deaf” is also used to refer to individuals who are born Deaf or deafened in early childhood (Ladd (2005b). This is because their primary experiences and allegiance are not with the dominant hearing world but are with sign languages, Deaf communities, and Deaf cultures. For example, prelingual deafened people tend to accept their deafness rather than fix it. They view their hearing loss as an ingrained component of their existence and consider themselves a distinct linguistic and cultural group (Baines, 2007; Day et al., 2018). Prelingual deafened individuals, like everyone, seek to find a sense of belonging and may find it in a group of people with similar experiences. The collective experience of sharing a language and similar norms and values forms a unique culture among people with hearing loss. It was believed that Deaf communities had a way of life that was mediated through sign languages. Hence, in the 1970s, the term ‘Deaf’ was given to distinguish this from other individuals with hearing impairment who did not share this belief (Ladd (2005b).

It is important to note that the severity of hearing loss and age of onset also play a role in their identification. For example, a prelingual deaf person may view deafness as a sensory deficit, while a post-lingual deaf person views deafness as a sensory deprivation (Baines, 2007; Denmark, 1985). Post lingual deafened people tend to grieve over hearing loss or seek a cure (Lane et al., 1996).

1.1.3.5 Conclusion. For a comprehensive view of deafness, these four aspects – audiometry, age of onset, communication mode, and identity, give the fundamental understanding of deafness and the diversity of deaf people. Each deaf person comes with a unique background that influences their life experience and identity as a deaf person.

1.2 Conceptual definitions

After introducing deaf identities in the above section, it seems best to address the conceptual definitions of the terms *deaf* and *Deaf* before proceeding to the impacts of deafness on development. Hence, in this section, conceptual definitions are inserted here rather than at the usual end of chapter one.

1.2.1 deaf

For this study, the researcher will use the term *deaf* (with a small case 'd') to refer to the general group of people who lost their hearing, regardless of when or degree of hearing loss. They may or may not communicate using sign language or have a membership preference in the Deaf or hearing community. Since this research is about the experiences of deaf people who may subscribe to either deaf identity, the researcher chose to use the general definition of the deaf in writing to maintain a neutral perspective of what being deaf is without giving it a preconception of the existing Western social construct on deaf identity.

Also, the term *deaf* is used in the general sense to reduce the confusion of the back-and-forth changes of deaf identity definitions used in research. The first wave of deaf identity politics used the binary term *deaf – Deaf* (as defined in Ladd (2005b) in the above paragraphs) to indicate the two different memberships to hearing/Deaf culture. However, the second wave of deaf identity politics took the postmodern perspective that deaf identity is diverse and fluid (McIlroy & Storbeck, 2011). This identity fluidity has complicated the binary definition of *Deaf* and *deaf*. Hence, for the sake of simplicity, this research uses the term *deaf* as a general reference to people with hearing impairment.

1.2.2 Deaf

The term *Deaf* (capitalized 'D') is used specifically to refer to the concept and definition that Ladd (2005b) and Western Deaf studies have used. Deaf refers to people living with hearing impairment whose membership and allegiance is with the Deaf community. They consider themselves a cultural and linguistic minority who share the same language (sign language), experience, values, culture, heritage, and way of life as Deaf people.

As this concept is coined, defined, and widely used in Western countries (e.g., the United States of America, the United Kingdom, and Europe), and most literature in Deaf studies is based on this concept, this research will retain the definition of *Deaf* according to the Western context and culture, which includes

Western values.

1.2.3 Malaysian Deaf

The Deaf culture and identity from the West have influenced Malaysia even though the culture in Malaysia is different. At this point, Malaysian Deaf culture has not yet been documented; it is unclear how similar it may be to the Western Deaf culture. Since this research explores the current deaf identity scenario in the Malaysian context, it is best to distinguish between the Western Deaf identity and Malaysian Deaf identity. Hence, the researcher will use the term *Malaysian Deaf* or *Malaysian Deaf culture* to make that distinction.

Malaysian Deaf will be defined as a general reference to Malaysians with hearing impairment who identify themselves as a linguistic minority and share the same values, direction, and allegiance to sign language, the Deaf community, and a claimed Deaf culture (whether it is truly Malaysian Deaf culture or the Western context of Deaf culture).

1.3 Impact of Deafness on Development

A comprehensive understanding of deafness cannot be confined to its physical impairment. Hearing impairment impacts language acquisition, which affects emotional, cognitive, behavioural, and social development. Without intervention or appropriate assistance, unmonitored poor development indirectly affects the deaf person’s mental health and well-being. In other words, deaf individuals are a vulnerable at-risk group to mental health issues, especially if there is no intervention for prevention.

This section explores the impact of deafness on development. It begins by reviewing deaf people’s mental health vulnerabilities and how deafness affects development. It concludes with the language acquisition debate, which has a monumental impact on the direction of education for the development of deaf people.

1.3.1 Mental Health Vulnerabilities

Previous studies have indicated that deaf individuals have lower psychological well-being than their hearing counterparts (Fellinger et al., 2012). Deaf persons exhibited higher rates of depression, anxiety, insomnia, emotional distress, and lower quality of life compared to the general population (Fellinger et al., 2005; Jiang et al., 2020; Kvam et al., 2006; Werngren-Elgström et al., 2003). Children with severe hearing impairment were also at greater risk of developing psychiatric disorders or poor psychosocial adjustment compared with their hearing peers (Gentili & Holwell, 2011).

Other than mental health, deaf children were also more at risk for psychological difficulties as compared to their hearing peers. The occurrence of psychological challenges such as positive self-perception and anxiety was four times more than in typical hearing children (Martikainen et al., 2002). Emotional and behavioral problems were twice as common in deaf children (Stevenson et al., 2010; Vostanis et al., 1997). Deaf individuals who reported more significant communication difficulties, less acceptance of their hearing loss, and lower self-esteem also faced an increased risk for mental distress (De Graaf & Bijl, 2002). These reports demonstrated higher vulnerabilities of deaf children compared to their hearing counterparts.

1.3.2 Deafness and Development

The mental health vulnerabilities of deaf children underscore the need to investigate further how exactly deafness impacted development and might have resulted in mental health concerns. First, deafness is considered a hidden disability that is easily neglected as the general population is not aware of the effects that hearing impairment can have on individuals (Mackenzie & Smith, 2009). Deafness is not merely a physical impairment of hearing; it has a cascading effect that impacts the individual's linguistic, emotional, and social development. If diagnosis and appropriate interventions are delayed, hearing impairment can harm development, especially in young deaf children.

Hearing impairment deprives the developing brain of the auditory stimulation necessary for hearing, speech, and language (Kral et al., 2001). It affects speech and language development and results in sensory, cognitive, emotional, and academic defects in adulthood, causing delayed development of communicative-linguistic abilities (Shojaei et al., 2016). This is because language development refers to spoken language development, not sign language.

Indeed, language plays a significant role in development. It is crucial for communication, meaning-making, experience sharing, hypothesis articulation, thought abstraction, emotional labelling, and identification (Gentili & Holwell, 2011). Language is like the primary vehicle needed to assist other areas of development (e.g., emotional, cognitive, social). Without language, deaf children struggle with emotional regulation, understanding the sense of self, and behavioral difficulties (Gentili & Holwell, 2011). Gentili and Holwell elaborate - without language, deaf children struggle to identify and label their own emotions, which is needed to develop the ability to decode their emotional state and regulate emotions better.

Second, the lack of language also affects the deaf child's sense of self (Gentili & Holwell, 2011). When there is a lack of language, interaction with caregivers is likely reduced, which affects the child's attachment style and the parent's ability to 'tune in' to the child. The lack of effective communication further prevents the child from elaborating on life events through abstract thinking. It stops the child from integrating their experiences into their sense of self.

Third, without language, the developing executive system is affected (Gentili & Holwell, 2011). The deaf child has less control over their actions, greater difficulty in learning how to think abstractly, is unable to adjust to new situations, and is less able to understand others' points of view and mental states. This leads to a higher likelihood of developing emotional and behavioral difficulties. However, deaf children who signed fluently (not language deprived) performed executive function similarly to their hearing counterparts (Kotowicz et al., 2023). This indicated that deafness does not necessarily impair executive function. Acquiring sign language seemed to play an important role in executive function, as Kotowicz and colleagues also reported that sign language receptive skills predicted executive function in deaf children.

Hearing loss also affects the individual's developmental cognitive skills (Mackenzie & Smith, 2009) and poses a barrier to education and social integration (WHO, 2016). Difficulties in interpersonal communication can lead to significant social problems (e.g., isolation and stigmatization) (Mackenzie & Smith, 2009), and such communication problems affect the individual's mental health (De Graaf & Bijl, 2002). Deaf children from hearing families without sufficient communication have higher mental health issues compared to their hearing counterparts (Gentili & Holwell, 2011).

Communication difficulties further increase deaf people's social challenges, which may result in increased mental health concerns. Deaf individuals raised in hearing environments encounter specific challenges and distinct risks that can impact their socio-emotional well-being (Eichengreen et al., 2021). Adversities that increase psychological distress among deaf persons include deaf stigmatization (Mousley & Chaudoir, 2018) and bullying victimization in school (Cheng et al., 2019). Isolation, tension, and struggle are common themes revealed in the narratives of deaf people's lives (Leigh, 2009).

In a study by Johannes Fellinger et al. (2009), deaf children were reported to have high depression rates, and it was significantly related to negative communication experiences at home and in school. These deaf children experienced being teased, maltreated, and neglected, like typical children. However, it was difficult for them to understand themselves compared with typical hearing children. When deaf children could not make themselves understood in the family, they were four times more affected by mental health issues compared to those from families who communicate successfully. Poor communication may lead to social exclusion and result in mental distress and suicidal ideation in deaf people (Akram et al., 2018; De Graaf & Bijl, 2002).

Figure 1.1

Summary of the Impact of Hearing Loss on Development

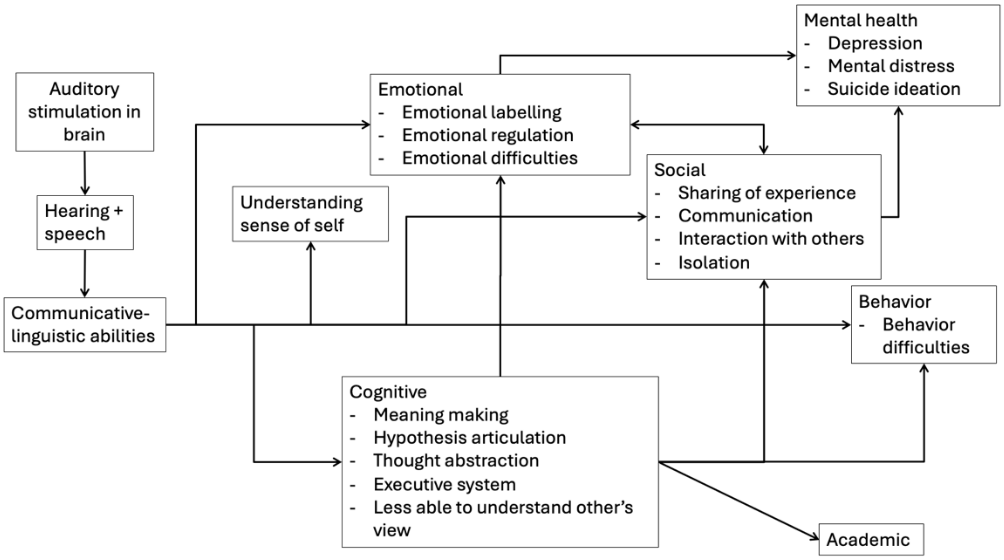


Figure 1.1 summarizes the direct and indirect impact of hearing loss on the different aspects of development according to the various research listed above. The research clearly showed the dire need for deaf children to acquire and develop language for better development in various aspects.

The intervention focuses on preventing language deprivation; the standard solution is acquiring a spoken language. Recent research shows that language deprivation is not inevitable for deaf children who have acquired sign language (Pontecorvo et al., 2023). Is sign language another alternative to prevent language deprivation and reduce developmental delays in the different domains? There have been arguments among researchers and educators about which language deaf children should acquire and how it should be acquired. Specifically, Which mode of communication or language should be taught to deaf children for language acquisition – spoken or signed? The following section discusses this heated debate among scholars and educators.

1.3.3 The Language Acquisition Debate

Research reported that deaf children often have limited access to language (spoken or signed) during their early childhood (Pontecorvo et al., 2023). This is not surprising as most deaf babies are born to hearing parents who do not have reason to suspect deafness (Mitchell & Karchmer, 2004) and, hence, do not anticipate deafness. It has also been reported that parents generally do not know any sign language at the time of the deaf child's birth (Mitchell & Karchmer, 2005). How will the deaf child acquire a language when he cannot hear the spoken language and if no signed language is accessible to him?

While hearing technology and language interventions may be accessible, Pontecorvo et al. (2023) observed that the majority of deaf children still do not reach age-expected spoken language proficiency milestones for a variety of reasons (Gagnon et al., 2021; Sosa & Bunta, 2019; Yoshinaga-Itano et al., 2018). Although it has been established that early exposure to language would have a profound impact on language proficiency (Boudreault & Mayberry, 2006) and cognitive, social, and emotional development (Goodwin et al., 2022; Langdon et al., 2023), the debate goes on about the best practices to support language acquisition for deaf children (Pontecorvo et al., 2023).

The primary emphasis in rehabilitation for deaf children is acquiring spoken language for development. Spoken language is also needed to communicate with the hearing world. Hence, the debate is whether sign language hinders or helps spoken language development among deaf children. This is an important debate because of its implication on the deaf child's development. Thus, if sign language hinders spoken language development, this would imply that the focus of interventions should not be on acquiring sign language but a spoken language. It also asks if there are any benefits for the deaf child to learn sign language. The arguments for this debate will be briefly summarized below.

The argument that sign language will harm spoken language acquisition is based on two reasons – (1) cross-modal plasticity of the brain and (2) multilingual child-rearing practices. The cross-modal plasticity of the brain is clearly explained by Pontecorvo et al. (2023). He states that "In the absence of one type of sensory input, the areas of the brain typically dedicated to that sense (e.g. hearing) can be used to process information from other senses (e.g. vision)" (p. 1292). The timing is also considered to be critical in the reorganization of these neural regions.

Research reported that later age of cochlear implantation was associated with poorer spoken language and speech recognition (Tobey et al., 2013). The correlation result of such studies has been interpreted as causal evidence by some researchers, hypothesizing that the “visual has taken over” (also known as the *visual takeover hypothesis)*(Kral & Sharma, 2012). In other words, the argument is that “exposure to sign language in the first three years of life locks the language system into a vision-only configuration that prevents possible future acquisition of auditory language” (Lee & Giraud, 2007, p.283). This hypothesis, however, has been challenged and countered in recent research. The greater the use of the auditory cortex for visual information (cross-modal plasticity), the better speech perception (Mushtaq et al., 2020). This suggests that the relationship between cross-modal plasticity and speech is a correlation driven by a third variable (e.g., access to language) and not a causal relationship. This provides evidence that acquiring sign language would not hinder the development or acquisition of a spoken language.

The second argument that sign language hinders the acquisition of a spoken language is the multilingual child-rearing practices. The concern is that “the child who has to learn two or more languages has less input per language than a child who is learning only one language. Such competition can negatively influence learning a language” (Knoors & Marschark, 2012, p.293). This suggests that learning sign language and a spoken language (bilingualism) is not a good practice for acquiring a language. However, this argument is countered by theories of linguistic interdependence and linguistic transfer, which state that learning one language can support learning another language (Cummins, 1979). In this sense, learning sign language can assist in learning a spoken language. It was further argued that sign language acquisition can prevent language deprivation and make spoken language more accessible to learn (K. Davidson et al., 2014; Pontecorvo et al., 2023).

Pontecorvo and colleagues concluded the debate by offering empirical evidence through their study that learning sign language does not hinder the acquisition of spoken language. The results of their research indicated that learning sign language offers deaf children a broader language base on which to develop language and other domains. These recent studies provide empirical evidence to guide decisions about language exposure and language acquisition for deaf children. It supports the importance of deaf children acquiring sign language, especially when many areas of development depend on communicative-linguistic skills.

1.4 Views of Deafness

Deafness affects development. Over the years, the government, doctors, social workers, parents, and concerned members of the community have attempted to assist deaf individuals to prevent further detrimental effects of deafness. The type of help offered depended on the understanding and perspective of deafness (e.g., the medical model and social model of deafness) at that time. To further understand the different views of deafness and how it has progressed over the years, it is helpful to understand the history of deaf people that has been documented. The section below will provide an overview of deaf history, followed by the different views of deafness.

1.4.1 Deaf History

Western literature on Deaf studies recorded a history of events that affected and changed the course of deaf people's lives and views of disability (Ladd, 2005b). In the past, deaf people have used sign language to communicate. Native Americans have used sign languages for storytelling and religious ceremonies for thousands of years. Evidence also dates to the 15th century, when Deaf people played prominent roles in the Ottoman Court. At the same time, the British Sign Language vocabulary was traced back to the 1630s (as cited in Ladd, 2005).

Sign language was freely used in European countries and the United States until the Milan Conference in 1880. It was the first international conference of deaf educators (International Congress on the Deaf, 1880). After deliberations at the Milan Conference, it was declared that oral education (also known as oralism) was superior to manual education, and a resolution was passed to ban the use of sign language in schools. As a result of this ban, schools in Europe and the United States switched the method of education to speech therapy without sign language for deaf people. Sign language and Deaf teachers were removed from the schools. The number of Deaf professionals (e.g., writers, artists, and lawyers) also declined.

Teachers applied the Milan Convention resolutions in classrooms, where simultaneous use of articulation and signs was seen as a disadvantage to articulation, lip-reading, and the precision of expressing ideas. Tactics such as having hands tied up behind their backs, taped to desks, beaten, or having their hands sat on were used to enforce pure oralism (Fischer, 1993).

In 1974, a team of researchers investigated the results of oralism practices and found alarming adverse outcomes of oralism practices for deaf students. The deaf students left school with the reading ability of an eight-year-old; their speech was incomprehensible except to their teachers, and their lipreading skills were no better than those of a hearing person who had little practice (Conrad, 1979). Though these devasting results were published in 1979, the media was silent about it. The deaf people were outraged at the indifferent attitude of the society and compared oralism to a Deaf holocaust where “one destroyed bodies, the other destroyed minds” (Ladd, 2005b). Thus, the Deaf resurgence emerged.

In 1999, the British Deaf community had its first political march with 30,000 petitions for an official government recognition of British Sign Language

(BSL). At the same time, the media promoted medical interventions for hearing restoration, such as the “new miracle cure for deaf babies” and the “wonder cochlear implant operation to abolish deafness” (Ladd, 2005b). The deaf people became skeptical of hearing people that “they would make things better for us” and seemed to trust no longer hearing people. Ladd (2005) stated that “fewer still are aware that in some countries, leadership is still in the hands of hearing people who wish at any cost to suppress these Deaf subaltern voices” (pg. 32). The deaf people felt the need to defend themselves and thus, emerged the Deaf identity politics.

This brief Deaf history provides a preview of people's different views about deafness. The following sections will describe how the view of deafness changed from the medical model to the social, culture-lingual, and diversity models.

1.4.2 Models of Disability

When a person is born deaf or has lost hearing, how does society view that individual? This section attempts to answer this question by briefly explaining the different disability models and how they have progressed over the years. Each disability model sheds light on how the deaf person is viewed (or perceived), the direction of the interventions, and the outcome of its application.

1.4.2.1 Welfare Model. According to the Office of the High Commissioners of Human Rights [OHCHR] (2019), the charity model (also known as the welfare model) views deaf people as "passive objects of kind (charitable) acts or welfare recipients only, rather than as empowered individuals with equal rights" (p.4). Deaf people are not considered as capable of providing for themselves on account of their hearing impairment. They are considered a burden on society, which gives them benevolence. They are perceived as objects of pity, dependent on the goodwill of other people. They do not control their own lives and have little or no participation in society. Society responds by providing care and assistance only, reducing individuals to recipients of charity and welfare.

1.4.2.2 Medical Model. The medical model views deafness as a pathology or medical condition that needs to be treated (Baines, 2007; Bingham et al., 2013). Hence, the main focus of treatment is to rehabilitate and restore hearing so that the individual can be integrated with the hearing world for normal development. According to OHCHR (2019), under the medical model, "disability resides in the individual, and doctors know best how to correct and manage any impairment, regardless of consent, will and preferences of the individual" (p. 4). Society seeks to normalize and diminish impairments to enable participation instead of removing barriers.

The term usually used to describe a person's physical condition is *hearing impairment* in the medical field. The person may be referred to as a *hearing* *impaired* or *hearing disabled*. However, this kind of labelling has a negative connotation for the deaf person. It is negative because it focuses on the impairment and is associated with disablement. It is viewed as “an anomaly to be medically fixed and persons with hearing disability as damaged and incomplete” (Amar-Singh, 2023, p.1). An impairment may be a disability that becomes a disablement if there is no intervention for development. Secondly, the term “impairment” focuses on the person's lack, highlighting the impairment and forgetting that the individual is more than his impairment.

Although the intention of using these terms is for medical description purposes, when it is unfairly associated with disablement by society, people with hearing disability are viewed as a *disabled* group. In return, they are treated as a disabled person who is confined to their impairment and not able to do anything for themselves. This attitude towards people with disability (PWD) originated from a belief that “PWD is not a fully human being because of the absence of or damage to a physical faculty” (Ladd, 2005, p. 7). Hence, the blame is put on the victim for the inability to achieve equality. Therefore, hearing and speech must be restored to achieve equality with the hearing-dominant society. This is another reason why interventions are focused on restoring hearing through hearing aids, speech therapy, cochlear implants, etc.

1.4.2.3 Social Model. In 1980, the disability movement emerged, opposing the view that PWDs are a disabled group. The disability movement pointed out that:

> Societies constructed were solely for the benefit of non-disabled people… And any attempt to gain equal access and rights was seen as an "adding on" process, then left at the mercy of benevolence, munificence, and charity" (Ladd, 2005, p.15)

In other words, from the social model's perspective, PWDs are disabled because of the existing social structure that is unequal. The environmental barriers create disablement and disability (Forber-Pratt et al., 2019; Pena et al., 2016). OHCHR (2019) states, "Disability is the consequence of the interaction of the individuals with an environment that does not accommodate the individuals' differences" (p. 4). Due to the lack of accommodation, they cannot participate in society. The social model puts the person at the center, not his impairment, recognizing the values and rights of PWD as a society. Therefore, disability is seen not as a mistake of society but rather an element of diversity.

Hence, the social model insists that PWDs should have fundamental equality as human beings entitled to full citizenship, following the social movement in 1980. In 1990, this social equality was enforced. Society was responsible for ensuring equal access and full citizenship for all PWDs. A refusal of this responsibility was seen as a social or political discrimination. Other strategies under the social model are to remove environmental barriers and provide equal access. For example, providing TV subtitles and using flashing lights as doorbells. Providing access enables deaf people to live more equal lives and have their needs met.

1.4.2.4 Cultural-Linguistic Model of Disability. Some deaf people joined the disability social movement because they lacked the power to express their views. However, some other deaf people felt uncomfortable with inclusion in the disability social model because the criterion for inclusion is physical deafness—the medical model they opposed (Ladd, 2005). They felt the social model did not meet the deaf community's deeper needs about their "being in the world."

The Deaf community had more in common with linguistic minorities. Hence, the cultural-linguistic model of deafness focused on establishing that deaf people are a linguistic minority group. Therefore, *Deaf* (capitalised 'D') is given to this linguistic minority group to distinguish it from those who view themselves with a disability. According to Ladd (2005), this cultural-linguistic model is a concept that is hard to grasp because of its dual category membership, which addresses (1) non-hearing issues and (2) language and cultural issues.

The cultural-linguistic model's focus is not to gain increased disability allowance or access but rather for deaf children to receive deaf-centred education in their language so that quality of life in the collective Deaf culture is maintained and enhanced. There is much emphasis on preserving the language and culture because for the sign language user, "home" is the Deaf community that co-exists alongside the majority culture members that do not understand them. They hope to persuade the majority hearing society to learn sign language so that both communities can move in and out of each other's world.

1.4.2.5 Diversity Model. The diversity model of disability recognizes the inaccessible and often oppressive environments that surround people with impairments. However, it differs from the social model in that it places disability as a unique cultural group because of the experience of impairment, regardless of the individual's environment. This perspective complicates the social model in that it recognizes the unique human variations that disabled people hold, both in their bodies and subsequently as part of their identities. They celebrate the experience of disability as a cultural phenomenon, with cultural outputs – unique contributions made because of, rather than in spite of, the position and identity of disabled people (Forber-Pratt et al., 2019).

This model comprises both personal and collective concepts. It involves the experiences of the extent which one feels shame or takes pride in disability, the degree to which one has integrated disability into one's sense of self, and the type of contact, camaraderie, and engagement one has with the larger disability community (Caldwell, 2011; Darling & Heckert, 2010 as cited in Forber-Pratt et al., (2019).

The disability community itself is not a homogenous group; understanding it as a homogenous group can perpetuate harmful ideas about individual disability experiences and identity. The disability community is a group of people who experience impairment and societal discrimination based on that impairment; the community is large and represents many different intersectional identities and understandings (Forber-Pratt et al., 2019).

1.4.2.6 Conclusion. Table 1.3 below summarizes the different models of disability and its characteristics. The different models of disabilities revealed the various perspectives of viewing deafness. Each of the models provides insights into the complexity of deafness. While each model of disability provides a solution according to their emphasized perspective of deafness, it is worth noting the different resources each model offers for the diverse individuals living with hearing disability.

Table 1.3

Summary of the Models of Disability and Its Characteristics

Model	Terms	Characteristic	Solutions
Charity	-	Burden on society Objects of benevolence	Provide assistance and welfare
Medical	Hearing impaired Hearing disabled	Pathology focused that needs treatment	Hearing and speech restoration
Social	People with hearing disability / impairment	Remove social barriers for equal access	Access
Linguistic-cultural	“Deaf”	Language and culture preservation	Sign Language
Diversity	People with hearing impairment/disability	Personal and collective disability experience and culture Disability part of identity	Embrace diverse disability

1.4.3 View of Deafness in Malaysia

According to the historical background recorded by (Albrecht et al., 2001), the earliest conceptualisation of disability adopted by Malaysia was the medical and welfare (also known as charity) models of provision. The fundamental starting point was the medical model - the biological reality of impairment. Hence, the approach then was to “care” for PWDs by “preventing” and “treating” the functional limitations associated with mental or physical disability (Lee & Low, 2014). The medical model led to the welfare model in policy and practice, whereby PWDs were “helped” and “taken care” of. At that time, Malay terms such as “Orang Kurang Upaya (disabled person) and “Orang cacat” (handicapped person) were commonly used to refer to PWDs.

According to historical reports (Lee & Low, 2014), during the post-independence period from 1957 to 1990, Malaysia adopted a socio-welfare model for PWDs. This model impacted the educational system in Malaysia. Public education accessibility and educational opportunities for all were the outcomes of this model change. Integration programs in schools were one of the initiatives at that time. However, special education was not the top priority.

The argument for inclusive education arises from the United Kingdom (UK) and the United States of America (USA) (Lindsay, 2003). It promoted a shift of philosophical paradigms from welfare to a social model, which soon gained global consensus. This paradigm shifts to the social model significantly impacted Malaysian education policies from 1990 onwards. It resulted in three main educational options: special needs, integrated programs, and inclusive education. To improve access to quality education, the PWD Act (Government of Malaysia, 2008) brought about another paradigm shift from the welfare model to a human rights model, which promoted full participation in society (Lee & Low, 2014).

Table 1.4

Timeline of the Disability Models Adapted in Malaysia

Period	Timeline	Adapted Model of Disability
Pre-independence	1990 – 1957	Medial and welfare model
Post-independence	1957 – 1990	Socio-welfare model
Millennium	1990 - present	Social model Human Rights model

While these models of disability are reported to be implemented in the policies, how well has it been received by society and deaf people today (in the 2020s)? Also, the linguistic model of deafness is missing in Malaysia's documentation. Chong and Hussain (2022) conducted qualitative research exploring the identity construction and experiences of 15 Malaysian deaf people aged 27 – 54. They explored how mainstream society viewed deaf people and how deaf people identify themselves – as PWD or a linguistic minority.

Research results suggested that mainstream society viewed deaf people as PWD rather than a linguistic minority (Chong & Hussain, 2022). To look closely, the deaf participants reported how the mainstream society treated them, which was based on the welfare model of disability where PWDs are viewed as incapable, dependent, and need to be helped. Examples from Chong and Hussain (2012) showed that mainstream society thought of deaf people as dependent on others (e.g. not accepting communication through paper writing, not wanting to give clarifications through writing, and asking to speak to a hearing person instead), incapable of taking care of themselves; or had a mental illness. These perceptions of mainstream society are evidence that society's view of deafness is still in the charity/welfare model and has not yet moved to the social model of disability. Some of the deaf participants, on the other hand, wanted to convey that they are a linguistic minority (linguistic, cultural model) so that mainstream society can be mindful to include language accessibility (social model). However, as Chong and Hussain's (2012) research showed, the Deaf linguistic identity has not been firmly established in Malaysia.

Another observation from Chong and Hussain's (2012) study is that deaf participants have a variety of views of what PWD means to them. Although the term PWD is an acceptable and respectable term in the social model, according to OHCHR (2019), it is disliked by some deaf participants because of its negative connotation and association. Deaf participants viewed the term *PWD* as negatively associated with the medical model (e.g. there is something wrong with the deaf person; deaf people are only seen as impaired; it's only for the visible disabilities), welfare model (e.g. deaf people becoming dependent and expect being financially cared for), and social model (e.g. deaf people were not capable of doing many things that hearing people do). Hence, they might prefer to use another term to distinguish themselves from these negative connotations. One more commonly preferred and accepted term is *Deaf person* or *deaf person.*

In the big picture, policies have shifted from the welfare model to a social and rights model. At the same time, deaf people express a need to incorporate the linguistic model with the social model. However, on the grassroots level, mainstream society is still stuck in the welfare model and seems to have no clue about deaf people being a linguistic minority (Chong & Hussain, 2022). This would explain the confusion and complication of how to view deaf people in Malaysia. There is such a wide variety of perceptions ranging from a mix of the models by different people in both mainstream society and deaf people themselves.

One point of discussion about the view of deafness in Malaysia is whether both the mainstream society and deaf people themselves are ready, equipped, and willing to move away from the charity model. The linguistic model will wean off the welfare model that treats deaf people as ‘dependent’ and hence provide welfare assistance. Are the deaf people in Malaysia ready to let go of welfare and be empowered to be equal, independent members of society? Is mainstream society (including parents and educators) also sufficiently equipped to assist and support the development and empowerment of deaf people to live independent lives? Sadly, Chong and Hussain (2022) concluded in their recent study that the deaf typically accepts mainstream society's evaluation by identifying with it and playing the expected PWD roles. Unless the mainstream society changes its view of deafness and empowers deaf people, this transition from the charity model to the social model will take a long time.

1.5 The Situation in Malaysia

The overview of the disability models provides context to the language situation, parental challenges of deaf children, and the government's provision for deaf people in Malaysia.

1.5.1 The Language Situation for Deaf People

In Malaysia, the solutions implemented focus on prevention and rehabilitation based on the welfare and medical model. However, they may need to address the communication and social inclusion issues (linguistic and social modal) sufficiently. The Malaysian government's blueprint encourages social inclusion for deaf people; however, deaf people still generally struggle with social inclusion in a predominantly multilingual hearing society. Hence, this section highlights the communication challenges deaf people face in Malaysia.

1.5.1.1 The Multilingual Malaysia.

Malaysia has a rich ethnic and linguistic diversity, with 69.8% of the population being Malay (69.8%), Chinese (22.4%), Indian (6.8%), and others (1.0%) (Department of Statistics Malaysia, 2021). Malay, also referred to as Bahasa Malaysia, is the official national language generally used by the whole population. Other languages used widely across the country include English, Chinese, Tamil, and other dialects (Pregel & Kamenopoulou, 2018).

As for the deaf people in Malaysia, *Bahasa Isyarat Malaysia* (BIM), Malaysian Sign Language, has been recognised as the official language for deaf people (Persons With Disabilities Act, 2008). However, according to Chong (2018) who reviewed BIM's history and current usage, BIM was mainly used for private or public social interactions. More BIM usage needs to be made in both mass and social media. He further observed that the Malaysian deaf community has yet to reach an understanding that BIM is a separate and independent language, which is not *Kod Tangan Bahasa Malaysia* (KTBM - manually coded Malay), that has been used for *Total Communication* in the deaf schools since 1978. This complicated signing situation in Malaysia is due to the historical development of the language for the deaf.

According to records, while BIM began with the natural development of repeated gestures that became sign words, its development ceased when the language of the deaf was changed to oralism, total communication, and KTBM.

BIM also had some influence from American Sign Language (ASL). The development of BIM “restarted” in 2018 when the Malaysian Federation of Deaf (MFD) started compiling active sign words from the deaf community throughout Malaysia and compiled them into a book in 2000. Two more BIM books were published in 2003 and 2016, respectively (Chong & Hussain, 2021; Chong, 2018).

1.5.1.2 The Language Used in School. In the deaf school setting, *Bahasa Malaysia* (written/spoken) and KTBM are the primary mediums used for education (Pregel & Kamenopoulou, 2018). Chong and Hussain (2021)reported other communication methods also used in the classrooms – Total communication, manually coded Malay, Malay cued speech, oralism, and hybrid sign languages. Instead of using BIM, which has been developed and used among deaf interactions over time, teachers use Bahasa Isyarat Komunikasi (BIK - Sign language for communication), which is based on the textbook produced by the Department of Education. Chong and Hussain (2022) highlighted that signs illustrated in the Bahasa Isyarat Komunikasi textbook are not used in the Deaf community and were either invented or imported from other countries.

Although it has been suggested that BIM should be used as the language of instruction for deaf education (Chong & Hussain, 2021), there is yet a proper, thorough documentation on the linguistic description of BIM. The complex historical development and evolving nature of BIM over the past 70 years have also complicated the “sign language” situation among the deaf and mainstream society. Hence, the implementation of teachers using BIM in the deaf classroom at this stage is impossible without a clear description and acceptance of BIM by the government and educators.

Nonetheless, social connections in schools with teachers and classmates and at home with family are equally important. Meaningful communication, whether through speech, writing, or signing, is crucial for ensuring the equitable engagement of deaf students in the classroom (Lee et al., 2021). However, there needs to be more understanding of the importance of having such an inclusive environment in Malaysian schools (Khairuddin et al., 2018). Interpreting services for classes with deaf students are still insufficient, and there is also a shortage of teachers proficient in sign language (Nasir & Efendi, 2016).

Communication among classmates in Malaysian schools varied based on the selected educational program. Reports indicated that Malaysian deaf students enrolled in the inclusive program felt isolated. In contrast, those in the special education and integrated program enjoyed communication in sign language with fellow deaf students (Khairuddin et al., 2018). This shows a deficiency in communication with hearing peers, possibly attributable to language barriers. Fellinger et al. (2009) supported this potential explanation by discovering the correlation between language level (signed or spoken) used in interactions at school and peer relationship difficulties.

1.5.1.3 The Language Used at Home. The language situation at home for the deaf person varies according to the choice of language used at home. Foreseeing that Malaysia is a multilingual and multiracial country, each family has its own variety of spoken language, which includes its own mother tongue (e.g., Tamil for the Indians; Mandarin or/ Hokkien for the Chinese). The additional language used at home increases the language and communication challenges for the deaf person.

Here is an example of the language complication in a typical Chinese family in Malaysia: A Chinese family is likely to use spoken Chinese dialects at home. However, the deaf child learns written Bahasa Malaysia and English in school. The parents of deaf people who belong to the older generation may not quite understand English or Malay, not to mention making it a conversational language (spoken or written) at home.

Some parents may try to communicate with their deaf child with any means, such as gestural communication, visual language, minimal BIM, or KTBM (Chong & Hussain, 2022). Some parents in Kuala Lumpur could use basic sign language to communicate with their deaf children (Marippan & Yasin, 2020). Parents could sign and understand the child's sign language and correctly signal the alphabet, numbers, and name codes of the child, teacher, and friends.

However, parents had a low level of using KTBM, BIM, ASL, and SEE. BIM is almost always not accessible at home for the deaf person (Chong, 2014).

In addition, various communities in Malaysia might employ different written or spoken languages for communication. Deaf individuals would need to adjust to this multilingual communication landscape, which can pose a challenge, especially for those with limited proficiency in written and spoken languages. In short, the language used at home varies from family to family, depending on their linguistic preferences. The language situation is complicated because more languages are involved, but it also comes with limited accessibility for parents and deaf children. Poor communication and family disconnection often result when parents and deaf children do not share a common language.

1.5.2 Challenges of Parents

Parents play an important role in their children's development. They are also usually the main caregivers. There is more than ninety per cent of babies with hearing loss are born to hearing parents, with no reason to suspect hearing loss issues (Mitchell & Karchmer, 2004; Schein & Delk, 1974). Hence, the diagnosis of the child’s hearing loss often leaves parents unprepared to raise a deaf child. They face different challenges, such as dealing with their own emotions of accepting the child’s hearing loss (Zaidman-Zait et al., 2016) and making important decisions for the child’s future development (Porter et al., 2018). As parents play a crucial role in the development of the deaf child, attention has to be given to understanding the needs and challenges of parents as they raise their deaf child. So, this section will briefly point out parents' challenges in raising a deaf child while more details will be described in chapter two's literature review.

Parents' first challenge is the emotions when receiving and accepting their child's hearing diagnosis (Hamzah et al., 2021). Parents who once dreamed of a typical child's future face an unexpected new reality. Research has observed that some parents go through an emotional journey that is like Ross' stages of grief (Kampfe et al., 1993) as they come to terms with their children's hearing loss (Young & Tattersall, 2007; Zaidman-Zait et al., 2016). This is an important time for parents to be properly supported and counselled (Hintermair, 2006).

Other than accepting their child's hearing loss, parents also reported experiencing parenting stress (Dammeyer et al., 2019; Hartshorne & Schafer, 2018; Park & Yoon, 2018; Yap et al., 2018) are concerned about their ability to parent their deaf children (Vukkadala et al., 2019; Zaidman-Zait et al., 2016). This is not surprising as parents have little or no experience with anyone who is deaf, and therefore, there is no frame of reference (Kurtzer-White & Luterman, 2003) for what is expected. Parents may wonder what deaf people do and how they live (Nguyen, 2008). They, too, have questions about effective communication with their deaf children (Humphries et al., 2019). These questions about raising and making decisions for deaf children become important issues for parents to address.

Soon after the confirmation of hearing loss, the parents of deaf children are required to make decisions for their children's future development (Porter et al., 2018). The journey can be overwhelming to parents, as it includes being presented with technical information and the need to make decisions about interventions for the child's hearing restoration such as cochlear implants (Chang, 2017; Hyde et al., 2010), language acquisition (Kurtzer-White & Luterman, 2003), communication modality (Bowen, 2016; Crowe, McLeod, et al., 2014), and educational choices (Bagley et al., 2001; Takala et al., 2018).

1.5.3 Provision of the Government

The government also plays an important role in supporting children and their parents by providing resources for their development and well-being. The support provided by the government also extends to taking care of the welfare of deaf adults. The government's provision and support are mainly provided with an understanding of disability from the welfare and social modalities.

These types of support include establishing rehabilitation and training centers, special schools, financial aid for education and medical treatment, discounts for transportation and telecommunication, and employment opportunities (Jabatan Pembangunan Orang Kurang Upaya [JPOKU], 2023). To access these welfare supports, PWDs are required to register with the Social Welfare Department. PWD with hearing impairment is eligible to register if their hearing loss ranges from 15 dB (children) and 20bD (adults) to >90dB (JKM, 2018b). Below is the description of governmental support for the PWD, specifically highlighting those for people with hearing impairment.

1.5.3.1 Financial Assistance. The support from the government includes financial assistance. To encourage PWD to work and live independently, the Social Welfare Department gives a monthly allowance of RM 350. If the PWD's monthly salary is below RM 1,200, and the applicant is age sixteen and above, and is not staying in an institution that provides free food, clothing, and accommodation (JPOKU, 2023). To start a business, a one-off launch grant worth a maximum limit of RM 2700 is available for PWDs. Even for those unable to work, the Social Welfare Department prepares the financial help of RM200 for two months (to be reviewed after 12 months) according to certain terms and conditions to qualify for this financial aid.

Financial assistance was not limited to daily basic living needs but also extended to education. The Ministry of Higher Education (MOHE) provides financial aid (school fees and allowance) for those enrolled in government universities and MOHE-selected private universities, polytechnics, and community colleges.

Another form of financial assistance is through discounts and payment exemption benefits. Such special discount packages are available for PWDs for transportation and telecommunication, while payment exemptions are available for medical treatment and certain documentation fees. Fifty per cent discounts are available for PWD card holders for bus services, light rail transit system (e.g., intercity train rail service, more commonly known as Keretapi Tanah Melayu [KTM]), and domestic flight tickets that are bought over the counter. Telecommunication and multimedia benefits include free monthly landline rental service, free calls to the service manual directory, and a special internet service package.

Medical treatment fees of government hospitals are fully waived for PWDs by the Ministry of Health (MOH). Hearing aids, by doctor's recommendation, are available for individuals who are unable to afford them (JPOKU, 2023). There is no mention of available funds for cochlear implants. If hearing aids are purchased, tax exemption for hearing aids amounts to RM 6000. There is also an exemption from the payment fee of late registration for birth certificates and identity cards (known as MyKad in Malaysia) and the charge of replacing a lost MyKad. Passport application and renewal for PWD are of no charge. These special benefits certainly reduce part of the financial burden of PWDs.

1.5.3.2 Social and Developmental Support. Apart from financial assistance, the government has considered other practical needs to equip PWD with skills and opportunities for independent living through program and schemes. Namely, they are community-based rehabilitation (CBR) program, more commonly known in Malay as *Program Pemulihan Dalam Komuniti* (PDK), institution services, and special education.

The PDK program are spearheaded by WHO and was brought into existence in Malaysia by the Social Welfare Department, who which has been directly involved in the designing, evaluation, and modification of the community-based rehabilitation program (JPOKU), 2023). This is one strategy in the local community development for rehabilitation, training, education, equal opportunities, and the social integration of PWD. PDK program is implemented with the combined efforts of PWD, families, community, and services from the health, education, vocational, and social sectors. Activities at the PDK program include social and language development, fine and gross motor skills, sports and recreation, vocational training, music therapy, special Olympics sports, and horse-riding therapy.

The benefits of PDK program for the PWD are that (1) the appropriate programs are offered according to the specific needs of the PWD; (2) PWD are not separated from family, friends, and the community that they grew up with; (3) it cultivates independence among the PWD; and (4) it builds and strengthens connections and support between PWD and their family members. This program is being run throughout the whole nation with the active involvement of the community (Kementerian Pembangunan Wanita Keluarga dan Masyarakat [KPWKM], 2017). There are 554 PDK One Stop Center nationwide, including 41 centers in Perak. CBR One Stop Center is the focal point where the community can seek for advice, obtain, information and assistance for special needs and skills. In short, it functions as a PWD center for early intervention, information, reference, registration, and advocacy.

This is a reasonable effort in policies that intend to integrate the PWD with the community. However, how effective is the execution of the policies? Are the programs tailor for the special needs of the deaf person? Are facilities accessible for deaf people and their families? Are the resources and recommendations biased to hearing rehabilitation and spoken language modalities only? There is no documented information about this.

Other than the PDK program, there are institutional services, training centers, vocational training, and medical rehabilitation for PWD (JPOKU, 2023). However, these services are more for PWD with physical, learning, and mental disabilities, and none of the listed centers is for PWD with hearing disabilities. These programs do not cater to the needs of persons with hearing disabilities. According to the Social Welfare Department, counselling services are provided to empower PWD for career development and independent living (JPOKU, 2023). However, it is uncertain if BIM interpreting services are available for persons with hearing impairment in these programs. Although there are no official statistics on the number of BIM interpreters, according to MFD (as cited in Lau (2017) in *Malaysiakini*), there are less than 100 certified sign language interpreters for a population of 32,157 persons with impaired hearing in Malaysia.

1.5.3.3 Educational Support. In accordance with Act 685, Article 28 (Persons with Disabilities Act, 2008), the National Education Blueprint of Malaysia, the Ministry of Education has made plans to ensure that students with hearing impairment would have opportunities for quality education relevant to their needs (Ministry of Education Malaysia, 2013). For these students with special needs, the Ministry of Education has prepared three options of education for them - (1) the inclusive education program (IEP), (2) the Special Education Integration Program (SEIP), and (3) special education schools (Ministry of Education Malaysia, 2013). Each type of education provided tries to meet the different needs of the students with disability.

First, the Inclusive Education Program is for high-functioning special education needs students who can cope with the mainstream curriculum. Students will learn in a mainstream school with other regular students, and there will only be a maximum of five students with special needs per class. However, BIM interpreting services may not be available for students with hearing impairment in the classroom.

As for the Special Education Integration Program, students with disability and moderate functioning would learn in mainstream schools along with the regular students, but they will learn in different classes to cater for their special needs. On the other hand, special education is designed to meet the learning needs of students with lower functioning. They will be taught a simplified curriculum focusing on basic life and social skills. There are 22 primary schools and six secondary schools with special education for the deaf nationwide (Bahagian Pengurusan Maklumat dan Bahagian Pendidikan Khas, 2018; Kementerian Pendidikan Malaysia [KPM], 2018).

One of the challenges consistently raised in education for deaf students is the language used in classrooms. Chong and Hussain (2021) found that the communication methods used by teachers in Special Education Needs in Malaysia (e.g., total communication, manually coded Malay, Malay cued speech, oralism methods, and hybrid sign languages) are ineffective, leading to learning struggles for deaf students in the classroom. At the same time, there is yet no proper documentation on the linguistic description of BIM, and the complex evolution of BIM has also added to the confusion of using BIM in the classroom. Please refer to *Section 1.5.1 The Language Situation in Malaysia*, for more details on the language situation in Malaysia.

In Malaysia, 34 special education schools nationwide are exclusively for various disabilities, including two schools based in Perak (KPM, 2018). There are also six secondary vocational schools for PWD based in Johor, Pahang, Selangor, Kedah, Penang, and Sabah (Bahagian Pengurusan Maklumat dan Bahagian Pendidikan Khas, 2018). About 23% of primary and secondary schools have inclusive or integrated special education programs. However, these figures do not distinguish the number of schools catering to the hearing impaired, nor are the teachers sufficiently trained and equipped to manage the PWD, especially for the hearing impaired.

1.5.3.4 Employment Support. As for employment opportunities, starting on 1 April 2008, the government began a 100% employment and employment opportunities policy. The Workforce office also has a PWD placement system under the human resource ministry. For the private sector, a committee established in 1990 developed a code of practice to hire PWDs in the private sector. A business initiative assistance scheme is available for PWDs who want to start their own business and employ other fellow PWDs.

Another government initiative is Disability Equality Training (DET), whose goal is to change the perspective of disability—that impairment is not the reason for disability (JKM, 2018b). These good efforts assist the deaf in finding employment. However, the effectiveness of DET, deaf people’s employment experience, and the kind of jobs and wages offered have yet to be documented in research.

1.5.3.5 Conclusion. The government provided support and aid to the deaf people in Malaysia based on the medical and welfare model of disability. Although the official list of provisions is comprehensive for the welfare of deaf people in different domains (e.g. financial aids are given for medical treatment, transportation, and education), resources, support, and interventions seem to be provided according to the medical model that focuses on hearing rehabilitation and speaking. But even so, there was a limit in these medical and financial provisions: hearing aids are provided, but there is no mention of sponsoring cochlear implants and speech therapies in the list.

Since these medical interventions and resources are limited, providing other resources for communication and education is logical, especially in early interventions for deaf children. There seems to be a provision for sign or visual language to be accessible to deaf children through special kindergartens and the special education system. However, the debate about using BIM as the medium of instruction is still ongoing. The acceptance, use and development of BIM is lacking; offering bilingualism modals in early interventions is unrecorded. There is also no provision for BIM interpreting services for inclusive education for the deaf. Lack of this support and resources limits the deaf person's development and places a barrier to becoming an independent and equal member of society, which is the focus of the social model that Malaysia is transitioning to.

1.6 Problem Statement

The problems to be addressed through this study are the mental health vulnerabilities of deaf people, the parental challenges of raising deaf children, the need for a good support system, and the knowledge gap in the literature about deaf people in Malaysia.

1.6.1 Mental Health Vulnerabilities of Deaf People

Over the years, research has reported the vulnerability of deaf individuals to mental health problems (Kvam et al., 2006). Deaf persons had poorer psychological health (Fellinger et al., 2012), poor psychosocial adjustment (Gentili & Holwell, 2011), poorer quality of life (Fellinger et al., 2005), more emotional and behavioural problems (Vostanis et al., 1997), higher psychological difficulties (Martikainen et al., 2002), higher distress (De Graaf & Bijl, 2002), and higher rates of depression and anxiety (Kvam et al., 2006). Because of these vulnerabilities, Kvam and colleagues (2006) emphasised the need for society to be aware of the special risks deaf persons encounter concerning mental health.

One of the special risks deaf persons have been the different experiences related to stigma and discrimination as a deaf person in childhood (Kvam et al., 2006). Most deaf and hard-of-hearing people were raised in hearing environments, leading to potential challenges and distinct vulnerabilities that impact their socio-emotional well-being (Eichengreen et al., 2021). These challenges encompass isolation, tension, and struggle (Leigh, 2009). Difficulties such as the stigmatisation of deaf people (Mousley & Chaudoir, 2018) and instances of bullying victimisation in school (Cheng et al., 2019) have been linked to heightened psychological distress among deaf persons. Social exclusion, psychological distress and severity of hearing loss are risk predictors of suicidal ideation for adults with hearing loss, while psychological well-being is a protective factor (Akram et al., 2018). Hence, there is a need to explore the situation in Malaysia further.

There are various factors that would contribute to the mental health of a deaf person. However, since the view of deafness shifted from the “medical model” to the “cultural model” about three decades ago, more attention has been given to viewing deaf people as a linguistic and cultural minority rather than a group of people who share the same disability (Glickman, 1996). This new direction in research focuses on the importance of deaf identity for mental health (Chapman & Dammeyer, 2017; Glickman, 1996). For example, individuals with stronger group identities had better self-esteem, as having a group identity protected their self-esteem from the majority’s negative attitudes (Bat-Chava, 2000; Crocker & Major, 1989). As little is known about the identity of deaf people in Malaysia, it is necessary to explore so that suitable interventions and support can be provided to reduce the risk and vulnerabilities of deaf people’s mental health.

1.6.2 Parental Challenges in Raising a Deaf Child

Early interaction and emotional connection in the relationship between hearing parents and deaf children are important for the deaf child’s development (Kurtzer-White & Luterman, 2003; Loots & Devisé, 2003). However, it is a challenge to establish early interaction and emotional connections in the parent-child relationship without a common language when the child is deaf. Parents may also be caught off guard by what to expect when parenting a deaf child.

It is common for any new parent to experience stress and adapt to the new addition to the family. What more for parents with a deaf child? Research has estimated that ninety per cent of deaf children are born to hearing parents (Mitchell & Karchmer, 2004). Hamzah et al. (2021) state that emotions were identified as the biggest challenge faced by Malaysian parents during the process of their child’s hearing loss diagnosis. Parental emotions influence the acceptance of parents towards their child’s diagnosis. They may also experience grief for the child’s hearing loss, anxiety and stress, and feelings of incompetence in parenting a deaf child (Feher-Prout, 1996; Zaidman-Zait et al., 2016). In such instances, emotional and social support is very important for parents of deaf children.

In addition, there is a general lack of awareness of the specific effects hearing loss has on the individual (Mackenzie & Smith, 2009); parents may not know how to manage the problem and depend heavily on the professionals and government for knowledge and support for the development of the deaf child. Early intervention programs are vital to assist parents in the development of deaf children. However, similar to other countries, early interventions in Malaysia may also be inclined to focus on listening and speaking modalities for language development (Greene-Woods, 2020; Hamilton & Clark, 2020). In early interventions, valuable resources such as bilingualism or the sign language modality are missed opportunities for reducing language deprivation and improving parent-child communications (Greene-Woods, 2020).

Although there have been studies from other countries about the experiences of parents with deaf children, there is little documentation about parenting deaf children in Malaysia. As parents are the main contributors to the child's development, it is important to explore the challenges, experiences, and coping strategies of parents with deaf children in Malaysia. This is so that parents are better supported and equipped to help their deaf child develop to the best of their potential.

1.6.3 The Need for a Good Support System

There is a need for a good support system for the parents to care for their deaf child as it is essential for the child's development. Without it, parents struggle to meet their own and the special needs of the deaf child, affecting the child’s crucial development. A good support system would include the providence of professional sources of support with family-centered services and coping services (Poon & Zaidman-zait, 2014), parental resources (Hintermair, 2006), information resources on the role of sign language in language acquisition, cognitive development, and literacy (Humphries et al., 2019), and social support (Dunst & Trivette, 1994) including parent-to-parent support (Henderson et al., 2016) . In fact, with social support, hearing parents cope better and have better well-being (Åsberg et al., 2008; Hintermair, 2006; Zaidman-Zait, 2007). These resources are needed by parents so that they can provide a nurturing environment for the deaf child’s early childhood development.

As for Malaysia, the government and various organizations in the country provide support services such as early intervention, family support, education, and parent support groups. These organizations play an important role in supporting the government's work and providing choices for the availability of services and rehabilitation to deaf people (Majudiri Y Foundation for the Deaf, 2006). There is a society for the deaf in every state of the country. However, each state's services and quality of social support systems may vary. Organizations based in the cities (e.g., YMCA Kuala Lumpur) have more established services and support for deaf people (YMCA of Kuala Lumpur, 2021).

Although Ipoh is a city, there are only three known organizations that serve the deaf community - Persatuan Orang Pekak Perak (POPP, Perak Society of the Deaf), Persatuan Sukan Orang Pekak Perak (PESDEAF, Perak Sports Society of the Deaf), and YMCA Deaf club. Professional healthcare personnel in hospitals refer parents of deaf children to rehabilitation programs such as speech therapy or early intervention programs. Still, these centers do not help develop communication in sign language. There seems to be a lack of services catering to the deaf child's special needs for holistic development, especially quality communication skills.

In addition, the Malaysian government has strategized and started implementing action plans for PWDs in Malaysia through KPWKM (KPWKM, 2017). However, the action plans are for all disabilities and may not specifically address the specific needs of people with hearing impairment. There has been little documented feedback from deaf people about the implementation of the action plans. As the development of an individual is influenced by the environment directly or indirectly, as in Bronfenbrenner's ecological system theory (1979), the government's efforts and support to the PWDs and their family will influence the development of the deaf person's identity development. Therefore, there is a need to explore the support system of deaf children and their parents.

1.6.4 The Knowledge Gap

The deaf people in Malaysia consists of 0.1% of the population (JKM], 2018a). It is considered a minority of the population. The Malaysian deaf community is underexplored as few research documented the life experience of deaf people in the Malaysian context. There is only one study that explored the deaf identities in Malaysia that was published recently (Chong & Hussain, 2022).

Most of the research in Malaysia surrounds topics on education (Khairuddin et al., 2018; Khairuddin & Miles, 2020; Zainuddin et al., 2009), technology (Chuan et al., 2017; C. Y. Wong & Khong, 2011), employment (Dewi et al., 2020; Harun et al., 2019; Khoo et al., 2013; Tiun et al., 2011; Yusof et al., 2012; Yusof & Zulkifli, 2019). The other more well-researched topic was religion and the deaf people in Malaysia (Ghadim et al., 2013; Mohad et al., 2018; Mohad & Mokhtar, 2015). There are more recent studies about BIM (Chong & Hussain, 2021; Chong, 2014, 2018; Chong & Hussain, 2022; Chong & Jaafar, 2014)

As for the identity development of deaf people in the Malaysian context, only a limited number of research has been done (Chong & Hussain, 2022; Nakamura, 2002; Pregel & Kamenopoulou, 2018). Identity has been looked at from the anthropological view (Nakamura, 2002) and constructive view (Chong & Hussain, 2022). The anthropological view looks at the external, bigger picture of how deafness, ethnicity, and minority politics mould deaf identities in Malaysia. The state, institutional and cultural forces of the country shape the deaf identity. Interestingly, it was reported that disability was more relevant than ethnicity in shaping individual and social identities (Pregel & Kamenopoulou, 2018).

Chong and Hussian (2022) extended the research on deaf identity construction by using interpretive phenomenological epistemology to construct insightful accounts of participants' personal and interpersonal experiences in mainstream society. They explored the experiences of 15 Malaysian deaf leaders who had more than ten years of serving the deaf community. Through the reports of the deaf leaders, they found that mainstream society seemed to treat deaf people as a PWD rather than a linguistic minority group. Half of the participants (7 out of 15) agreed that deaf people viewed themselves as a PWD rather than a linguistic minority. The research concludes that deaf people typically accept society's evaluation by identifying with it and playing the expected roles of PWD. The linguistic identity of deaf people has not been strongly established among the deaf people in Malaysia. The term *PWD* also seem to carry a negative connation and reference to the medical and welfare model's view of deafness, although the term *PWD* is considered a respectable term by (OHCHR, 2019).

The findings of Chong and Hussain (2022) have provided more insights into deaf identity constructions from the grassroots level in the Malaysian local situation. However, the study’s results are limited to the perception of deaf identity in Malaysia and the personal experience of deaf leaders. Although the study did not state more about the deaf leaders’ background, they are likely based in Kuala Lumpur, an urban city, as most deaf activities and events that require deaf leadership and development are based there. Does the results of Chong and Hussain (2022) based on deaf leaders’ responses represent the identity development of deaf people of different backgrounds from other parts of the countries? Hence, this study would like to fill in the gap by exploring the identity of deaf people of a different background (e.g. not leaders) and from a different location in Malaysia (e.g. Ipoh, less urban).

Chong and Hussain’s (2022) study based the deaf identity construction on two main types of identity – PWD and linguistic identity. The identity of deaf people in their study was based on these two pre-conceived categories that Western countries have established in Deaf studies. This is a top-down approach of understanding identity of deaf people. However, would deaf people view themselves outside these two categories that other people have labelled them with? Therefore, this study would like to fill in the gap by using the bottom-up approach, exploring how deaf people arrive at their current perceived identity, which may (or not) be limited to two deaf identities (PWD and linguistic minority).

Another gap in knowledge in the Malaysian context is the experiences of deaf children's parents. As parent's emotional experience influences their acceptance of their child's hearing loss diagnosis (Hamzah et al., 2021) and decision-making for the child's development, it is important to understand Malaysian parents' thoughts, needs, challenges, and experiences to provide better assistance. Resources and support provided by the Malaysian government may be different or lacking compared to other more developed countries. Hence, reviewing parents' experiences in the local context will provide better insights about the Malaysian situation.

Most literature are from more developed countries and there are limited studies about the parents' experiences in the Malaysian context. Among those experiences of parents in Malaysia that have been recorded include the emotional experience when receiving the child's diagnosis (Hamzah et al., 2021) and the inclusion of deaf children in mainstream schools (Khairuddin & Miles, 2020). There is a gap about parent's experiences that needs to be filled as the experience of parents will provide context to the deaf person's identity development. Hence, this research hopes to bridge this knowledge gap to better understand parents' experience and its influence on the deaf person's identity.

1.7 Research Objectives

Therefore, to understand the identity development of a deaf person better, this research intends to explore (1) the experiences that shape a deaf person’s identity, (2) the experience and role of hearing parents bringing up a deaf child, and (3) the suggestions for improvement of existing support systems for the deaf people.

From Bronfenbrenner’s ecological system theory (1979) as the study’s theoretical framework, it is noted that the immediate and indirect environment influences the identity development of a deaf person. Hence, the first objective of the study is to explore the growing-up experience of the deaf person in terms of their relationship and experience with family, school, and anyone else that might have contributed to their development. This is to understand the microsystem of the child.

Secondly, this study also intends to investigate the support system and parents' experience in raising the deaf child. This will shed light on understanding how the other layers of society affect the parents’ parenting decisions, which shape the immediate environment of the deaf child. Decisions that parents make are based on government policies, available resources, and parents’ underlying views about deafness and their deaf child. It is essential to investigate the deaf person’s environment and experience to understand the development of their social identity. In this case, parents are one of the main people in the deaf child’s life. Hence, this study’s objective includes exploring the parents’ experience and the support system for deaf people in Malaysia.

After exploring the elements of the environment that affected the deaf child during that period (1980-2019), the research's third objective is to collect suggestions from both hearing parents and deaf children for further improvement of the existing structure to assist in the development of deaf children. These will be insightful as the country develops over time.

1.8 Research Questions

The three research questions for this study are as below:

1. What are the experiences that shape the deaf persons' identity?
2. What are the parents' roles and experiences in bringing up a deaf child?
3. What are the suggestions for improvement in existing support systems for the deaf people in Ipoh, Malaysia?

1.9 Significance of Study

1.9.1 Practical Contribution

One of the main concerns for the deaf community is their mental health vulnerabilities, as they tend to be socially excluded and isolated by the predominantly hearing community. Exploring the deaf person's life experiences at home and school will provide insight into factors necessary for cultivating an inclusive society. This objective aligns with the Sustainable Development Goal (SDG) 4 that focuses on the importance of providing equal access to quality early childhood development education, encompassing all levels of education (primary, secondary, tertiary), and vocational trainings for all individuals, including those with disabilities (United Nations Department of Economic and Social Affairs, 2023). The results of this study will assist government bodies, educators, and parents in formulating well-designed programs and activities that would integrate deaf children. This integration not only ensures they receive a quality education but also have better employment opportunities in the future.

Previous research highlights the significance of the deaf identity for self-esteem (Bat-Chava, 2000; Crocker & Major, 1989) and mental health (Chapman & Dammeyer, 2017; Glickman, 1996). Given the limited investigation into Malaysian deaf individual's identity, this study holds substantial importance. Rather than solely acquiring information about deaf people, it is crucial to directly glean insights from the deaf people themselves concerning their own experiences and perceived identity. Addressing this gap is important for the well-being and growth of the deaf community. Therefore, this research aims to amplify the voices of the deaf people, offering them an opportunity to share their personal experiences of living amidst a predominantly hearing community. The narratives of the deaf people will provide insights to their encounters, challenges, and needs as deaf people while navigating the multilingual environment of Malaysia. These narratives will also shed light on the formation of their identity through these experiences. Subsequently, stakeholders can employ this knowledge to assist deaf children in developing a healthy identity during their formative years.

The results of the study will also offer insights into raising awareness about deaf people – their language, culture, and behavioral norms, especially within mainstream society. This awareness about deaf people has the potential to reduce instances of discrimination, stigmatizations, and bullying often encountered by deaf people in hearing settings (Cheng et al., 2019; Eichengreen et al., 2021; Kvam et al., 2006; Leigh, 2009; Mousley & Chaudoir, 2018). Comprehending communication needs and sign language proficiency can empower the hearing community to foster greater inclusivity both in society and the workplace. Initiatives aimed at raising awareness about deaf people and sign language could also mark the initial steps towards bridging the communication divide between the hearing and deaf communities.

Furthermore, the results of the study will also enhance parents' comprehension of the challenges faced by deaf children, fostering a shift from negative perceptions and attitudes towards deaf people to positive ones. These insights may also provide the government and social workers with valuable knowledge to design programs aimed at helping parents grasp the diverse models of disability. Such understanding would enable parents to adjust their perceptions of disability in a manner that alleviates the stress associated with the parenting journey. Educating parents about deaf children and their needs is of paramount importance, given that parents are the main caregivers of deaf children. By raising proper awareness and offering education, parents can effectively manage parenting stress, cope with potential grief resulting from their child's hearing loss and cultivate improved communication and relationships with their deaf child. This proactive approach also serves to prevent instances of parental neglect or ignorance concerning the needs of the deaf child, which can adversely affect the child's overall development.

This study holds additional significance as it doesn't solely focus on the perspective of the deaf child but also takes into consideration the experiences of hearing parents. The insights from the parental experiences in this study will illuminate the gaps and deficiencies in the existing support system required for parenting a deaf child. These findings offer valuable information for the social welfare department to assess the effectiveness of the current support framework available for parents with children diagnosed with hearing loss. By increasing resources and refining the support system, parents will be better guided upon receiving a diagnosis of hearing impairment in their child. This initiative ultimately facilitates a smoother journey for parents, ensuring they receive the appropriate guidance and resources.

Lastly, this study is significant as it would reveal the firsthand experiences of hearing parents raising a deaf child and the unheard experience of deaf individuals in the Malaysian context. The journey and strategies of coping with or managing deafness are a valuable source of knowledge for others who are in similar situations. A study by Flaherty (2015) attested to this idea to prepare other hearing parents with deaf children about the possible challenges they would face.

Just as qualitative research draws out a rich description of a person's life experience, parents' experiences may foster appropriate actions to be taken for better outcomes (Marshall & Rossman, 2016). Hence, the insights into the parents' journey, along with the thoughts and feelings of deaf participants and their parents, would provide useful information to educate and create awareness among the stakeholders, such as professional healthcare workers, relatives, teachers, the community, etc.

1.9.2 Theoretical Contribution

The result of this research hopes to contribute to deaf studies in Malaysia and globally. Few research has been documented on the experience of deaf people living in Malaysia. Hence, the new knowledge provides insight into how deaf people cope in a multilingual country. These insights on the struggles, challenges and cultural situation of the deaf person and the hearing parent may be a helpful reference for other multilingual countries who are interested in the development of the deaf community.

This study's theoretical contribution is that its exploration of the identity development of Malaysian deaf people adds to the understanding of the existing Western deaf identity theories (e.g., Glickman’s social identity theory). It also reviews the usefulness of Bronfenbrenner’s ecological system theory for the development of a deaf person’s identity in the Malaysian context.

CHAPTER 2

LITERATURE REVIEW

This study explores three research questions about deaf people's experience, the parents' experience, and the support system for deaf people in Malaysia. To understand how the support system and parent's experience influence the experience of the deaf person, this chapter will begin with the support system for deaf people, parents' experience raising deaf children, and the deaf person's experience. Since identity plays an important role in a deaf person's well-being, this chapter includes literature and theories on the identity of deaf people. The chapter concludes with the theoretical and conceptual framework of this study.

2.1 Support System for Deaf Children

Children with hearing impairment and their parents need the most support during the early developmental years. Hence, much research has concentrated on the types and effectiveness of early interventions for the deaf child. This section is divided into three parts: hearing screening, early interventions for deaf children in Malaysia, and early interventions in other developed countries.

2.1.1 Hearing Screening and Diagnosis in Malaysia

Late identification of hearing impairment leads to missed opportunities for early intervention services to help with language acquisition (Hall et al., 2019). Hence, screening newborns for hearing impairment is of utmost importance. The Joint Committee on Infant Hearing (JCIH) endorsed early detection and intervention for infants with hearing loss through the universal newborn hearing screening (UNHS) (Joint Committee on Infant Hearing et al., 2000). The goals of the JCIH are to (1) screen infants by one month of age, (2) confirm diagnosis by three months, and (3) provide interventions by six months.

According to (Wong et al., 2021), there are no national programs for newborn hearing screening in Malaysia, but local hospitals have taken the initiative to conduct UNHS. A retrospective analysis of the universal newborn hearing screening in four public hospitals in Malaysia for the years 2015 and 2016 by (Wong et al., 2021). They reported that the coverage rate (the number of infants screened within one month of birth divided by total live births) in 2015 was between 54.9% and 90%. In 2016, there was a significant increase in coverage, but only one hospital (Perak) reached the 95% coverage rate benchmark. However, all four hospitals showed unacceptably low returns for follow-up for the second and third screening in both years (62.4% - 81.3%). One reason for the poor follow-up screening is the geographical distance, where most audiology services and facilities are available only in the capital and major cities, and the availability of UNHS programs in selected public hospitals (Wong et al., 2021).

Other reasons for the poor follow-up return include the lack of awareness and knowledge about childhood hearing loss among parents and healthcare professionals such as otolaryngologists (ENT), paediatricians, and neonatal intensive care unit nurses (Hamzah et al., 2021; Mazlan & Wong2018; Wong et al., 2019, 2021). A systematic review of early hearing detection and intervention (EHDI) programs for infants and young children in low- and middle-income Asian countries revealed that newborns and infants were mostly screened by audiologists while screening older children was mostly done by otolaryngologists, school instructors, and nurses (Deepashree et al., 2023). This indicates that other than healthcare professionals, other professionals such as audiologists and educators are also in the front line, meeting parents during screening and diagnosis. Their role is crucial in providing information, recommendations and referrals for early intervention to prevent delayed development. Hence, awareness and knowledge about childhood hearing loss and intervention among these frontliners are important.

The poor follow-up return rate reported in the study by Wong et al. (2021) indicated that there were children with possible hearing impairment who were supposed to come back for diagnosis assessment dropped out of the radar and did not get a diagnosis. These children may return for a diagnosis at a later age, but this would mean a delay in receiving interventions. The reported average age of confirmed diagnosis was two years old in 2017 (Yusoff et al., 2017) and 3.6 and 4.2 months in 2015 and 2016, respectively (Wong et al., 2021). This was considered late as it was beyond the recommended timeline of three months. Hence, interventions were delayed. Hearing aid fitting at two years and three months old, and cochlear implantation at three years and five months old (Yusoff et al., 2017).

Hamzah et al. (2021) reported other challenges of the medical professional services system that may have delayed intervention for the deaf child. The healthcare professionals lack information to ease parents' initial shock and acceptance of the child's hearing diagnosis, leaving parents in suspense about what to do next. There was also a delayed for further intervention because of the longer process of confirming the diagnosis, the late referral to other hearing health professionals, lack of knowledge among medical health professions, and lack of hearing facilities for hearing test.

2.1.2 Early Interventions in Malaysia

The early interventions after diagnosis are based on the medical model of disability, which focuses on hearing restoration and rehabilitation. Fitting hearing devices or cochlear implants and speech therapy are the first interventions for the deaf child. However, it is important to note that in Malaysia, not all deaf children may have access to these interventions.

Cochlear implants were not for all children with hearing impairment. They had to fulfil a few criteria in order to qualify for the surgery. The child should not be more than four years old and have a severe sensorineural hearing loss in both ears where hearing aids are of no effect (Seriman et al., 2021). If the child qualified for cochlear implants, there was no stated guaranteed funding for cochlear implants from the government. Parents may not be able to afford it. On the other hand, the government has funding for hearing aids (JPOKU, 2023).

With hearing rehabilitation through hearing aids, speech therapy is part of the intervention. It was reported that one of the fundamental challenges of the speech-language pathologist (SLP) profession is the inadequate number of SLPs in Malaysia (Chu et al., 2019). There are about 300 SLPs in Malaysia, with a ratio of one SLP to 100,000 people. SLPs in Malaysia mostly provide services for paediatrics. While deaf children fitted with hearing aids may benefit from speech therapy, the question is whether parents are able to afford the services and if they have the resources, time, and energy to support the child throughout the speech therapy.

Other than medical interventions, early intervention programs for deaf children are available from birth to age 3. At the preschool level (ages 4 – 6), the Ministry of Education provides special education preschool programs for the deaf (Bari et al., 2016). One example of early intervention and preschool programs in special schools is Tadika Istika Jaya (MFD, 2024). It is in these early intervention programs in special schools that sign language is introduced and used as the main form of communication. Deaf children in special schools, as early as age two, will also be taught motor skills, sign language for communication, etc. At age 4, a second language (e.g. Malay) is introduced, and deaf children are taught to write and speak. At ages 5 to 6, the students are exposed to both English and Malay and are able to handle the mainstream preschool curriculum. Upon completion of the special preschool, the deaf students would be ready to enter primary school.

While these early interventions are available for deaf children in Malaysia, the execution of early intervention program in Malaysia for students with special need (including deaf students) is less clear in practice as there is a lack of documentation on its implementation process (Bari et al., 2016). However, one of the reported challenges of the implementation of early intervention is that the teachers lack the knowledge, skill, and experience to conduct the early interventions (Abdullah & Bari, 2014). Abdullah and Bari did not indicate if it was teachers who taught specifically the deaf students, but this feedback is important to investigate further if it truly is. The knowledge and views of teachers towards deaf students would influence how early intervention and education are executed.

2.1.3 Early Interventions in Other Countries

From the above-reviewed literature, early intervention for deaf children mainly relied on medical intervention and special education programs provided by the government. This showed a reliance on the knowledge and recommendation of healthcare professionals and educators for the deaf child's development. Literature from Western countries, however, revealed a different perspective on the early interventions for deaf children.

According to JCIH (2019), the principles of early hearing detection and intervention are concentrated on "maximizing language and communication competence, literary development, and psychosocial well-being for children who are deaf or hard of hearing (p.3)". These principles have guided the designing and development of suitable programs for early interventions in developed countries such as the UK and the USA.

According to Wright et al. (2021), After early detection of hearing impairment, early intervention in the UK starts with specialist support programs that include language acquisition and learning skills. In the USA, parents are given information from the audiologist, written information and a discussion with a medical professional (Scarinci et al., 2018). Thereafter, the early intervention system begins with counselling and an information session with an early intervention provider for the deaf. The families will be linked to local education pathways that offer access to sign language training and a six-month program of support (Wright et al., 2021).

With the priority focusing on the deaf child's language and communication development, early interventions have placed emphasis on parental support and providing deaf children with language and communication rather than solely depending on medical professions and hearing rehabilitation. In fact, recent research gravitates towards providing family-centred early interventions (FCEI) (Maluleke et al., 2021; Moeller et al., 2024) and balanced communication approach options that include sign language (Greene-Woods, 2020).

2.1.3.1 Family Centered Early Interventions (FCEI). Parents are seen as the most important agents for supporting their young children's language development (Turan, 2019). Therefore, it is logical that early interventions for deaf infants should include them. However, in a South African review (Maluleke et al., 2021), the importance of the active role of the deaf child's family in the rehabilitation process was stressed. In fact, the Health Professions Council of South Africa recommended that early interventions must be family-centred within a community-based model of service delivery that is culturally congruent. Similarly, (Moeller et al., 2024) argued for FCEI that support for the deaf child should not be limited to parents but extended to include the family. "Family" refers to how the family is defined in any context (Moeller et al., 2024). They are the ones who need to be invited to participate in the interventions. For example, if "family" in Child XYZ's context includes grandfather, parents, sister, and cousin. All these family members should be invited to participate in the intervention for the deaf child.

The FECI is guided by five foundational values : (1) being family-centred, (2) responding to diversity, (3) involving invested parties (families and DHH individuals), (4) supporting holistic child development, and (5) ensuring fundamental human rights (Moeller et al., 2024). The FECI recognises that families rather than professionals are in the best position to identify the child's needs and strengths as they are constant in the child's life. Hence, the focus is to build on the family's existing strength, support parental self-efficacy, and provide or mobilise the support needed to address family-identified goals (Brand et al., 2018a; Dunst, 2017; Dunst & Espe-Sherwindt, 2016; Kilgo, 2022).

Other than that, FCEI needs to involve invested parties (Moeller et al., 2024). For example, family-to-family support and DHH adult-to-family support. Prior research has shown that family-to-family support positively influences families' well-being, knowledge, and empowerment (Henderson, Johnson, & Moodie, 2014). FCEI emphasises holistic interventions. Szarkowski and Hutchinson (2016) suggested that holistic interventions may include approaches to learning, social and emotional development, language and literacy, cognitive, physical and motor development, and perceptual development (e.g. auditory, visual, vestibular).

2.1.3.2 Bimodal and Bilingual Early Interventions. In the West, early interventions are believed to provide balanced options that include all types of communication approaches. However, given the variety of communication approaches available and the epistemology of professionals making recommendations, there seems to be bias in the system. Intervention systems in practice are inclined to focus on listening and speaking modalities for language development (Greene-Woods, 2020; Hamilton & Clark, 2020) rather than including the sign language modality. Bilingualism (spoken and signed language) has not been encouraged as there is a belief that acquiring sign language would affect acquiring listening and speaking skills (Harmon, 2013).

Greene-Woods (2020) argued for the need for bilingualism as part of the early intervention. Often, the quality of access to sound is hard to determine until the child is able to respond using spoken language. To wait till that time, the child’s language development has been severely delayed. However, bimodal bilingual strategies can avoid these preventable language delays, assist in developing more effective spoken language, and provide better cognitive outcomes compared to spoken language interventions alone (Davidson et al., 2014; Hassanzadeh, 2012).

Another recommendation for bimodal bilingual early interventions is to involve deaf adults (Gale, 2021). The benefit of connecting deaf adults with deaf infants and their families early is that it can reduce parental stress and increase confidence in raising their deaf child (Hintermair, 2000). Secondly, deaf adults model visual language strategies, which helps with language development and reduces language delays (Humphries et al., 2012). Deaf adults are also valuable collaborators in early interventions because they can share personal experiences, teach visual strategies, and show possibilities to the parents and deaf children (Gale, 2020). Deaf adults become models that provide deaf children with shared ontological experiences of being deaf and can provide guidance on how to navigate society as a deaf person, maintain a positive self-image, develop self-esteem and confidence, learn to be assertive, and ask for help when needed (Cawthon et al., 2016; M. Kusters, 2017).

2.2 Experience of Parents

Parents play an important role in the child's life. The role and involvement of parents are even more crucial for the development of a deaf child. In fact, the family is considered one of the most crucial elements for the successful development of a child with hearing loss (Moeller et al., 2024; Sneed & Joss, 1999). Therefore, this section reviews literature about the experiences of parents with deaf children – parent's response to the child's diagnosis of hearing loss and the parental stress that comes with parenting a deaf child.

2.2.1 Parents' Response to Child's Diagnosis

The initial stages of diagnosis are usually difficult for parents with normal hearing (Burger et al., 2005). Many parents whose infants were diagnosed with hearing loss are not ready to handle the reality that is assumed. According to Schein and Delk (1974), more than 90% of babies with hearing loss were born to hearing parents, with no reason to suspect hearing loss issues. Malaysian parents reported having felt guilty for not being aware of their child's development, confused about how their child could be deaf and found it hard to accept the diagnosis (Hamzah et al., 2021). Some other Malaysian parents felt embarrassed and dejected that their child was deaf (Chong & Hussain, 2022). Other reported common emotions that parents experienced upon diagnosis of the child's hearing loss include feeling shocked, sad, grieved, anxious, and concerned (Chong & Hussain, 2022; Gilliver et al., 2013; Hamzah et al., 2021; Kurtzer-White & Luterman, 2003; Young & Tattersall, 2007).

As the majority of parents of deaf children are hearing, the diagnosis of a child can be distressing (Christiansen & Leigh, 2004), and it has a great impact on the family. Some Malaysian parents were shocked and could not believe the diagnosis. So, they sought a second opinion in the hope that the initial diagnosis was incorrect (Hamzah et al., 2021). In some instances where the diagnosis was institution-initiated (e.g., newborn screening), parents had to cope without any preparation and without any time to 'enjoy' their child as 'normal' (Kurtzer-White & Luterman, 2003). When their child is suspected to have hearing loss, parents who once held dreams of the child’s future as a normal child are forced to face an unexpected new reality. These parents rarely have the opportunity to work through the emotional process of integrating their deaf child into the family (Leigh, 2009).

Hence, it was said that parents go through a personal emotional journey of accepting and adapting to the child’s hearing loss, which is like the Ross’ stages of grief (Kampfe et al., 1993). The first and initial stage is that parents experience shock and numbness to the situation. Then, upon recognising the situation and consequences, they may feel a range of negative feelings such as frustration, depression, incompetence, confusion, guilt, anger, and disappointment. The third stage is when the individual is in denial of the diagnosis and the situation. It is common for hearing parents to search for different ways to “fix” the problem. Lastly, parents acknowledge and accept the diagnosis, which leads to an openness to discuss and assume responsibility for interventions (Kampfe et al., 1993). Each parent may not experience all four of these stages or may not be in a certain order.

However, other researchers do not agree with using Ross’ model of grief, which is based on death, to explain parental grief responses in general (Bruce & Schultz, 2001). They explained that there is an expectation that grief will be resolved and the loss accepted, just like how it is with the episode of death. On the contrary, grief may be ‘non-finite’ and occur over the lifespan. This is especially true if there is a difference between the idealised child and reality. Hence, if this model of grief based on death is used, parents' grief may be interpreted as pathological because they fail to meet the expectation of resolving their grief as if the child's hearing loss was time-limited and episodic (Kurtzer-White & Luterman, 2003).

Kurtzer-White and Luterman (2003) continue to explain that grief is continuous with trigger events that remind parents of the discrepancies between their expectations and the child's actual performance, which contributes to the ongoing emotional stress. Parental grief is usually associated with developmental milestones where parents are reminded of the loss of what their child would be able to do if they did not have this hearing loss. When triggered, the cycle of grief repeats. Kurtzer-White and Luterman (2003) further emphasised that this parental grief must be acknowledged during diagnosis and over the child's developmental life. Acknowledging this 'non-finite' grief would supposedly help parents understand their emotional responses throughout the journey of raising their child with hearing impairment.

2.2.2 Parental Stress

There is no doubt that parenting is stressful, and what is more for parents of children with hearing impairment. Research has reported that parents of children with hearing impairment experienced higher context-specific stress than parents who had typical hearing children (Quittner et al., 2010). Fathers of deaf children are more stressed when compared to fathers of children without disabilities (Mavrogianni & Lampropoulou, 2020).

In addition, parental stress has been one of the main topics explored in the literature across the globe, focusing on its relationship with parents' acceptance and reaction towards the child's hearing status, coping, resources, social support, and child's social-emotional and attachment outcomes (Quittner et al., 1990, 2010). Other studies reported that parenting stress is related to communication difficulties between parent and child, child's age at diagnosis and degree of hearing loss (Pipp-Siegel et al., 2002), the child's mode of communication (Åsberg et al., 2008), hearing devices (Sarant & Garrard, 2014), delays in child's acquisition of language (Dirks et al., 2016), behavioural problems (Quittner et al., 2010), and perceived support for the child and family (Åsberg et al., 2008; Meadow-Orlans, 1994).

2.2.3 The Challenge of Decision-Making

The source of parental stress is connected to the unique challenges that the hearing parent faces in raising their child with hearing loss. A study by Whicker et al. (2019) explored parents' challenges in caring for children with hearing loss and found that the unique challenges that parents faced were related to decision-making and planning, interprofessional collaboration, and child communication and behaviours. The main decisions parents had to make for their child with hearing loss are related to hearing restoration, implantable devices, language acquisition, and communication modality (Kurtzer-White & Luterman, 2003; Porter et al., 2018).

Parents need to make these decisions that would have a lifelong impact on their deaf child. Parents struggle because they have no knowledge or experience of deafness (Mitchell & Karchmer, 2004). Also, most parents had little or no experience with anyone who was deaf; therefore, they had no frame of reference for what was expected (Kurtzer-White & Luterman, 2003). It is likely that their understanding of deafness and deaf people is based on cultural stereotypes or information from the media (Kahneman, 2011). Regardless, parents need information and knowledge to make such decisions. Without sufficient information, knowledge, and support, parents' stress levels are high (Hintermair, 2004; Lederberg & Golbach, 2002; Meadow-Orlans, 1994; Pipp-Siegel et al., 2002; Sarant & Garrard, 2014).

2.2.3.1 Obtaining Information. After parents receive the diagnosis of their child's hearing loss, they require information to make decisions on treatment. The challenge parents face is to find relevant and sufficient information to make the decisions. A Korean study reported that parents were frustrated when the diagnosis was received without support or when the hospital only provided partial information (Park & Yoon, 2018). Similarly, there was a lack of information given by healthcare professionals in Malaysia, leaving parents feeling burdened (Hamzah et al., 2021). In South Africa, parents reported that the lack of knowledge and information about hearing loss made it difficult for parents (Davids et al., 2021).

On the other hand, when there was information within reach, the provision of information came from different sources. For example, information about cochlear implants was from ear, nose and throat surgeons and audiologists (Alkhamra, 2015). Sources of information about communication modalities came from teachers of the Deaf, speech pathologists, and deaf adults (Crowe, Fordham, et al., 2014). However, when decision-making was related to implantable devices, parents sought information from other parents (Chang, 2017; Fitzpatrick et al., 2011).

With all these available information, parent face a new challenge of what to do with the information received. There was difficulty in understanding the information provided, and it affected their ability to make an informed decision (Mulla et al., 2013). Parents reported they received information that was not balanced or advice which was conflicting from professionals (Matthijs et al., 2017; Nelson et al., 2017). While some studies reported that parents felt they had sufficient information to decide (Fitzpatrick et al., 2011), other studies showed that parents felt that they needed more information (Chang, 2017).

2.2.3.2 Making Decisions. After obtaining information, how are these difficult decisions made? Professionals are to promote informed choice and decision-making, where parents require information that promotes understanding about their options, the benefits, risks, and uncertainties of each option, and the short- and long-term consequences of choosing each option (Porter et al., 2018). But who makes the decision for the child's intervention?

According to Charles and colleagues (1999), there is the paternalistic model (clinician-driven) and the informed decision-making model (parent-driven). In between these two models is the shared decision-making model, where parents and professionals share the decision-making process (Charles et al., 1999). The current preferred model is to 'empower' parents and assist them in becoming autonomous decision-makers. Patients reported feeling abandoned by their clinicians when they had to make the decisions alone (Elwyn et al., 2012). Therefore, the shared decision-making process seems to be ideal where "both clinicians and clients share the best available evidence when faced with the tasks of making a decision, and where patients are supported to consider options, to achieve informed preferences" (Elwyn et al., 2012, p.1).

2.2.4 The Challenge of Communication

The other main challenge parents face is communication with their deaf child. Research revealed that parent-child interaction plays a key role in the child's language development as the reciprocal social exchanges between infant and parent establish a context for language learning (Leclère et al., 2014). Communication is indeed important, but it is also a complicated issue for parents of deaf children (Holmström, 2022). How do parents communicate with their deaf child? Parents with little or no experience with deafness or deaf people may not know how to decide on the communication modality, so they seek professionals for advice.

Among the professionals, there is a debate over the two main approaches for communication modalities – the medical model (deafness is viewed as a disability) or the cultural-lingual model (deaf people are viewed as a cultural and linguistic minority) (Bagga-Gupta, 2016). Many NGOs provide a medical perspective where cochlear implants are encouraged, while other NGOs provide a cultural-linguistic perspective where the importance of sign language is stressed (Holmström, 2022). While such a variety of perspectives and information are offered, hearing parents need to think carefully through these conflicting perspectives when deciding what communication modality would be best for their deaf child (e.g., spoken vs. signed language). Research reported that the conflicting views on communication have made it hard for parents to navigate information, advice, and make informed decisions (Lyngbäck, 2016).

2.2.4.1 The Choice for Spoken Language. Hearing parents who have little knowledge about deafness and deaf people would usually meet medical professionals first before they meet deaf people. Hence, the first advice they hear is from a medical view, which is to restore hearing. The typical interventions are for cochlear implants, hearing aids, and speech therapy. Evidently, studies reported that professionals often advise parents to focus on learning spoken languages and avoid or delay learning sign language (Crowe et al., 2014; Decker et al., 2012; Lyngbäck, 2016; McKee & Vale, 2014a).

While there are benefits to restoring hearing at an early age with today's available technology, one concern that arises in opting for spoken language as the communication modality is that it requires effort for parents to train their deaf child to ensure good spoken language development. Parents may play the role of teacher and trainer, more than just being the parent (Bruin, 2018). Nonetheless, research showed that although parents varied in their choice of communication modalities with their deaf child (e.g., oral approach, sign-supported speech), the majority of hearing parents still preferred to use spoken language for their deaf child (Lederberg et al., 2013a).

2.2.4.2 The Choice for Signed Language. Humphries and colleagues (2019) held a different opinion from the medical view of deafness. They were not against the medical view of restoring hearing, but rather, they stressed the importance for the deaf child to have access and opportunity to learn language as early as possible, whether it was spoken or signed (Humphries et al., 2022). Since sign language is the only language accessible to deaf children at birth until hearing devices are introduced at a later age, hearing parents should use sign language as the first communication modality. This is more so because sign language plays a role in the deaf child's early years of language acquisition, cognitive development, and literacy.

It is argued that the negative consequences of language deprivation can be mitigated if sign language is introduced without delay to a deaf child (Hall et al., 2019b). Recent research concluded that learning sign language does not hinder acquiring spoken language (Pontecorvo et al., 2023). In fact, early language exposure through sign language improves language acquisition and the ability to master other languages, including English (Hall et al., 2019b; Humphries et al., 2019). Sign language enables the deaf person to communicate without relying on technology (Zakay et al., 2021). Therefore, even when hearing parents optimise the access to sound for their deaf infants, visual attention to communication is just as important (Harris & Chasin, 2005), even though parents are generally less intuitive to using supporting visual attention for communication (Waxman & Spencer, 1997).

Secondly, the whole family is encouraged to learn sign language simultaneously as the deaf child learns (Humphries et al., 2019). Learning sign language together is one of the strongest bonding experiences that the deaf child and the family can have. Parents and deaf children who used sign language only reported perceiving more support and had lower stress (Åsberg et al., 2008). It is ideal that the whole family learns sign language, but hearing parents struggle with learning and using the language. Research in Ghana reported that parents were not able to communicate with their deaf children because they lacked proficiency in sign language (Opoku et al., 2022). Similarly, in South Africa, hearing parents reported that communication was difficult, hard, and frustrating (Davids et al., 2021).

Some of the concerns in learning sign language is that the opportunity to attend courses varies between countries and locations, and courses designated for parents are sparse (McKee & Vale, 2014a; Napier et al., 2007; Snoddon, 2015). There was also a lack of instructional guidance and materials for learning sign language (McKee & Vale, 2014a). These barriers made it harder for hearing parents to learn and acquire sign language for communication with the deaf child.

Another way to facilitate the acquisition and use of sign language is to participate in deaf environments where deaf people gather and sign language is used. Such platforms provide opportunities for learning and socialising with other deaf people (Weaver & Starner, 2011). However, a deaf environment may also be characterised by conflicts, annoyances, and condemnation when parents compare their situations and opinions with others on that social platform (Åkerström & Jacobsson, 2009). Some parents were viewed as too ideological or too passive. They also received different advice and support from professionals, which can be confusing.

2.2.4.3 Other Communication Challenges. Better quality communication within the family may reduce the level of stress in the family (Mapp & Hudson, 1997). However, communication in the family with hearing and deaf misers is challenging. The “dinner table syndrome” is a common phenomenon where the deaf member is usually left out of family conversations that take place over dinner or during family time (Meek, 2020). The deaf member is usually excluded from family conversations due to difficulties in communication. One study revealed that hearing families got used to communicating via texting rather than speaking directly to deaf family members. Eventually, the deaf child slowly became an outsider at home (Park & Yoon, 2018).

Parents may have to adjust their communication in a range of ways (Ahmad & Brown, 2016). Other efforts include mothers playing the role of the family mediator to improve communication between the deaf child and the other hearing family members (Park & Yoon, 2018). However, playing this role was too demanding and tiring, as extensive efforts were needed to achieve the goal of better communication in the family. The other family challenges mothers face include - paying insufficient attention to hearing siblings of the deaf child, higher parental expectations on hearing siblings helping the deaf child, expectations for siblings of a deaf child, and lack of communication within the family (Park & Yoon, 2018).

2.2.5 The Challenge of Educational Choices

Another stress of parents is their concern for their deaf child's education (Ebrahimi et al., 2017). Educational choice is usually closely linked to communication modality choices. There is a dichotomous approach to education for the deaf – hearing restoration and auditory-oral education vs non-surgical approach and American sign language (Zakay et al., 2021). Parents are provided necessary information to weigh the risks and benefits before making an informed decision for their deaf child's education.

There is a growing trend in America to send deaf children with cochlear implants to mainstream schools, which require oral communication (Moores, 2010). A Korean study revealed that mothers also preferred to send their deaf child to mainstream education because it was thought to enhance the child's social skills for the future, especially when they would eventually need to interact with hearing people (Park & Yoon, 2018). Some studies showed that deaf babies who are implanted before 12 months old could "catch up" with their hearing peers (Levine et al., 2016). Therefore, parents need not worry about future education since the child would be able to function in the hearing classroom.

The other educational choice for deaf children is special education. Deaf schools use sign language as the main mode of communication. Research in

America showed the impact deaf schools have on the deaf child's cultural identity (Nikolaraizi & Hadjikakou, 2006), which is significant for psychological well-being (Chapman & Dammeyer, 2017; Hafele, 2001). The presence of Deaf role models, such as their Deaf teachers and Deaf peers, improves their self-esteem (Interlandi, 2005). With support from the worldwide Deaf community, sign language, and a lifestyle driven by visual experiences, a deaf child is given the opportunity to have a full and meaningful life without the need for surgery (Zakay et al., 2021).

Special education seems to be beneficial for deaf people in developed countries. However, the educational opportunities may not be the same for underdeveloped or developing countries. Parents struggle to determine the optimal course for the education of their deaf child within the limited educational choices available in the country. Mothers had difficulty obtaining practical information and reported a lack of available information about the education transition (e.g., special schools to mainstream education) (Park & Yoon, 2018). A Korean study reported that some parents decided on mainstream education while others were determined not to utilise special schools for various reasons. Parents were concerned that their deaf child would receive adequate and equal education if their child studied in a special school that also catered for other multiple disabilities (Park & Yoon, 2018).

2.2.6 The Need for Support

As the majority of parents of deaf children are hearing, the diagnosis of a child can be distressing (Christiansen & Leigh, 2004). Parents' unresolved feelings of diagnosis affected parenting morale (Sealy et al., 2023). How well parents adapt to these challenges also depends on their personal (e.g., acceptance of a child's deafness, parenting self-efficacy) and social coping resources (e.g., formal and informal social support) (Quittner et al., 1990). These reports are telltale signs that parents need support and guidance in raising deaf children. All these concerns may be addressed by providing early intervention programs and social support systems for hearing parents with deaf children.

Parents may benefit from the counselling and the support of early intervention programs as they acquire knowledge about hearing loss, assistive devices, how to manage them, and how language develops in a young child (Ahmad & Brown, 2016). Early intervention programs also assist parents in capitalising on their communication interactions with their children (Rees et al., 2015). This knowledge is helpful for parents in managing their deaf child. However, the support system should not be limited to just knowledge about the deaf child's development; it also needs to include other elements of social support. Parents voiced a need for various supportive services such as different treatment methods for speech therapy, network building among families, and integrated informational support (Park & Yoon, 2018). Collaboration with deaf adults in early intervention may also help reduce parental stress as they model strategies for adapting to life for deaf children (Gale, 2021).

Perceived support was important as it significantly predicted parenting stress (Åsberg et al., 2008). The lack of support also made parenting deaf children a lonely journey (Davids et al., 2021). So, having parent support groups are beneficial as parents often look to other parents to learn from their experience raising deaf children (Chang, 2017; Fitzpatrick et al., 2011; Henderson, Johnson, Moodie, et al., 2014). Parent support groups provide a platform for sharing knowledge and experience as a form of encouragement in the parenting journey.

2.3 Experiences of Deaf People

According to Erikson (1968), the social environment plays an important role especially in the adolescents' life as they focused on the opinions and expectations of others. For the deaf child, the family and school make up the social environment and are the main influences on their identity development. This section of the literature review explores the deaf person's experiences at home and in school and how it influences their identity.

2.3.1. Social Experiences in Family

Ninety per cent of deaf children are born to hearing parents (McKee & Vale, 2014b; Mitchell & Karchmer, 2004). Across research studies, participants are often the only deaf person in the family (McKee & Vale, 2014b; Sheppard & Badger, 2010). Being the only deaf child in a hearing environment, they may feel lonely, alienated, and vulnerable to negative self-perceptions (Olivia, 2004). The exclusion and isolation from family in childhood may also lead to depression (Sheppard & Badger, 2010).

Interviews were conducted with depressed culturally Deaf adults about their childhood experiences (Sheppard & Badger, 2010). They revealed in the interviews that they were the only deaf person in the family and had felt isolated as a child because there was no common language within the family. They grew up feeling defective and like a burden to the family. These experiences make them feel hopeless and depressed, and they may attempt suicide to escape.

These reports of deaf people feeling excluded from family interactions and isolated are not exceptional incidents. It is so common that a term has been given to describe this phenomenon. It is known as the “dinner table syndrome”. It originated from the scenario where the deaf person is left out from family conversations over the dinner table and became “a metaphor for all the conversations that are not completely accessible when deaf people are in situations with hearing groups” (Meek, 2020; p. 1677). Family members also tend to exclude deaf members from conversations when communication is difficult, slowly making the deaf person an outsider in the family (Park & Yoon, 2018).

Some deaf people reported developing strategies to avoid asking for clarification in missed conversations. They do so by reading at the table, laughing when others do to make it appear they understand, or being excused early from the table (Lewis, 2016). Although deaf people may avoid awkward conversations, they miss out on essential conversations and incidental learning during dinner time and are left isolated (Meek, 2020). They miss out on the family's discussion about different topics ranging from the local or international news to what they did at work or school or what events transpired during the day (Meadow-Orlans et al., 2000).

On the other hand, when families use sign language, positive relationships are fostered between the deaf and hearing siblings. The experience of having a deaf child also brings families closer (Nybo et al., 1998). The more use of sign language, the more fluent and natural communication is, and the deaf child is treated like their other siblings (Marschark, 2007). The siblings of the deaf child also are playmates, companions, friends, protectors, helpers, competitors, rivals, and parental substitutes for the deaf child (Atkins, 1987). Such positive sibling relationships contribute to the deaf child's socio-emotional development, identity formation, and coping with deafness (Eichengreen & Zaidman-Zait, 2020; Woolfe, 2003). Support from parents contributes to positive self-worth and well-being (Kef & Deković, 2004).

2.3.2 Social Experiences at School

The deaf person's social experience at school depends on the type of school and its environment. The current trend in America is to place deaf students in mainstream schools for inclusion. Historically, deaf students were placed in residential and specialised schools (Angelides & Aravi, 2006; Leigh, 2009). Malaysian students can study in residential and specialised schools or schools with integrated or inclusive programs (Lee & Low, 2014). Hard-of-hearing children are likely educated in mainstream schools with minimal support services (Punch et al., 2006). Educational background varied, from general schools with or without support to residential schools for the deaf. In the last two decades, the trend in education has been moving towards integration (Hyde & Power, 2004).

It has often been debated that deaf children should be sent to mainstream schools because of the possible cognitive gains. However, would this be at the expense of the social consequences for the deaf students? Most deaf students who study in mainstream schools lack social contact (Punch & Hyde, 2011). Deaf students were more likely to be neglected by their peers and less likely to have a friend in the classroom (Nunes et al., 2001). Compared to their hearing counterparts, deaf adolescents experienced more peer problems and lower levels of friendship (Terlektsi et al., 2020).

The support of peers played an important role in the deaf students' social experience—for better or worse. The type of school deaf students studied in seemed to be secondary to the importance of the social support they received in school. It is not uncommon to hear of deaf students being bullied by their peers because of their differences. Students who self-identify as deaf are more at risk of being bullied (Kent, 2003). This may be due to the negative stigma of being deaf. So, deaf students cope by not self-identifying. Israelite et al. (2002) reported that the hard of hearing students wanted to hide their hearing differences because they felt mistreated due to the lack of understanding of the teachers. Some of them also did not like to be singled out as hard of hearing.

On the other hand, social experiences can be positive when supportive peers are present, and school is a place to bond (Israelite et al., 2002). Participants developed positive and rewarding peer relationships despite their earlier experiences of being bullied (Terlektsi et al., 2020). Some others cope by expanding social networks rather than withdrawing from them (Israelite et al., 2002). Deaf students perceive positive support when their specialised teachers are perceived to be sensitive (Israelite et al., 2002). Support from peers contributes to the positive self-worth and well-being of the deaf person (Kef & Deković, 2004).

The presence and friendship with other deaf people may counteract negative emotions experienced when in unsupportive hearing environments.

This highlights the importance of the Deaf community, which provides a platform to socialise with other deaf people. The Deaf community was also the place where the deaf people learnt about their cultural Deaf identity (Chong & Hussain, 2022). The presence of deaf role models in the community also contributes to the young deaf person's self-esteem, confidence, and identity (Cawthon et al., 2016).

2.3.3 Family, School, and Identity

Identity is closely connected to each person's experiences (Ohna, 2003). Deaf people's experience at home with hearing family members and their experience in school with teachers and peers influence deaf people's developing identity. In the family, parents played an important role in helping the deaf child develop their own identity. When deaf children have positive attachments with their caregivers, the deaf child securely explores the environment and learns to face challenges competently. This safe exploration helped to develop the deaf child's self-confidence and a secure sense of self (Sarason et al., 1990). Parental acceptance and support also facilitated deaf adolescent's ability to navigate the balancing process between their uniqueness and similarities to others (Leigh, 2009) as they learnt about themselves and their identity in society.

To further understand how the deaf person's experience influences their identity, Punch and Hyde (2011) conducted interviews with teachers, parents, and the deaf adolescents themselves. They found that adolescents were worried about peer relationships and struggled with their concept of self. The academic and social experiences that involved interaction with classmates and teachers also play a crucial role in deaf students' identity development (Hadjikakou, 2011; Hadjikakou & Nikolaraizi, 2007). Peers and authority figures in school had been identified as a 'powerful force' in the making and moulding of identities (Davidson, 1996).

A study by Hadjikakou and Nikolaraizi (2007) further revealed that the type of school impacted the cultural Deaf identity of deaf students. They found that deaf students who graduated from hearing schools identified with hearing culture and preferred to be with hearing people. However, those who graduated from hearing schools but met culturally Deaf people later in life felt immersed in both cultures. They tended to have relationships with both hearing and Deaf people. Lastly, those who attended both Deaf and mainstream schools identified with the Deaf culture. The result of this study reinforces the idea that the type of schooling experience directly impacts specifically the cultural Deaf identity of the deaf person.

2.3.4. Deaf Person's Identity Journey

2.3.4.1 Acknowledge deafness. McIlroy and Storbeck (2011) explored what it means to be deaf among deaf participants. The deaf participants were of different family and educational backgrounds and had different self-described identities (e.g., hard of hearing, Deaf, hearing impaired). The results of their study captured deaf people's experiences and awareness of being deaf. A few were not aware of themselves as different and deaf. Some of them discovered they were deaf and different and struggled for inclusion versus exclusion. Some others experienced the trauma of exclusion and discovered the limitations of their hearing and social acceptance. It seems that participants "did not know what it meant to be deaf" until the environment reflected their limitations and differences. For example, they discovered they could not participate in music or could not follow what was going on during activities with the hearing crowd. Results seem to indicate that it was a journey of discovery of what it means to be deaf – a rediscovery of who they are and where they belong. In McIlroy and Storbeck (2011)'s observation, they stated:

> Deaf identity is not a static concept but a complex ongoing quest for belonging, a quest that is bound up with the acceptance of being deaf while "finding one's voice" in a hearing-dominant society (p.1).

2.3.4.2 Accept Own Condition. How do the individuals cope with their hearing loss? In Skelton and Valentine's research (2003) on exploring deaf identities and their complexities, research participants reflected stories of how they responded to their own deafness. Here is a story of an individual who turned deaf at age five. She went through a stage of complete denial about her deafness but later learnt to accept her differences and learn to communicate in a different way. However, another person who was born deaf expressed that being deaf was normal and was confident in himself. He recognised the differences between himself and other hearing people but did not view the difference as a loss on his part. Another person who is able to hear more in one ear than the other experienced being bullied in school for being deaf. He expressed embarrassment being deaf and did not feel he belonged or was contented in either world. In short, some individuals identified themselves more with the deaf world, the hearing world, or the in-between.

Those who identified themselves as culturally hearing viewed their hearing loss as a disability. Holding this perception causes individuals to behave in two ways – accept their limitations and live within their limitations (may not be reaching their full potential) or keep striving to be like hearing people (read lips, speak) while battling with feelings of insufficiency and exclusion. There may be frustration of not being understood, a drop in self-esteem for not meeting up to society's expectations, and a sense of isolation and loneliness.

Those who identified themselves as culturally deaf have accepted themselves as different. They take pride in being Deaf. It seems that each deaf individual would have a unique journey of discovering the deaf world, which redefines them of who they are and where they belong. Deaf people feel connected because they share similar experiences – they know and feel how it is to be deaf. From McIlroy and Storbeck's observation (2011) on deaf participants' identity development, they noted that a transition from one identity to another suggests an ongoing reflective process of discovering one's identities. Whether an individual with hearing loss identify themselves as culturally hearing, culturally deaf, marginal cultural, or bicultural, it is important to accept oneself as is and then move on and accomplish goals in life (Kemmery & Compton, 2014).

Parents can help their deaf child by understanding the complexities of deaf identity, where it is developing and a journey of discovery. As Kemmery and Compton (2014) pointed out, it is not only to understand but also to acknowledge and respect perceptions towards the deaf individual that may differ between the deaf and the hearing persons. Being open and respectful of different perceptions of identity gives positivity to individuals with hearing loss to be successful in life.

2.3.4.3 Adapt to Environment. In the journey of discovering their identity as a deaf person, they would also need to learn how to adapt to the environment around them. Every person with hearing loss is brought up in unique environments; no two are the same. Though most are born into hearing families, every family member relates to the deaf family member differently and uses a variety of communication methods. A setting with family members differs from a school setting (deaf/regular school). According to Kemmery and Compton (2014), the lives of those with hearing loss could fluctuate depending on the context, setting, technology used, and people with whom they interact. The fluid identity of a person seems to help the individual to adapt to the many different settings one experiences in life. Even family members adapt their communication methods to their child with hearing loss.

Students with hearing loss also serve as advocates or informants to explain and describe to others their hearing losses and accommodations that assist with hearing and communication. Caregivers expect their deaf child to be accountable for hearing aids and advocate for their own needs during interactions (Kemmery and Compton, 2014), but do Malaysian deaf know how to do so? They cannot do so if they do not know their own identity and, therefore, harder to reach their full potential.

2.3.4.4 Advocate for Needs. Parents advocate for the needs of their children with hearing loss from a young age (e.g., inform schools about their child's special needs). It is the parents' desire to see their child advocate their own needs for themselves (Kemmery & Compton, 2014). When individuals with hearing loss advocate for themselves, it shows a sign of independence - being able to manage the world's challenges.

2.3.5 Summary

Discovering one's identity as a deaf person is a unique journey. Deaf identity itself is complex, and the perception of the deaf and hearing people differ. The journey includes aspects acknowledging their deafness, accepting their deafness, adapting to environment, and advocating for own needs.

2.4 Identity

"Who am I?" This is a question that men seek an answer to. Erikson theorised the process of identity formation (Schachter, 2005) and has become well-known for his contribution to the concept of identity (Erikson, 1968). According to Erikson, identity is a universal developmental task which forms the foundation for a person's general sense of well-being (Rogers, 2018). In fact, the development of a strong identity enables individuals to have commitment, better self-confidence, a sense of independence, and fidelity in relationships, while a poor identity may result in difficulties with commitment, bad mental health, weak sense of self, and lack of confidence in self and own abilities (Arnold, 2017; Block, 2011; Ragelienė, 2016).

Erikson states that identity is formed through a psychosocial process, where the self and society are actively and jointly constructed (Erikson, 1968). Jones and Mc Ewen (2000) also support this concept where the personal identity is not formed in isolation but is "defined, at least in part, by group memberships, and social categories are infused with personal meaning" (p. 5). While our core identity is the "inside self" that consists of personal attributes and characteristics, our "outside self" identity is easily named by others (e.g., gender, race) (Jones & McEwen, 2000). Deaf people may be given "outside self" identity labels such as 'person with hearing disabilities' by hearing society, but what would the deaf person's "inside self" core identity be?

According to Erikson’s psychosocial developmental theory, teenagers go through a stage of searching for their identity and how they fit into society (Erikson, 1968). Hence, discovering one’s identity is viewed as a journey rather than a destination (Walters & Auton-Cuff, 2009). Their sense of self is developed through social interactions and is constantly changing due to new experiences and information acquired in daily interactions with others. Often, their identity is made referenced by their life experiences and social exposure. For example, the internalisation of the deaf children’s family and school experience becomes a part of their identity (Chong & Hussain, 2022; Leigh, 2009; McIlroy & Storbeck, 2011).

2.4.1 Identity Constructs of Deaf People

From the literature above, there were many different views about deafness, which influenced the deaf person’s perceived identity. Since the emergence of the social and cultural model of disability, many researchers investigated the identity of deaf people. The identity of deaf people has become increasingly popular and essential, especially in Western countries, where identity politics and strong advocacy for human rights are prevalent. Hence, this section would like to review the literature surrounding the theories on the cultural Deaf identity of the person.

There have been many theories to explain the Deaf identity constructs. Namely, they are the disability framework, racial identity development paradigm, social identity paradigm, acculturation paradigm, and narrative approach. For a better understanding of the development of deaf identities, this section will look at some of the more popular identity theories – Lee Meyerson's three patterns of adjustment, Carty's six stages of deaf identity development, Davis' binary deaf identity, Glickman's four stages of deaf identity theory, and Holcomb's seven categories of deaf identity.

2.4.2 Lee Meyerson's three patterns of adjustment

One of the earlier documentation related to the identity of deaf people was Lee Meyerson's three patterns of adjustment (Garrettson, 1963). In the 1960s, deafness was seen as a disability generally presumed to be a communication handicap. Deafness and its behaviour were perceived as abnormal, deviant, and stigmatised in society. Total communication and oralism were the primary communication methods in classrooms.

In this context, Meyerson observed that depending on the type of school situation, family and environmental factors, and personal need for independence and self-expression, deaf school leavers may find themselves in one of the three categories. The categories were named as adjustment pattern one, two and three.

Very briefly, adjustment pattern 1 describes those who search to connect with other deaf persons and reject the hearing world; adjustment pattern 2 describes those who aspire to the hearing world and reject the deaf world; and adjustment pattern 3 describes acceptance of the commonality between those with hearing impairment and normal hearing.

Although Meyerson's observations about deaf people's experiences were categorised into social adjustment patterns and not considered "identity," they were foundational to the development of other theories that describe deaf people's experiences or identities.

2.4.3 Carty's Six Stages of Deaf Identity Development

Carty (1994), on the other hand, proposed six stages of deaf identity development that involve the psychological aspect of a deaf person's exploration and embrace of Deaf identity. These stages are, in order, confusion, frustration/anger/blame, exploration, identification/rejection, ambivalence, and acceptance. The process of determining one's Deaf identity starts with the realisation by the person that they are different compared with the general population, which makes them *confused* at this discovery. They feel *frustration, anger,* or *blame, which may result in self-hate if internationalised or manifest in non-confo*rmity or outbursts if externally expressed.

Next, the person *explores* identity options. Their exploration is shaped by the availability of information about deafness. They then either *identify* with or *reject* the Deaf community. This may be a premature decision at this stage. *Ambivalence* may follow for a while. Lastly, acceptance comes when the person has enough information and experience to make a decision about their identity.

2.4.4 Davis' Binary Deaf Identity

According to Davis (2002), specifically in Deaf studies, identity is traditionally defined around the disability-difference binary. This perspective presents identity as either a "disabled deaf person, or as a Deaf person with a difference" (p.9). In other words, there are only two categories (deaf or Deaf) that deaf people fit into, either one or the other. These two categories seem to be the general simple perspective of deaf identity. However, due to the individual unique life experiences of deaf people, other researchers found that deaf identity was beyond binary categories.

2.4.5 Glickman's Deaf Identity Theory

Glickman (1996) explains Deaf identity from the racial identity development paradigm. Similar to other racial minority groups, deaf individuals were considered a minority group that shared similar experiences of oppression as members of other minority groups do (Glickman, 1996; Ladd, 2005a). They were seen as not “normal” and “damned for their differences” (Branson & Miller, 2002). Other than the shared experiences of oppression, they also had a shared language (sign language) and Deaf norms or values. Glickman (1996) developed identity categories to support this theory. Four stages –hearing, marginal, immersion and bicultural - describe the journey a person goes through in forming their own identity.

The first stage is “culturally hearing,” which refers to living like hearing persons as much as possible by conforming to norms for people who speak and hear. They hold on to the dominant (hearing) culture’s attitudes and beliefs about hearing loss and identify with hearing people and their values, whereby deafness is viewed as a disability. Their primary method of communication is oral language and speech.

The second stage is cultural marginality, which describes the deaf person as not fully identifying with either Deaf or hearing groups and exists on the fringe. They shift loyalties and are confused about their relationship with the deaf and hearing world. This uncertainty is tied to difficulties in experiencing oneself as a deaf person and may lead to social isolation.

The third stage is immersion in the Deaf world, where the deaf person is in love with Deaf identities and Deaf cultures at the same time, disowns the hearing culture. They view deafness as a positive value and adopt the deaf culture and usage of sign language fully. This identity is sometimes known as the "radical or militant" deaf stance.

Lastly, the fourth stage is when the deaf person recognises the strengths and weaknesses of both deaf and hearing people and more fully integrates the values of both the hearing and Deaf cultures. They have integrated their deaf pride in a balanced way into their full humanity. Oral and sign language are equally important, and the deaf person strives to find their place in both the deaf and hearing world. Table 2.1 summarises each stage's process.

Table 2.1

Glickman's Deaf Identity Development Theory

Stage	View of Deafness	View of Deaf community	Emotional Theme
Hearing	Pathology	Uninformed & stereo-typed	Despair & depression
Marginal	Pathology	Shifts from good to bad	Confusion & conflict
Immersion	Cultural	Positive, non-reflective	Anger / "in love with Deafness"
Bicultural	Cultural	Positive, personal, integrated	Self-acceptance & group pride

Glickman (1996) pointed out that Deaf identity development is not necessarily a linear progression across the stages, but rather, there may be recycling through the stages depending on individual circumstances and attribution about the meaning of identities and their positive or negative valence.

As Leigh (2009) notes, children's development into adults involves the interaction of cognitive, emotional, and social characteristics with multiple environmental influences, initially within the family and then later within the community and school. Leigh pointed out that her family and educational experience moulded her identity as a deaf person. Schlinger (2012) also suggested that family and parental attitudes towards deafness and experiences in the education system strongly influence Deaf identity development.

2.4.6 Holcomb's Bicultural Identity Development Theory

While Glickman's deaf identity theory focuses on individuals coming to terms with their deaf identity and developing a sense of self, Holcomb's deaf identity theory focuses on developing bicultural awareness within the individuals as they navigate between the Deaf community and hearing society. Holcomb provides seven categories of possible identities for deaf people. Table 2.2 provides a description of each deaf identity category.

Table 2.2

Holcomb's Bicultural Deaf Identity Theory

Categories	Explanation
Balanced bicultural identity	Deaf persons who feel equally comfortable in both deaf and hearing cultures
Deaf-dominant bicultural identity	Deaf persons who are primarily involved in the deaf community but can relate well to hearing persons
Hearing-dominant bicultural identity	Deaf persons who have limited involvement in the deaf community but who can interact comfortably with deaf people
Culturally isolated identity	Deaf persons who reject all involvement with other deaf people
Culturally separate identity	Deaf persons who prefer to interact with other deaf people as much as possible and keeps contacts with hearing people to a minimum
Culturally marginal identity	Deaf persons who are truly comfortable neither in the deaf community nor among hearing people
Culturally captive identity	Deaf persons who have had no opportunity to meet other deaf people and learn about deaf culture.

2.4.7 Summary

The identity development of deaf people is indeed complex. As the views of deafness changed over the decades from the medical and charity model to a social and cultural-linguistic model, so did the deaf identity theories. The deaf identity theories progressed from an adapting pattern to a psychological process, from binary categorical deaf identities to stages of embracing a culturally deaf identity and the process of navigating their bicultural identity.

The deaf identity development situation in Malaysia is likely closer to Glickman’s deaf identity development, where there is progress between the hearing cultural identity (medical model-based) and the Deaf identity (social model-based). This is evident in the observation that Malaysia’s transition from the medical model to the social model for deaf people has been slow (Lee & Low, 2014). This is also supported by the results of Chong and Hussain’s (2022) study, where they found that the cultural awareness of deaf identity among Malaysian deaf people is low. Hence, among all the identity theories stated above, Glickman’s Deaf identity theory is selected for this study's theoretical and conceptual framework.

2.5 Theoretical Framework

The literature showed how a deaf person’s identity is shaped by his sense of belonging based on his experiences with the social world as a deaf person in his unique environment (e.g. home, school). Three theories are used to frame this study. Bronfenbrenner’s ecological system theory provides the context for the deaf person’s environment. Tajfel’s social identity theory captures the process of group identification that shows the deaf person’s sense of belonging. Glickman’s deaf identity theory proposes the possible final identity outcome.

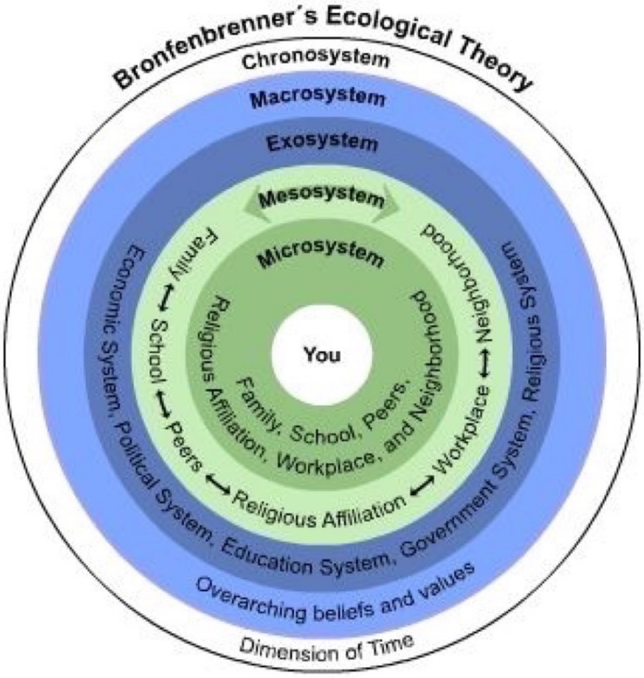
2.5.1 Bronfenbrenner's Ecological System Theory

Bronfenbrenner's ecological system theory explains how the different layers of the environment influence a child's development (Bronfenbrenner, 1979, 1990). Changes or conflicts in any one layer will ripple throughout other layers. To understand a child's development, it is necessary to look at the child, his/her immediate environment, and the interactions among the larger environments.

The five different environment levels that influence the person are the microsystem, mesosystem, exosystem, macrosystem, and chronosystem. The microsystem refers to a child's relationships and interactions in his or her immediate environments, such as his or her family, school, and neighbourhood. The mesosystem is the layer that connects the structure of the child's microsystem or the interactions between the microsystems. For example, parents interact with teachers in school. The exosystem is the larger social system in which the child does not function directly with but is affected by it. For example, parent's work schedules, school systems, or community-based resources. The macrosystem is the outermost layer in the child's environment, including beliefs, culture, and values. Lastly, the chronosystem encompasses the dimension of time-related to the child's environment. Refer to Figure 2.1 for an overview of Bronfenbrenner's Ecological System Theory.

Figure 2.1

Bronfenbrenner's Ecological System Theory



2.5.2 *Perspectives Emerging from Social Identity Theory*

The second theory used to frame the research is the social identity theory of Tajfel (1970). Tajfel's social identity theory explains how social identity is formed. However, it did not indicate the specific type of social identity. Some of the identity theories that emerged from this social identity theory are Davis' binary deaf identity and Glickman's deaf identity theory. (Davis, 2002; Glickman, 1996). Glickman's deaf identity theory was selected as part of this study's framework. This section provides background information on Tajfel's and Glickman's social identity theories.

2.5.2.1 Tajfel's Social Identity Theory. Tajfel's social identity theory (1970) suggests that groups are part of our identity and self-esteem. Identity is derived from the groups that people associate with. There are three mental processes that a person goes through to form his group membership – social categorisation, social identification, and social comparison. Social categorisation is when people sort similar people and objects to understand and identify with them. Then, he would modify his behaviour, attitudes, and beliefs to match the group he belongs to. This is called social identification. The last mental process to form group membership is when the person compares the in-group with the out-group to affirm his identity. The formation of group membership makes the person feel that he belongs, and it influences his self-esteem.

What about the identity of deaf people? Would they build a group membership based on categorising the in-group (deaf community) or the out-group (hearing community)? Tajfel's social identity theory may explain that the deaf person forms his social group membership with the deaf or hearing community based on (1) social categorisation - how he would categorise the groups (Deaf vs hearing), (2) social identification – if he would modify his behaviour, attitude and beliefs according to the group they feel belonged (Deaf culture vs hearing culture), and (3) social comparison – comparing the Deaf community with the hearing community to affirm their belongingness. Research reported that those with a Deaf identity had better self-esteem (Bat-Chava, 2000), proving the theory right. It was believed that a coherent disability identity would help the individual to adapt to disability and navigate the social stressors and daily hassles (Forber-Pratt, Lyew, Mueller, & Samples, 2017; Forber-Pratt & Zape, 2017) as cited in (Forber-pratt et al., 2020).

As deaf people are among the most diverse groups of people alive today (Leigh, 2009), various researchers studied deaf identities to obtain a better understanding of deaf people. A few theories reveal different insights into the formation of social identity (Glickman, 1996; Schowe, 1979). These theories elaborate on the social identity theory by describing how a person with hearing impairment adjusts to the group membership of the Deaf community, developing their Deaf identity. Hence, this study will base its theoretical framework on Glickman's (1996) theory, as the Deaf community is established as a linguistic minority group according to the social-cultural model of deafness (Ladd, 2005a).

2.5.2.2. Glickman's Deaf Identity Theory. This study selected Glickman's (1996) Deaf identity theory as it provides a comprehensive understanding of the stages a deaf person may go through while searching for his or her Deaf identity. Glickman's theory is based on the theoretical progression of racial identity stages where differences and oppression experiences are recognised, and discriminatory status in life is acknowledged. It is assumed that deaf people experience discrimination in life because of their differences and the way mainstream society has ignorantly mistreated them.

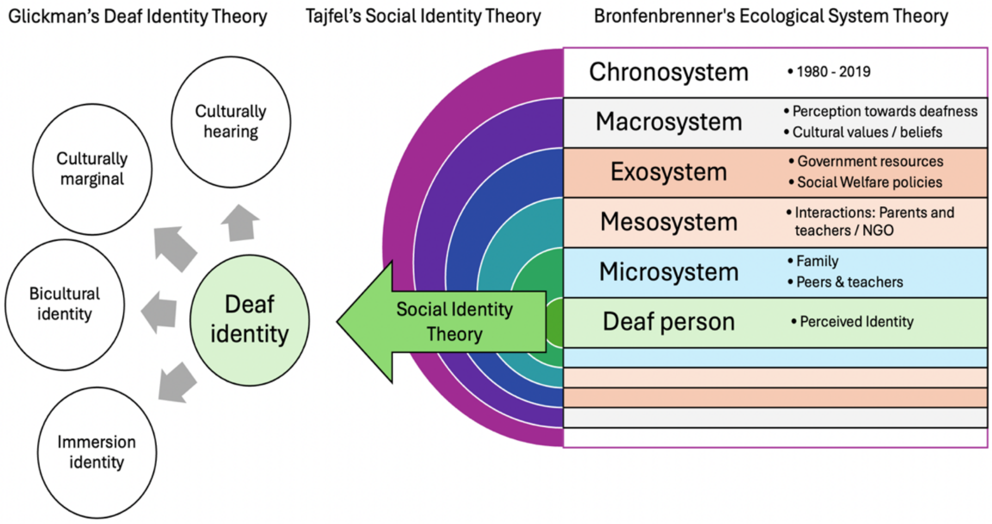
Therefore, Glickman's four stages in his social identity theory progress from a self-construction as "hearing identified" or marginal towards a more Deaf-orientated stance (Leigh, 2009), eventually finding a balance in their identity. The four stages of Glickman's deaf identity theory are *culturally hearing*, *culturally marginal*, *immersion*, and *bicultural*. Very briefly, the first stage is *culturally hearing*, which refers to living like hearing persons as much as possible by conforming to the norms and beliefs of people who speak and hear. The second stage is *cultural marginality,* which describes the deaf person as not fully identifying with either Deaf or hearing groups and existing on the fringe. The third stage is *immersion* in the Deaf world, where the deaf person strongly embraces the Deaf cultural values but simultaneously disowns the hearing culture altogether. The last stage is when the deaf person recognises and fully integrates the values of the hearing and Deaf culture.

2.6 Conceptual Framework

The conceptual framework of this study combines Bronfenbrenner's ecological system theory (1979), Tajfel's social identity theory, and Glickman's Deaf identity theory (1996). Figure 2.2 illustrates how these three theories are connected, forming the conceptual framework and placed in the environmental context of a deaf person in Malaysia. The study hopes to explore the unique environmental factors that have influenced the development of a deaf child in Malaysia from 1980 to 2019.

Figure 2.2

Conceptual Framework of the Study



Deaf identity is developed based on the experience and exposure one receives while growing up. As deaf identity is complex, a person with deafness may be like other ethnic minority people who develop their identity based on recognising their differences and the oppressive experiences that come with them (Glickman, 1996). These positive or negative experiences may directly or indirectly come from the individual's environment.

Just as in Bronfenbrenner's ecological system theory, the direct and indirect environment influences a child's development (Bronfenbrenner, 1979) and shapes a child to what he is today. Each layer of the child's environment plays a role in developing the deaf child's identity - hearing, marginal, immersion, bicultural- and is influenced by their environment.

The microsystem for the deaf person includes relationships with family members, schoolmates, teachers, and other people in the community. The mesosystem is the interaction between the mother and teachers or community workers for the special development of the deaf child. The exosystem is the education system for deaf people and the availability of community-based resources and programs, while the macrosystem is the beliefs and attitudes towards deafness in society. The chronosystem is the time context where the events, resources, views, and experiences occur within a certain period. For the context of this study, the chronosystem is between 1980 and 2019, starting with parents' accounts of when their deaf child (the deaf participants of this study) was first diagnosed with hearing loss.

CHAPTER 3

METHODOLOGY

This chapter begins with the researcher's background to provide an introduction and context to the research methodology. It is followed by the research design (ethnographic research), data collection method (participatory observation and semi-formal interviews), data collection procedures, and data analysis.

3.1 My Position as a Researcher

I was first exposed to the deaf community in Ipoh in 2011. A curiosity to understand how this people group viewed the world sparked my interest in communicating with them. Having learnt the basic letters in sign language, I attempted to communicate with a few deaf members weekly. I would not say that they had fully accepted me as their friend then, but they would spare me five to ten minutes each time to help me with my sign language. Each time, I learnt new vocabulary and was slowly able to express myself, though it was hard to understand what they were signing.

After three months, I was invited to join their weekly Bible studies at church and social activities at YMCA Ipoh. This gave me more exposure to observe and learn about the language and culture of this deaf community. After six months of joining the group, I was soon asked to help in teaching and interpreting. By then, I could express myself in sign language and had acquired a fundamental understanding of what they were saying. It took about three years to fully understand what they were signing.

Once I acquired the basics of communicating in sign language (2012 onwards), I became the bridge to connect the hearing and deaf community, specifically in Ipoh. This involved speaking for the deaf and relaying or interpreting the spoken message into sign language. I was assigned to help interpret messages and conversations for Ipoh deaf friends in 2012 and have been interpreting ever since. These interpreting services were voluntary. At that time, I was unaware that sign language interpreting could be an actual profession. All the people I knew who assisted deaf people with communication were teachers or social workers. I have yet to hear that one may get paid for their sign language interpreting services. I did not think that my sign language interpreting was good enough to receive payment as I had no prior formal training. Little did I know then that the sign language interpreter profession has yet to be established. I was learning on the job while trying to meet the communication needs of my deaf friends in Ipoh.

Interpreting without guidance was a struggle. In 2015, my father (also learning sign language and interpreting like me) found an organisation that could provide us with some exposure and training in sign language interpreting. Although the course did not offer extensive training on interpreting (e.g. intensive on-the-job training with a personal mentor to provide feedback), it offered exposure to sign language interpreting in Malaysia and an opportunity for peer learning and group mentoring. To graduate, students were required to pass the assessment, which tested various skills (e.g. expressive skills, receptive skills, interpreting skills, fingerspelling, and knowledge). This diploma in sign language interpreting was the only sign language interpreting course offered in Malaysia at that time. There was another Malaysian sign language interpreting course offered by the YMCA, but it was no longer offered. None of the courses were accredited by the Malaysian Qualification Agency (MQA). Both my father and I signed up for the one-year diploma in sign language interpreting by RC Deaf Missions Kuala Lumpur in 2015.

We graduated in 2016. During this diploma course, I gained more exposure to different interpreting settings (e.g., medical interpreting, educational interpreting, news interpreting, etc.). Through this program, I met other deaf people outside of Ipoh. They were mainly from different parts of Kuala Lumpur and Penang. Friendly interactions with them allowed me to observe the diversity of deaf people—they had very different backgrounds and mindsets. Such exposure opened my mind to see and understand how diverse the deaf population can be.

Since 2016, my deaf social network and interpreting opportunities have increased. I mostly interpreted for social events (e.g. weddings and graduations), hospital visits in Ipoh, training workshops and talks in Kuala Lumpur. Organisations and companies paid me for my interpreting services for training workshops and talks in Kuala Lumpur. On occasions when the deaf had to pay from their own pocket, I offer pro bono interpreting services. As for the interpreting in Ipoh, I still mostly do it without charge. The request for interpreting services was made by word of mouth, and requests came in based on situations and needs. I served as an interpreter on a need basis.

After data collection in 2019, the COVID-19 pandemic hit the country. Physical meetings were prohibited during the national lockdowns. Like everyone else, the Ipoh deaf community went online to connect with the rest of the world. During this time, the deaf community and sign language interpreters familiarised themselves with using online meeting platforms such as Zoom. Ever since online meeting platforms became ubiquitous, sign language interpreting opportunities have expanded from the limits of Ipoh to the national and international levels.

In 2020, I met other sign language interpreters through online platforms and served together in providing sign language interpreting services for programs that lasted one to six months. To meet the needs of the deaf community by providing professional sign language interpreting services, the team of sign language interpreters decided that it was best to start a Limited Liability

Partnership (LLP). It was named Enomenos Malaysian Interpreters for the Deaf (EMID). EMID has taken up a wide range of interpreting assignments, both in physical settings and online platforms, at both local and international levels. Being part of EMID has enriched my sign language interpreting experience. I was given opportunities to interpret online to reach deaf audiences beyond Ipoh. I also had the honour to be mentored by other sign language interpreters who are experts in the field. At the same time, I also gained more experience interpreting in different contexts - different topics to different deaf audiences.

Other than playing the role of an interpreter, my involvement also included listening to concerns and providing guidance and counselling to some of the younger deaf members. These roles were additional to the usual social interaction with the deaf community. Through these experiences, I was exposed to various deaf issues ranging from a communication breakdown, special needs of the deaf, complexity of deaf identity, diversity of sign language, attitudes, behaviors, and the culture of deaf people.

So, in 2017, I decided to do this research to document my experience and knowledge about the lives of the deaf community in Ipoh, Malaysia. Each deaf person seems to have a unique background and upbringing, which influences the deaf person's perception of themselves. The twelve years of experience (2011 – 2023) as a Malaysian sign language interpreter and my pre-entry into the lives of this deaf community paved the way for me to document my research findings.

This enriching experience of serving the deaf community has impacted me and contributed to the writing of this research. It is hoped that this research will give the deaf a voice and create awareness in the public about their often silent lives.

3.2 Research Design

The objectives of this study were to explore (1) the experiences of deaf children growing up in a hearing family, (2) the experience of hearing parent(s) bringing up a deaf child, and (3) the suggestion for improvement of the existing support system for the deaf community. A qualitative research design was adapted for this study instead of a quantitative research method for a few reasons.

The main reason for using the qualitative research method was the nature of the study; it explored the subjective experiences of deaf participants and hearing parents through a bottom-up philosophy. Secondly, the target people group was an unexplored, vulnerable minority that uses sign language. This field of study is at its early exploratory stage. Hence, an exploratory approach through the qualitative research method would bring up rich data that the quantitative research methods would not be able to.

The researcher adapted an ethnography research method that included participant observations and interviews to explore the experiences of hearing parent(s) and their deaf adult children. This section will describe the rationale for using ethnography as the overall strategy to answer the research questions, detailing how participant observations and interviews were conducted. It will be followed by a description of data collection procedures and data analysis.

3.2.1 Ethnography Research

This study adopted ethnography as the research method to explore the Malaysian deaf community, specifically one of the Ipoh deaf communities, as ethnography research methods are the most appropriate method to study an ignored or often marginalised population (Marshall & Rossman, 2016). Below is a brief description of deaf people and the situation in Malaysia, which justifies why the ethnographic approach was used for this research.

Deaf people lived and grew up in different places in Malaysia. Often, they are the only ones deaf in the family. They met other fellow deaf people when they entered the education system. Special needs schools usually consisted of congregations of larger numbers of deaf children. After leaving school, the deaf community that was formed in schools dispersed. Deaf individuals return to their hometowns or head to the city to search for work. Deaf clubs or places of worship became the next central place for deaf people to congregate. Deaf communities exist sporadically across the country according to locations – larger ones in the city, smaller ones in the smaller towns. It is within these congregations of the deaf community that the sign language and the deaf culture develop.

Deafness is invisible. Hence, on the outward appearance, a deaf person is seen as a regular person living a typical life. However, until we attempt to interact with a deaf person, will we realise the difference between their silent world and our hearing world? Without sign language, one would struggle to enter and understand their world. The breakdown of communication disconnects the hearing and deaf world. Unless one enters the deaf world through sign language or the deaf person steps out to communicate with the hearing world, the voice of the deaf community is unheard. The life experiences, culture, challenges, needs, and hopes of the deaf community will remain unknown, unexplored, and undocumented. Being the minority and silent (figuratively and literally), the deaf community are easily marginalised or ignored.

Therefore, the aim of this ethnographic research was to provide an insider's perspective for deeper understanding and authenticity into the diversity of the lives of deaf people (McIlroy & Storbeck, 2011). This ethnographic research recorded the descriptions of deaf people's life experiences, the complexities of deaf identity, and subjective understanding and interpretation from the deaf person's worldview. Ethnography that uses observation as its main cognitive mode will capture the unsaid messages and voices of deaf individuals telling their stories. This was especially helpful when sign language is a non-verbal mode of communication and an expressive language. From observations and interviews, the researcher can gain an emic view, which is the insider's or native's perspective (O'Reilly, 2012). Hence, to achieve the objectives of this study, the researcher will play the role of a participant observer and conduct interviews to collect data.

3.2.2 Participant Observation

According to Gobo and Molle (2017), participant observation considered the interaction between the researcher and social actors crucial to understanding behaviour. Therefore, to facilitate the data collection process of ethnography research, the researcher played the role of participant observer and adopted an active membership with the community being studied (Angrosino, 2007). Although the researcher has been fully involved in this community for the past nine years, data was collected through participant observation in 2019 for a duration of two months (1 July – 31 August 2019). Participants were aware of the researcher's role, the purpose and process of the research. They gave their consent before the participant observation started.

The participant observations were mainly done in two contexts – (1) two separate times during the weekly meetings and (2) during the interviews. The weekly meetings lasted about three hours each and were a time for socialising and learning religious matters. The researcher's observations focused on deaf participants' social interactions - the choice of interaction (e.g., whom they chose to interact with), mode of communication (e.g., native sign language, hand-coded Malay language) and content of communication (e.g., the topic of discussion). This information was recorded in an observation checklist with a section for additional field notes. The researcher participated in activities and conversations only when invited and did not actively take the initiative to be involved. This was intended not to interfere with the deaf participant's natural choice of social interactions. After the event, the researcher noted her observations. The researcher's involvement as a participant might have inhibited deaf participants from talking about true emotions about certain topics, such as the hearing interpreter's performance.

The researcher did not observe two deaf participants as they did not attend the weekly meetings. However, all participant pairs of parent and adult child were observed for their interactions before, during and after the interview, as they came together for the interview. Observations focused on the dynamics and interactions between hearing parents and deaf adult children and were recorded as field notes. Observations from the weekly meetings provided insights into participants' nature of communication and socialising.

3.2.2.1. Why Be a Participant-as-Observer? Due to their hearing disability, deaf people are very sight-sensitive. To keep track of the situation and safety of their surroundings, they are quick to acknowledge the presence of others that enter their radar. The presence of the researcher itself influences the situation/environment, regardless of being directly involved or observing from a distance. The only difference would be if the presence of the researcher influenced the reactions of the deaf community negatively. For example, the presence of an individual with unknown motives causes deaf people to be wary. Hence, it is better to be obvious and upfront with one's presence rather than to be a distant observer who is perceived to be 'hiding' with suspicious motives. Reducing this ambiguity of the person's presence and motive puts the deaf community more at ease with your presence.

To be involved by being visibly present also shows that one is interested in them. Having passed the test of genuineness and sincerity, the deaf people are more open to let another person into their world. So, to be involved directly by being present and genuinely interested, one can gain an insider's perspective which cannot be observed from afar. Hence, the researcher took on the role of a participant-as-observer.

The Ipoh deaf community knew about the researcher's intention of observing and doing research. In fact, in the earlier years, upon "gaining entry" into the deaf community in 2012, a few of the deaf community members encouraged the researcher to make more observations. They even took some time to explain to the researcher why deaf people behave and think the way they do. They seemed happy that someone took an interest in their lives, and they wanted to be known. Other deaf members who were well aware of the intention of the researcher seemed indifferent about it. They responded with a non-expressive face as if saying, “Ermm... ya… so?” – as if it did not matter to them what the researcher was doing. Perhaps these are signs that the researcher has gained their trust and acceptance into the community. More details on “gaining entry” into the deaf community are described below.

3.2.2.2. How was Trust Gained? It took time to earn the trust of the deaf people. Only when the trust was earned did the researcher gain entry into the deaf community. For about two hours per week for three months, the researcher would be physically present with the deaf for the church service. Attempts were made to communicate with the deaf during the tea fellowship after the church service. The researcher knew the alphabet in sign language and used that along with facial expressions and body language to connect. Each attempt to connect was very brief (5 minutes) as the researcher was limited in communication (poor receptive and expressive skills). The deaf community at that time was also not willing to spend more time with the researcher.

However, over the weekly attempts, one of the hearing leaders of the deaf community invited the researcher to their bible study group. It was during that time that the researcher was given an opportunity to introduce herself formally to the group in basic sign language. Trust was gained gradually over time.

It is hard to pinpoint the exact moment when trust was finally fully earned. It was after an intentional, consistent, thrice weekly (minimum 2 hours each time) interaction for two full years, which is about 600 hours, that trust was finally earned. Trust earned was slow, gradual, and tested over time through a careful, non-threatening entrance into the deaf community. Different boundaries were tested in earning trust and gaining entry – respecting deaf individuals' personal private boundaries, the researcher's genuineness and trustworthiness, and the communication barrier between both parties. Generally, it seemed that trust was given based on the researcher's sincerity (no ulterior motive being with them) and the consistency and tenacity of spending time with them and learning their language. All these gave the deaf community a lot of time to observe the researcher's behaviour and to discern her intentions. The researcher described gaining trust in different stages in Table 3.1 below.

The moment of full embracing of the researcher was when the deaf collectively fully trusted the researcher's presence and intentions with the deaf by opening up and sharing their personal lives. Trust earned is evident when the deaf were no longer trying to hide their signing or sharing of their personal life from the researcher (please note that signing is public); they included and actively invited the researcher in all their activities and daily life; and requested the researcher to be their ears and voice for them through teaching or interpreting.

Table 3.1

The Process of Gaining Trust of the Deaf Community in Ipoh

Stage	Time frame	Description
1	1st to 3rd month	Not rejecting researcher's physical presence in their midst, but not interacting with researcher.
2	3rd to 12th month	Accepting and feeling comfortable with researcher's physical presence, minimal interaction with researcher, no initiative to be interacted with, information (signing) is withheld from the researcher.
3	13th – 18th month	Accepting and feeling comfortable with researcher's physical presence, a few deaf showed more initiative to interact with researcher for general conversations, some information (signing) is given to the researcher.
4	19th – 24th month	The deaf are very comfortable with researcher's physical presence, more initiative by the deaf collectively to include and interact with researcher for general conversations, more information (signing) is given to the researcher, some initiative of the deaf to teach and educate the researcher about deaf culture and norms.
5	25th month onwards	By now, the deaf are very comfortable with researcher's physical presence, researcher is included and interacted with for all conversations, more information (signing) are freely given to the researcher, more initiative of the deaf to teach and educate the researcher about deaf culture and sign language, the deaf makes request to help with interpreting and teaching topics/English that they needed help with.

3.2.2.3. Active Membership. There are three types of membership in the engagement with the community understudied – peripheral membership, active membership, and complete membership (Angrosino, 2007). For this study, the researcher adopted the active membership role to engage in the deaf community's activities but refrained from committing herself to the group's values, goals, and attitudes. For example, the research was present and responsive to conversation and discussion among the deaf community. However, she refrained from giving ideas or personal opinions in the discussions. She spent more time observing and occasionally clarifying when she may not have understood certain signs used in the conversation, which the deaf community gladly taught her so that she could follow the conversations.

The reason why the researcher chose to refrain from committing to the deaf community's values, goals and attitudes is that even though the deaf community may display a collective set of values, below the surface, each deaf individual may have a different personal set of values. Each deaf member may not explicitly express their personal opinions but would rather follow another or the majority's opinion. It is only in private that one gets a revelation of the individual's deaf member's opinion. The researcher did not want to be seen as taking sides on a certain value or goal. For example, the deaf person may hold different values on communication – the value of using speech and residual hearing to communicate or the value of pure sign language. As for the attitude towards deafness, one may view deafness as a disability/handicap in life and cease to strive for independence, or deafness is merely a linguistic and cultural difference.

Hence, the position as a participant-as-observer would be the most appropriate for this study. There is less risk to be misunderstood for taking sides with any individuals' personal values, goals, or attitude towards deafness. Her neutral position would also provide the same opportunities to connect with any of the deaf person present.

Secondly, the researcher also did not want to influence the group by any indication of "committing or not committing" to a certain value, goal, or attitude towards deafness. This is because the deaf community has the tendency to follow the one who is perceived to be more dominant or knowledgeable by the group. Although individuals may have different opinions or values, they will outwardly show or change to a different set of values, goals, or attitudes. This outward conformity will make it hard for the researcher to dig deeper and understand their true personal values, goals, and attitudes.

Similarly, the researcher was careful to not reveal values, goals of attitudes as a hearing person, and remained as neutral as possible. This is because there is an underlying sense of inferiority among deaf people, who may view hearing people as superior because hearing people have access to more knowledge and information through hearing. In order not to influence the existing dynamics of the groups' varied values, goals and attitudes, the researcher chose to be always as neutral as possible. Nonetheless, the researcher has taken precautions regarding her possible biases and recorded them in her reflexive journaling. This is discussed further in Section 3.6.4 Reflexivity.

3.2.2.4. Observational Checklist. The researcher prepared and used an observational checklist to provide some form of reliability, where observations are conducted in a systematic fashion. This checklist serves as a guideline to standardise techniques for recording and analyzing the data. Table 3.2 below (page 144) presents the observation checklist.

During the participation observation, the researcher used the observation checklist as a guide to record her observation. (View Appendix E for a sample.) Information recorded in the checklist was used during the data analysis.

Table 3.2

Observation Checklist

Interaction

1. How do deaf people relate to others (deaf friends, deaf strangers, hearing family members, hearing friends, hearing strangers)? Are there any differences among the different groups?
2. How do they choose their social circle? Who are the people they choose to hang out with during activities?
3. Who initiates conversations?

Mode of communication

1. What is the mode of communication among deaf when they interact among themselves? (Sign language, gestures, sign exact English, hand-coded Malay, drawing, written words, pictures, etc.)?
2. What is the mode of communication between deaf people and other hearing people (friends, family members, strangers)?

Conversation topics/ interaction content

1. What are the conversation topics of deaf people?
2. Do the conversation topics differ in private and public setting?

3.2.3 Interviews

The other method employed in this ethnographic research is interviews. Informal semi-structured and retrospective interviews were used to collect data directly from the deaf participant and their hearing parents. Informal interviews came most naturally and were used to explore the journey of both deaf individual and their parent. The retrospective interview also helped to reconstruct the past to obtain details about the earlier journey of parenting a deaf child and the deaf participants discovering their identity. The interviews were conducted over forty days, from 13 July to 23 August 2019. Before the data collection, the researcher obtained informed consent from the participants. They were briefed about the research's nature, purpose, procedure, privacy, and confidentiality. Participants were allowed to ask for clarifications about the research anytime.

A total of six pairs of deaf adult and one of their parent were interviewed. The interviews with the hearing parents were conducted in English or Chinese, whereas the interviews with the deaf participants were conducted in BIM. The researcher wanted to conduct the interviews between deaf individuals and parents separately. However, the researcher respected and proceeded with the preference of the parent-child pair regarding the interview situation. Every hearing parent–deaf child pair had a different preference and dynamic, providing the researcher with opportunities to observe the dynamics of the parent-child relationship. Table 3.3 describes the interview setting of the participants.

The deaf participants were asked about their experiences living as deaf people and the challenges they faced growing up in a hearing environment (family and community). Hearing parents were asked about their experiences and challenges bringing up a deaf child. An interview was conducted for each deaf participant and each hearing parent. A second interview was conducted only with Deaf Participants 1, 2 and 3 to seek clarification on their first interview's response and to obtain more information about their experiences.

Table 3.3

Interviewing Setting of Participants

Participant Pair	Interview with parent	Interview with child
1	Adult child physically present together in the interview	Interviewed alone
2	Adult child physically present together in the interview	Parent physically present together in the interview
3	Adult child physically present together in the same room	Interviewed alone
4	Interviewed alone	Interviewed alone
5	Interviewed alone	Parent physically present in the same room
6	Interviewed alone	Interviewed alone

Semi-structured interview questions were used to guide the interviews. A few pre-determined questions were asked, while other questions were asked spontaneously during the interview according to the natural flow and direction of the conversation. The purpose of having this flexibility was to allow the researcher to explore unexpected themes that might emerge spontaneously from the interview. Questions that were too structured would limit the response of deaf participants, whereas questions that were too unstructured would leave the deaf participant confused with what was asked. It also allowed the researcher to switch between being more structured for the deaf participant when needed and more open-ended for hearing parents.

Interviews were audio recorded for the spoken English and Chinese interviews with hearing parents and transcribed into written English. Interviews in Malaysian Sign Language were video recorded, then voiced interpreted before being transcribed into a written transcript. Table 3.4 lists the interview questions used as a guideline for the semi-structured interviews.

Apart from the main participants, which consisted of the deaf participant and hearing parents, when the researcher needed some help in understanding parts of the deaf culture (e.g. behaviour and value of the deaf community), the researcher asked the key informants. Examples of deaf culture that the researcher sought clarification from key informants included why deaf individuals would prefer to stay in groups, why they exclude themselves in certain situations, why they only go to cafes and not hawker stalls, why they prefer not to talk to hearing people who don’t know sign language, etc. Key informants are members of the community who have up-to-date cultural information. They can provide information about daily living norms and answer the researcher’s questions to understand the deaf culture. They were an excellent source of information that helped make sense of the data collected (Fetterman, 2019).

Table 3.4

Semi-Structured Interview Questions

Interview Questions for the Deaf Participant

RQ1: What are the experiences a deaf child goes through in discovering his/her identity?

1. Please share with me your experience growing up as a deaf person.
2. How do you view yourself as a deaf person?
3. What are some of the challenges you faced growing up in a hearing family?

Interview Questions for the Hearing Parent

RQ2: What is the parents' role in bringing up a deaf child?

1. Can you share with me about your experience when you found out that your child had hearing loss?
2. What was it like bringing up your child with hearing loss?
3. What were the challenges you faced while parenting your child with hearing loss?
4. How did you manage / overcome those challenges?

Interview Questions for the Deaf Participant and Hearing Parent

RQ3: What are the suggestions for improvement in the support system for the deaf community?

1. What assistance did you find helpful in bringing up your deaf child / growing up with hearing loss?
2. What support do you wished you had, when you were parenting your deaf child / growing up as a deaf person?
3. What do you think the government, school or community can do to help in the journey of parenting a deaf child / while you were growing up as a deaf person?

3.3 Participants

This research recruited six pairs of hearing parents and deaf adult children, which is a total of twelve individuals. Participants were selected through purposive and snowballing sampling methods. Participants were selected based on these criteria - (1) adult child to be the only deaf person in a hearing family, (2) aged between 18 – 39 years old, (3) a Malaysian citizen of Chinese ethnicity. Participants were excluded from the study if (1) both parent and adult child are deaf or if either parent or adult child, (2) are not Chinese ethnic, (3) are not Malaysian citizens, or (4) are no longer living or actively returning to Ipoh.

The main reason for these criteria was to narrow down the research to Malaysian adults who lived and grew up with hearing families. These adults would have already had a certain amount of exposure and self-discovery. By this age, it is assumed that they could also communicate and articulate their thoughts independently. They would also be in the stage of starting a career - either have been employed or are looking for employment. They might also be looking for relationships or were already in a relationship. Both are excellent periods to investigate how their upbringing and exposure prepared them to live independently and interact with society.

The advantages of prior acceptance and immersion in the group over the years to obtain data included (1) overcoming trust barriers with the deaf participant, (2) a pre-established effective communication system between researcher and deaf participant, (3) having a good rapport with parents to obtain personal experience that may not be usually shared with strangers, and (4) the opportunity to do natural observations without being intrusive.

Therefore, this study selected only Malaysian Chinese participants mainly because it is the community in which the researcher has immersed and gained entry over the past eight years (2011 – 2018). It took the researcher at least two years to learn the language for effective communication and gain proper entry into this Deaf community. She considered herself proficient in BIM by her sixth year when she graduated with a Diploma in Sign Language in 2016. This was two years before the data collection of this study.

The acceptance of the deaf community of "outsiders" was heavily based on trust. The lack of hearing ability has placed them in a vulnerable position to be cheated and taken advantage of, and hence, the 'trust' factor is very important to establish before one is accepted into their group. The amount of trust established determines the amount and depth of information freely shared. Hence, the researchers' pre-established trust relationship with the group was an important factor to consider when choosing the deaf participants for this study.

A second reason for limiting this study to Malaysian Chinese participants was that the researcher did not have an introducer to the other ethnic deaf community (e.g., the Malay deaf community). The researcher has yet the opportunity to establish a good connection with deaf people of other races. Hence, more effort and time may be needed to win the trust of the deaf individuals and their parents to participate in this study, and an added complication of establishing an effective communication system between deaf participants and researchers. Acknowledging these barriers to data collection, the researcher decided to focus on the current group, which is of Chinese ethnicity, that she has been accepted. The researcher, being Chinese ethnic, made connection easier with the Chinese deaf and their hearing parents.

The results of this study would be limited to the context of the Ipoh Chinese family's experience as their experience may be subjected to underlying Chinese cultural mentality and value system. Studies have not been done on other races. Hence, it will be an unfair conclusion to generalise the results of this study across all other races in Malaysia. Therefore, themes drawn out from the data would not typically represent the deaf community in Malaysia, as certain influencing factors should be considered (e.g., social and economic background, parents' educational level, etc.). Nonetheless, the results of this study would provide insight into a part of the bigger picture of the diverse deaf community in Malaysia.

3.4 Procedures

3.4.1 Recruitment

Upon approval from the university's ethics committee (Ref no: U/SERC/83/2018, as attached in Appendix A), the researcher invited selected members of the deaf community who met the criteria to participate in the study. The researcher sent out the invitations face-to-face, through text messages or a video message in sign language about the research. When the participant and his or her parent(s) agreed to the interview, an appointment was made according to the availability of both researcher and participant. The deaf participant also asked their parents if they would agree to be interviewed and passed the researcher the parent’s contact. The researcher followed up with a phone call to the hearing parents and explained the interview. Three pairs of participants were recruited in this manner.

Participants who declined to be interviewed gave recommendations of other deaf friends that met the criteria for the study. However, this effort was fruitless as deaf members were more reserved about being interviewed. Therefore, the researcher reached out to a hearing member of the deaf community, a long-serving interpreter of that group. She recommended a few other contacts of hearing parents who had deaf adult children. Three pairs of hearing parent-deaf child participants were recruited through her. Two of the deaf participants used to join YMCA activities a few years ago before the Deaf Club of YMCA closed. The researcher knew them but did not have their contacts. The last pair of hearing parent–deaf child participants was only contactable through this interpreter, so the interpreter helped to coordinate the interview session with this pair.

3.4.2 Interview Process

The interviews were conducted over forty days, from 13 July to 23 August 2019. The dates and locations of the interviews were confirmed by either the deaf participant or/and hearing parent. Dates were according to the availability of the participants. The location chosen was according to the preference of the participants. Two pairs preferred to meet at home. The other four pairs felt more comfortable meeting in a public place like a quiet café.

Before each interview, the researcher briefed the participants about the nature of the research, privacy and confidentiality of the interviews, informed consent for video or audio recording of the interview, and estimated interview duration. Participants were encouraged to seek clarification if they had any doubts, and it was their right to stop the recording, interview, or withdraw from the study at any time throughout the research. All the interviews went well with minimal disturbance.

With permission to video record the interview, one camera was set up in such a way that the whole dialogue in sign language with the deaf person was captured. As for the interview with the hearing parent(s), an audio recording was sufficient. Upon completion of the interview, the researcher welcomed the interviewee to clarify any doubts they may have about the interview conducted. Before the participants left, a token of appreciation was given for their participation in the interview.

3.4.3 Participant Observation

To facilitate the data collection process, the researcher was a participant-as-observer. She could fully integrate into the understudied deaf community and was treated as a friend and neutral researcher. She adopted an active membership role and engaged in core activities (e.g. interpretation or simple explanation of English words when needed during the meetings). She had refrained from committing herself to the deaf community's values, goals and attitude. This is because there were two different attitudes towards being deaf in the deaf group who attended the meeting—the pride of being Deaf and being a person with disabilities. The researcher did not want to be seen as taking sides or supporting either position.

The researcher was fully involved in this community for 8 years (2011–2018), and data was collected through participant observation in year 2019 for a duration of two months (1 July–31 August 2019). Participants and all the other deaf non-participants present were aware of the researcher's role, the purpose and process of the research, and gave consent to the participant observation during meetings.

The participant observations were mainly done in two contexts—(1) two separate times during the weekly meetings and (2) during the interviews. The weekly meetings lasted about three hours each time, and it was a time for socialising and learning religious matters. The researcher's observations focused only on the six deaf participants' general social interactions throughout the meeting—the choice of interaction (e.g. whom they chose to interact with), mode of communication (e.g. BIM, KTBM) and content of communication (e.g. topic of discussion). This information was recorded in an observation checklist with a section for additional field notes. The field notes captured other details of participants' interactions, such as the enthusiasm in interactions and duration of conversations with individuals or as a group. These observational data were used as supporting evidence to provide context for the themes that emerged from the analysis.

The researcher participated in activities and conversations only when invited and did not actively take the initiative to be involved. This was intended not to interfere with the deaf participant's natural choice of social interactions. After the event, the researcher noted her observations. The researcher's involvement as a participant might have inhibited deaf participants from talking about true emotions about certain topics, such as the hearing interpreter's performance.

The researcher intended to observe the six participants in the social context. However, two deaf participants did not attend the weekly meetings. Hence, only four deaf participants were observed in the social setting. On the other hand, all pairs of deaf participant and their parent were observed for their interactions before, during and after the interview as they came together for the interview. Observations focused on the dynamics and interactions between hearing parents and deaf adult children and were recorded as field notes. The Researcher also noted their communication mode, communication limitations, and the nature of their relationship. Observations from the weekly meetings and interactions between parents and deaf participants provided insights into deaf participants' nature of communication and socialising.

3.4.4 Challenges

There were challenges in recruiting the participants and during the procedures of data collection. The first challenge was recruiting the deaf participants. It was not as easy as the researcher initially thought. There were many verbal agreements, but when it came to setting up an appointment, the deaf participants hesitated. When the nature of the interview appointment seemed formal, there was hesitation as well. Hence, the researcher kept the interview as informal and casual as possible. This included the setting of interviews. The interviews were done in the participant's home (Deaf Participants 3 and 4), a café or restaurant of the deaf participant's choice (Deaf Participants 1, 2, 5 and 6).

Although the researcher knew some of the deaf participants' hearing parents, there was an initial reservation about the interviewer and the purpose of the interview. However, once a clear explanation was given for the purpose of the interview, the reserved hearing participants gave the deepest and richest information in the interview.

As for interviewing the deaf participants, they were willing and happy to share their life stories. However, the challenge in interviewing the deaf participants was that they did not always know how to respond to the interview questions asked. For example, 'How was your experience growing up deaf?' was too open a question and most deaf participants needed some prompting – Was it a good experience? How did people treat you? What did you like about it? Deaf Participants 1 and 3 were simpler in nature, where they answered with a simple "yes" and "no" and had nothing else to elaborate on when asked why. It was challenging to get the "detailed" stories, but the responses of the deaf participants reflected the nature of their thoughts and perspectives about their own lives.

The use of cameras to video the interviews of deaf participants was a bit more discreet. Although the deaf participants were agreeable to the video recording, most of the deaf participants (all except Deaf Participant 4) were conscious of being recorded and occasionally turned their attention to the camera. They were conscious about their appearance on the camera and, sometimes, concerned if the camera was still recording or shooting at the right angle. The researcher felt that this consciousness of the video recording was partially distracting to the flow of the interview. However, it was an exciting experience for the deaf participant to be recorded for such an interview. The presence of the camera did not prevent deaf participants from expressing themselves. They gave personal details about their lives and did not hide, and happily shared them. However, the presence of the camera caused a mild distraction in between the sessions.

3.4.5 Minimizing Social Desirability Tendencies

Social desirability bias in research is unavoidable. It happens when participants respond based on society's expectation rather than their own experiences and beliefs. In the context of the deaf community, social desirability bias likely occurred when interview questions were directed to assess their knowledge about certain subjects, topics, or news. Some deaf people may be embarrassed not to know and, therefore, pretend that they know by nodding their heads. The pressure to 'know' was higher when they were with people perceived as more academic, learned, or knowledgeable.

Often, hearing people were perceived to be more educated, and hence, deaf individuals may have felt intimidated and hid the fact that they did not know certain things they ‘ought’ to know. They sometimes pretended to know because they did not want to be perceived or treated as ‘ignorant’ or ‘stupid’ when they were unaware of the latest happenings or what was considered “common knowledge”. So, to avoid people’s perception of being ‘ignorant’ or ‘dumb’, they responded according to what they thought the ‘right’ answer should be rather than their true answer.

The researcher observed these social desirability tendencies among deaf individuals over the past ten years. Therefore, the researcher employed strategies to limit social desirability bias, such as identifying common cues for social desirability tendencies, introducing the study, establishing rapport, and asking questions (Bergen & Labonté, 2020). Before conducting the interview for this study, the researcher ensured that the purpose and objective of the study had been properly introduced and understood. The researcher also ensured that rapport had been established before asking the interview questions. Doing this at the beginning of the interview helped the participants to feel safe sharing their experiences, thoughts, and feelings with the researcher.

Next, the researcher avoided asking questions that tested their knowledge. Questions were phrased to focus on the experience of the deaf participants rather than the ‘knowledge’ of the deaf participants. For example, instead of asking, “What help does the government provide for the deaf?” the question was phrased as “From your experience, what resources from the government benefited you?”. As the focus is on the experience, deaf participants wouldn’t feel pressured to give “correct” answers or answers they think the researcher wants to know. Occasionally, the researcher reminded the deaf participants that she wanted to hear about their experiences. This was emphasised by signing “your experience” to assure them there was no right or wrong in the answers.

The same strategies (e.g. identifying possible cues of social desirability tendencies, proper introduction, establishing rapport, and asking questions) were used for the parent participants. The possible social desirability bias tendencies of parent participants are when parents want to show the researcher that they were good parents. Since asking about the parenting experiences may be sensitive (e.g. what they did), parent participants might have wanted to hide or emphasise certain information to give a good impression of their parenting.

For example, Parents 3, 5, and 6 did not want to talk about their spouse’s little involvement in parenting the deaf child. Parent 4 did not mention how she had thoughts about aborting her deaf child when asked about how she felt when she knew her child might be deaf. (This information was made known to the researcher through deaf participant 4 earlier). They changed the focus of the topic to what they did well for the deaf child. Understandably, parents might have felt embarrassed about how they thought, felt, or did as parents. Suppose the researcher were to ask more questions in those sensitive areas. In that case, parent participants might be untruthful about the matter to hide their embarrassment for what they may be perceived as lacking as parents. Therefore, the researcher did not probe further but noted the situation. This was to prevent the occurrence of more social desirability tendencies.

3.5 Reliability and Validity

According to Angrosino (2007), qualitative ethnographic researchers are not usually concerned with reliability as their research findings cannot be replicated. However, for observational research, conducting observations in a systematic fashion is a way to achieve the criteria of scientific reliability, such as using a standardised technique for recording and analysing the data.

To achieve reliability for data collection in this research, field notes were jotted down after the activity with the deaf. These notes included observations of behavior, the nature of the setting, the content of the topic/activity, and personal insights and reflections on the activity and interactions. These standardizations of the checklist to be observed will increase the reliability of the data.

As for the data analysis of the interview data, three independent inter-raters coded the twelve interviews to determine inter-rater reliability. Two coders were assigned to code three sign language interviews of deaf participants, while the other coded the six English transcriptions of hearing parent participants. As interviews with deaf participants were in sign language, the coders needed to have some background knowledge about sign language and deaf culture. This is because deaf individuals' expressions and the nuances in sign language differ from those in a translated language and are often lost in translation. Hence, to prevent the loss of meaning in translation from sign language to English, the researcher chose her coders based on their expertise in sign language and English (e.g. fluency and knowledge of deaf culture and norms) over academic qualification.

These two coders had a minimum of nine years of immersion in the deaf community and sign language interpreting experience. The first inter-rater coder had fourteen years of experience, while the second inter-rater coder had nine years of experience. The inter-raters coded the data by viewing transcriptions and recorded interviews before deciding on a suitable code. Although these two coders were not academically trained to do the coding, the researcher trained them on how to code the data. After a few attempts of coding together, the coders independently reviewed the recorded sign language interviews and translated transcripts.

As for the other six interviews with hearing parents, the researcher engaged another coder who was fluent in Chinese, Malay, and English and academically trained in qualitative research. There were two interviews in Chinese and one interview that used a little Malay. Hence, the researcher chose a coder who could meet the language criteria to prevent the loss of expressions and nuances in a language when translated. The coder who reviewed English-translated transcriptions of interviews with parents was a fellow Doctorate qualitative researcher student in Social Science. She is fluent in Chinese, Malay, and English and has about two years of experience coding data for others and her own PhD research project. She helped to code the six interviews of hearing parents.

After the coding, it was found that the independent coders coded the interviews differently from the researcher. According to Murchison (2010), the fact that they can be coded differently is a sign of the richness and complexity of the ethnographic record.

As for validity in analysing the data, the researcher used the technique of verisimilitude (Angrosino, 2007), which is a style of writing that draws the reader into the world that has been studied to evoke a mood of recognition. The researcher used rich descriptive language that was internally coherent, plausible, and recognisable by readers from their own experiences or other things they have read or heard about. These may also include reporting and making known possible personal biases as a researcher. The work that fulfilled these requirements was seen to be authentic in the eyes of the readers. Hence, these observations become ‘valid’ when rendered into a coherent, consistent narrative.

Furthermore, as ethnographic researchers enter the field, they may enter with a certain bias. To control the bias, it is common practice to make the specific bias explicit and add quality controls such as triangulation, contextualisation, and a non-judgmental orientation (Fetterman, 2010). Angrosino (2007) stated that “good ethnography is usually the result of triangulation, which is the use of multiple data collection techniques to reinforce conclusions” (p. 35). Triangulation was used to reduce bias by using data from different sources (e.g., information from interviews, observations, archival searches) to cross-check the observations findings. Reflexivity was a means for the researcher to reflect on their thoughts and be aware of how the researcher’s background affected their points of view. Transparent reporting helped to clarify the bias.

3.6 Data analysis

3.6.1 Transcription

Three verbal interviews were conducted in Chinese, then directly translated and transcribed into English by the researcher. To check for accuracy of interpretation, the audio and transcripts were given to another party for this purpose. The English interviews were transcribed into verbatim. As for the sign language video interviews, the researcher voiced and interpreted them in English before transcribing them into text. After that, two other sign language community interpreters who were familiar with this deaf community's expression in sign language helped to cross-check the accuracy of the translations. To ensure accuracy, if there were any doubts about the transcription, a researcher approached the participant to seek clarification.

3.6.2 Participant Observation and Field Notes

The field notes from the participant observation were recorded in two forms. One was in an observational checklist, and the other was the researcher's written observations about deaf participants' social interaction. The researcher analyzed data in the checklist and the written observations for each deaf participant. Codes were given for each emerging pattern in the observations. The codes were later combined with the thematic analysis of the interviews. Data from this source provided information to help with the triangulation of the deaf participants' social interaction situations.

3.6.3 Thematic Analysis

After transcribing the verbatims, the researcher examined the experiences shared by the participants using thematic analysis (Braun & Clarke, 2006). The researcher familiarised herself with the data by reading and re-reading it, noting down initial ideas. Then, codes were generated systematically across the data set.

Verbatims of the interviews were coded by the researcher and another three independent coders for inter-rater reliability. When there was a disagreement over meaning, the researcher and second coder discussed and came to an agreement on which codes best represented the data. These codes were grouped according to their similarities, forming an overarching theme. The emerging themes and patterns were then reviewed by checking if the themes were related to the codes and the entire data set. Lastly, the specifics of each theme were refined by generating clear definitions and names for each theme before producing the report.

The same approach was used for the fieldwork notes and observations. The themes between the different sources of data overlapped. Hence, it was decided to combine all data from different sources to be analysed. Later, all codes were combined for triangulation purposes. The results reported the theme and indicated the data source to clearly reveal the deaf participant's lived experience and parents' perspective of the matter. The analysis was reported in writing using reflexivity by providing descriptions of the researcher's reflections on her expectations, reactions, and thoughts about the situations or participants to provide context of how her subjectivity shaped her inquiry, interpretation, and conclusions.

3.6.4 Data Saturation

The interviews, transcription, coding, and thematic analysis were done concurrently rather than after the completion of all the interviews. Once the data had reached saturation, the researcher stopped searching for more participants to be interviewed. The point of data saturation for each research question is explained below.

Research question one explored the parents' experience and role in bringing up a deaf child. Data saturation was reached when Parent 5 repeated the same points as Parents 1 and 2, for example, the underlying hope for the child to be normal and the effort that they made to support the child's development. The researcher interviewed one more parent (Parent 6) to ensure that data was indeed saturated for this research question. Parent 6 mentioned similar points as Parents 1, 2, and 5 in the question of his experience bringing up his deaf son. Due to the repetition of points, the research deemed that the data was saturated for this research question.

As for research question two, which explored the deaf participants' experiences that shape his/her identity, four deaf participants were interviewed. As the researcher started the coding and preliminary thematic analysis, the four deaf participants seemed to express similar responses to the same question. They expressed their desire to belong – in the hearing world, in the deaf world, in both worlds. Deaf Participants 1, 2 and 4 expressed very similar answers for their experiences. Deaf Participant 3's answer was different; hence, the researcher continued to interview another two participants to see if answers would vary or new points would emerge. Deaf Participant 5 repeated a mixture of points expressed by Deaf Participants 3 and 4 while Deaf Participant 6 repeated points of Deaf Participants 2, 3, and 5). This indicated to the researcher that the themes were repeating. Hence, she considered this repetition of answers that data has reached saturation.

Lastly, research question three, which explored the suggestions and improvements for the existing support system, reached data saturation when deaf adult child and hearing parent participants revealed no more new information. Although Parents 1, 2, 5, and 6 and Deaf Participants 4 and 5 could only give more input for this question, the other participants' responses also showed how irrelevant, ignorant, or unconcerned they were about the existing support system for them. Across the participants that responded, all six mentioned the same general point, just with different details and examples, but with the same concern. The other six who had little to say to this question were also consistent in their response – no opinion about it, don't know much about it. The consistent information and responses given by the twelve participants indicated to the research that saturation has been reached for this research question. Hence, no additional participants were interviewed.

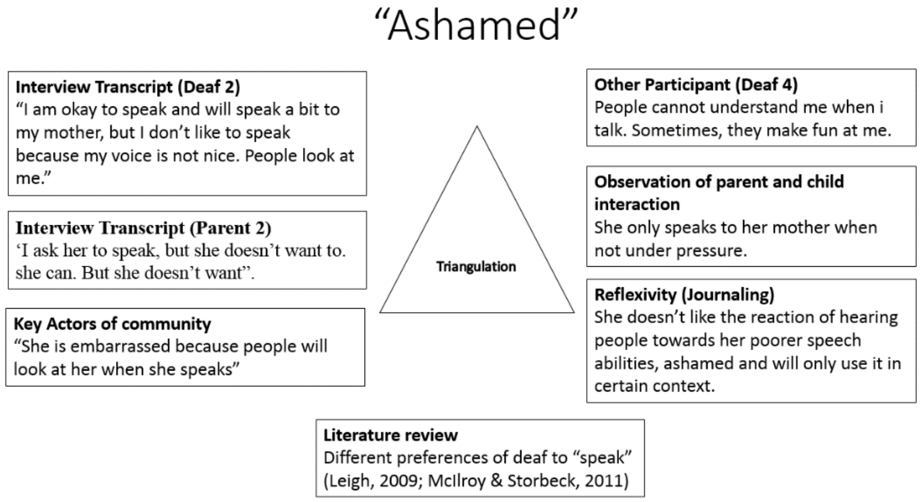
3.6.5 Triangulation

Good ethnography is the result of triangulation (Angrosino, 2007). Multiple data collection techniques are needed to reinforce conclusions. Data was collected via interviews with participants (parents and deaf child), casual conversations with non-participants (other deaf people in the Ipoh and Kuala Lumpur community, interpreters and individuals who served the deaf community), observations over nine years of the Ipoh deaf community, interactions on social media groups, current issues published in newspaper articles, opinions of medical interventions expert, and journal articles about deaf related matters. Two examples of triangulation will be illustrated below: triangulation of information and triangulation in the data analysis.

Here is an example of triangulation of information in this study. Information from parents in the interview is compared with the researcher's observation of the deaf child's current development and interaction with parents. Notes were compared with those of other parties, such as hearing aid centres, speech therapists, and experienced individuals involved with deaf work in Perak. For example, the researcher noted down in her field notes about the process of getting a hearing aid, the importance of using it and maintaining it from the parent's point of view. After the interview with parents, the researcher asked brief questions to deaf adult children about their preferences, experiences, and the importance of using hearing aids. To check if parents lack information or knowledge about it, the researcher enquired the local hearing aid centre about the nature of deaf individuals getting, using, and maintaining their hearing aids. This triangulation provided a clearer picture of the situation. Figure 3.1 illustrates another example of how triangulation was used in the coding of the data.

Figure 3.1

Triangulation in Coding the Data



Interview Transcript (Deaf 2)
"I am okay to speak and will speak a bit to my mother, but I don't like to speak because my voice is not nice. People look at me."

Interview Transcript (Parent 2)
'I ask her to speak, but she doesn't want to. she can. But she doesn't want".

Key Actors of community
"She is embarrassed because people will look at her when she speaks"

Other Participant (Deaf 4)
People cannot understand me when i talk. Sometimes, they make fun at me.

Observation of parent and child interaction
She only speaks to her mother when not under pressure.

Reflexivity (Journaling)
She doesn't like the reaction of hearing people towards her poorer speech abilities, ashamed and will only use it in certain context.

Literature review
Different preferences of deaf to "speak" (Leigh, 2009; McIlroy & Storbeck, 2011)

The theme "ashamed" was established through reviewing multiple sources that were used in the data analysis. These multiple sources refer to the interview transcripts, observations, researcher's reflexivity, statements from key actors of the community, and literature review. For example, "ashamed to speak" was coded for the expression of Deaf Participant 2 in the interview. This feeling of "ashamed" was also expressed by other deaf participants. Next, key actors of the deaf community also confirmed that the feeling of "ashamed" is typical in such situations. The researcher's observation of parents' interaction with deaf children, reflexivity in the field notes, and literature also reflected the same theme of feeling "ashamed" to speak. The findings from different resources supported the theme of "ashamed" that emerged from the data.

3.6.6 Reflexivity

Qualitative research, by nature, is subjective. The conclusions of qualitative research often rely on the researchers and their analysis and interpretation of the data. Hence, in order to be as objective and transparent as possible, researchers engage in reflexivity "to account for how subjectivity shapes their inquiry" (p. 241)(Olmos-Vega et al., 2023). Reflexivity is also a way to increase the trustworthiness of qualitative research (Finlay, 2002). Researchers are required to reflect on and clarify their expectations, assumptions, and (un)conscious reactions to context, participants, and data (Gentles et al., 2014; Olmos-Vega et al., 2023). Reflexivity also includes descriptions of how the researcher's motivations and prior experiences might influence the thought process throughout the research (Finlay, 2002). With an understanding of the importance of reflexivity in qualitative research, the researcher has written her reflections on this study in this section to give an account of her reflections on her assumptions and expectations regarding the context and participants throughout this research process.

Her motivation for the research is acknowledged here to promote transparency (Henwood & Pidgeon, 1992). Being in the Deaf community for the past twelve years has led the researcher to believe that the family's upbringing played a crucial role in the development of the deaf participant's view of self. She was motivated to understand parents' involvement with their deaf child and the resources needed for decision-making, which influenced the child's current state of well-being.

In the first four years, the few key actors in the deaf community educated the researcher about Deaf culture and Deaf identity from the perspectives of the social-cultural model. With such knowledge, the researcher thought that all the deaf members of her community shared the same Deaf identity, where they embraced their deafness and took great pride in it over the identity of merely having a disability.

According to the social model, their disability lies in the social barriers - communication barriers, and hence exclusion from the hearing world. There were common 'complaints' about hearing people who did not understand the deaf and that only a few hearing people could communicate with them in sign. The researcher had the impression and opinion that it is the hearing world that is hostile to the deaf community as the hearing people do not understand and are not willing to learn sign language to communicate with them. This impression included the ‘failure’ of parents to learn sign language and to develop a deeper relationship with their deaf child. Hence, this was the mentality that the researcher started her research with.

However, as the researcher listened to the narratives of deaf participants and hearing parents in the interviews, the data caused the researcher to reconsider her perspective. Contrary to the impression she had about the hearing world (e.g., parents not learning sign language), hearing parents actually put in a lot of effort to meet the needs of the deaf child. Many of those efforts are unseen and unspoken of by the deaf participant and deaf community. The deaf participant and general deaf community members seem to be unaware of the challenges hearing parents went through to help the child’s development. These efforts are highlighted in the results and have answered research question 1.

The researcher was surprised to hear the amount of effort parents put into providing for their deaf children so that they could lead as normal lives as possible. It was something that the deaf community never mentioned about. Although hearing parents have their personal limitations and barriers, there was no doubt they did their best to provide and to communicate. The researcher was touched by the parents’ efforts and saw some unresolvable challenges between the hearing parent and deaf adult child, and that they had to “make do” with their situation. Parents’ narrative caused the researcher to reflect on the challenges and struggles parents went through and what resources were lacking that would help parents make decisions for the welfare of their deaf child. It made the researcher reflect further on whether there were other factors that contributed to the parents' decision-making for the child and how it affected the deaf child’s development and identity.

In relation to the identity of the deaf participant, the researcher also commenced this study from the cultural-linguistic identity model perspective – where Deaf people identify themselves as a cultural and linguistic minority. The researcher was educated by the young adult deaf community members (25 – 35 years old) who advocated for Deaf rights according to the Deaf movement alongside the Kuala Lumpur deaf community. The Deaf movement is stronger in Kuala Lumpur, and it has slowly penetrated the Ipoh deaf community. Thus, the researcher viewed the narratives of the deaf participants in Ipoh with this understanding of Deaf identity. However, the behaviour and thoughts conveyed by the deaf participants seemed to indicate that they were not the Deaf identity that the researcher was told they were. This caused the researcher to reconsider how each deaf participant viewed themselves and how their upbringing influenced their current identity.

3.7 Ethical Concerns

It was the best interest of ethnographic researcher to ensure that the community under study was not harmed in any way throughout the process. The researcher was mindful to be honest and trustworthy with the participants, to keep the privacy and confidentiality of participants, and always consider how the participants may be affected by the research process itself.

Before collecting the data, the researcher was aware of the potential risks and benefits for the participant, which was made known to the participant during the briefing and informed consent before the interview. One of the risks that participants may not like was that a sign language interpreter would review their interview for transcribing and accuracy checking. This was because the deaf community is small; the sign language interpreter will most likely know the deaf participant (and vice versa). If the interviews were being transcribed into voice interviews, another ethical dilemma to consider was that this process may exclude the interviewee (Skelton & Valentine, 2003). Therefore, the researcher interpreted the sign video audibly, transcribed it into written English, and double-checked the transcription's accuracy with the participant before analysing the data.

As participant observation was covertly collecting data, the researcher had made known the purpose and procedures in the informed consent briefing.

A possible limitation in meeting the ethical guideline was that the observed participants did not know when exactly they were being observed.

One of the benefits of the research for participants was that sharing their life experiences can be used to help other families who may be going through a similar journey. They were indirectly helping others who were in their shoes. Parents were also given the opportunity to reminisce and reflect on their experiences. The interview also provided a safe place to share their thoughts, concerns, challenges, and suggestions for improving the situation. Perhaps some unexpressed emotions and experiences needed to be voiced out and heard. It is hoped that the interview mutually helped parent and deaf participants understand and appreciate their experience and that their voices would be heard.

CHAPTER 4

RESULTS

This chapter presents the study's findings. It begins with a description of the research participants. Then, a macro view of the results is presented. Next, the results of each research question are reported and discussed. Lastly, the section concludes with a summary.

4.1 Description of Participants

A total of six pairs of deaf adults and their hearing parents took part in this study. Participants consist of three pairs of hearing mother- - deaf daughter, two pairs of hearing father - deaf son, and one pair of hearing father - deaf daughter. The parents interviewed were the main caregivers of the deaf child. All hearing parents interviewed assumed the main responsibility between the spouses and looked into the needs of their deaf child in the early development years. This was the case except for Deaf Participant 4, whose main caregiver (mother) was ill, and her husband attended the interview instead.

Most of the participants were from middle social and economic backgrounds. Only Deaf Participants 3 and 4 came from low socioeconomic backgrounds and whose parents had lower education (up to primary education). All deaf participants exceeded their parents' education level, except for both deaf sons of hearing fathers. All but one deaf participant graduated with a polytechnic diploma in Graphic Designing. It is common for deaf students to be sent to pursue a polytechnic diploma after their secondary school studies. Three of them (Deaf Participants 1, 3, and 4) stayed in hostels away from home during their polytechnic diploma studies. Although five deaf participants graduated with a diploma in Graphic Design, only one (Deaf Participant 4) uses her graphic designing skills at work. The other Deaf participants currently work as production workers' assistant bakers or have yet to find a job.

All deaf participants had at least one ear with severe to profound deafness, and only one had a cochlear implant (Deaf Participant 2). Those who wore hearing aids (Deaf Participants 2 and 4) were the ones who were sent to mainstream primary school for a short period of time. Table 4.1 below describes the participants that were interviewed.

Table 4.1

Demographics of Deaf Participants and Hearing Parents

Participant Pair	1	2	3	4	5	6
Deaf Adult Child						
Gender	Female	Female	Female	Female	Male	Male
Age	20	24	34	37	36	25
Marital Status	Single	Single	Single	Married	Married	Single
Hearing Loss (L)	Severe	Mild	Profound	Severe	Profound	Profound
Hearing Loss (R)	Severe	Profound	Severe	Profound	Profound	Profound
Cochlear Implant	No	Yes	No	No	No	No
Hearing aids	No	Yes	No	Yes	No	No
Highest Education	Diploma	Diploma	Diploma	Diploma	Secondary	Diploma
Siblings	Yes	Yes	Yes	Yes	Yes	Yes
Hearing Parent						
Relation with child	Mother	Mother	Mother	Father	Father	Father
Age	48	55	60	70	69	65
SES	Middle	Middle	Low	Low	Middle	Middle
Highest Education	Secondary	Secondary	Primary	Primary	Secondary	Tertiary
Parent-Child Communication Mode						
Spoken Chinese	No	No	Yes	Yes	No	No
Spoken Malay	Yes	Yes	No	No	Yes	Yes
Written Malay	No	No	No	No	Yes	Yes
Home Sign	Yes	Yes	Yes	Yes	Yes	Yes
Sign Language	Yes	Yes	No	No	Yes	Yes

4.1.1 Communication Mode of Participants

Four of the parents (Parents 1, 2, 5 and 6), who were of the middle economic class, intentionally learnt sign language to communicate with their deaf child in the early years of development. They used a combination of basic sign language, home sign, and spoken Malay to communicate with their hearing child. Spoken Malay was used instead of their spoken mother tongue (e.g., Cantonese) because it was advised by their doctor to use only one spoken and written language to reduce the confusion of language. Since the Malay language was the national language used in school for learning, the Malay language was chosen as the main language for communication. This mode of communication was adopted when I was young. Parents also wrote in simple Malay for communication as their child learnt the written Malay language in school.

The other two parents (Parents 3 and 4) were from the lower socioeconomic class. They did not learn sign language to communicate with their deaf child. Parent 3 regarded his deaf daughter as a regular hearing person with some hearing loss and spoke to her as she wore hearing aids and learnt to speak. Home signs (signs that are used and usually only understood by parents and deaf children) were minimal. Their communication mode mostly used spoken Cantonese mixed with a little spoken Malay when needed. Parent 4 also used spoken Cantonese and some home sign to communicate. No writing or sign language was used.

4.2 Overview of Results

This section reports the themes that emerged from the interviews. The data was triangulated with other resources, such as observations and field notes. The research questions explored (1) the deaf persons' experiences that shape their identity, (2) the parent's experience bringing up a deaf child, and (3) their feedback about the social support system for deaf people. The emerging themes are summarised in Table 4.2, which provides a view of the themes and subthemes according to each research question.

Table 4.2

Summary of the Themes and Subthemes according to the Research Question

RQ1: What are the experiences that shape deaf persons' identity?

Theme	Subtheme
Being in the hearing community	Inability to keep up Excluded from communications
Being in the Deaf community	Communication without barriers Ease of learning
Being as I am	I am normal I am different
Connecting according to needs	Quality relationships Learning opportunities Personal space

RQ2: What are the parents' role and experiences in bringing up a deaf child?

Theme	Subtheme
Emotional coping	Grief Denial Rationalization
Perception of "normal"	Ability to speak Achieve independence Unique Physically regular
Parents' role	Provider Advocator

RQ3: What are the suggestions for improvement in existing support systems for the deaf people?

Theme	Subtheme
Awareness of needs	Satisfied with support Clueless of needs
Deaf-friendly communications	Direction communications Bridged communications
Support for financial independence	Provide job opportunities Job recruitment considerations Better remunerations
Essential education	Quality Holistic
Better implementation	No avenue for knowledge sharing Poor public awareness Low executive responsibility

Figure 4.1 clarifies how the themes align with the theories within the conceptual framework.

Figure 4.1

Aligning Themes within the Conceptual Framework

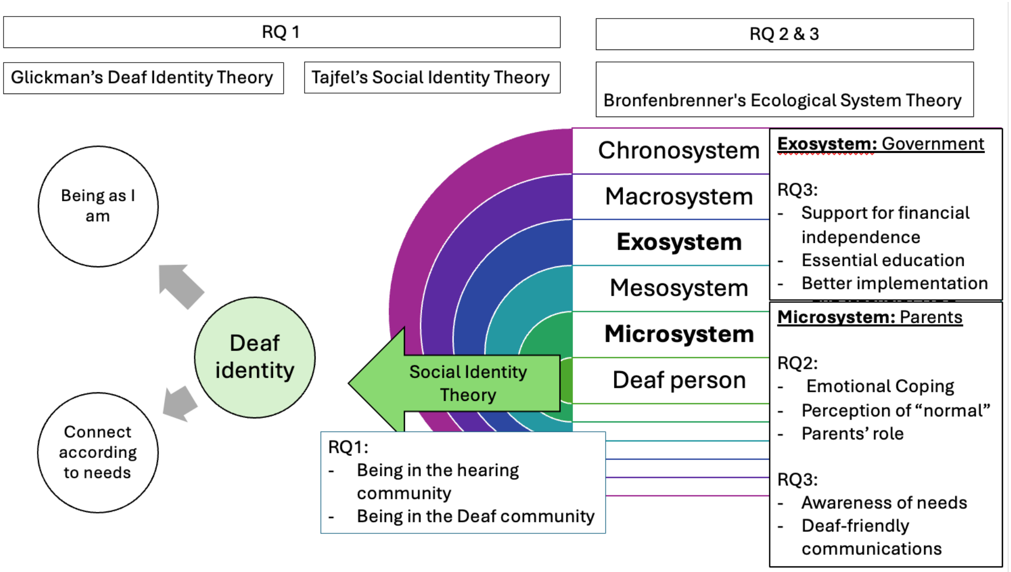


Figure 4.1 shows the overview of themes mapped to the conceptual framework of this study. The rest of the chapter will explore the details of each research question and its emerging themes. However, here is an overview of the study's findings.

Research question 1 explored deaf participants' experience growing up deaf and how it influenced their perceived identity. The themes that emerged for the deaf participants' identities were *being as I am* and *connecting according to* *needs*. These findings were unexpected, as the participants' expressed identity did not fit into the expected identity categories according to Glickman's deaf identity theory. According to Tajfel's social identity theory, it was expected that the experiences in the hearing and deaf community would influence deaf participants' choice of membership, belonging to either the hearing or deaf community, resulting in Glickman's deaf identity categories. However, the choice of membership seemed not to be based on the hearing or deaf group categories but rather on the social acceptance of a group.

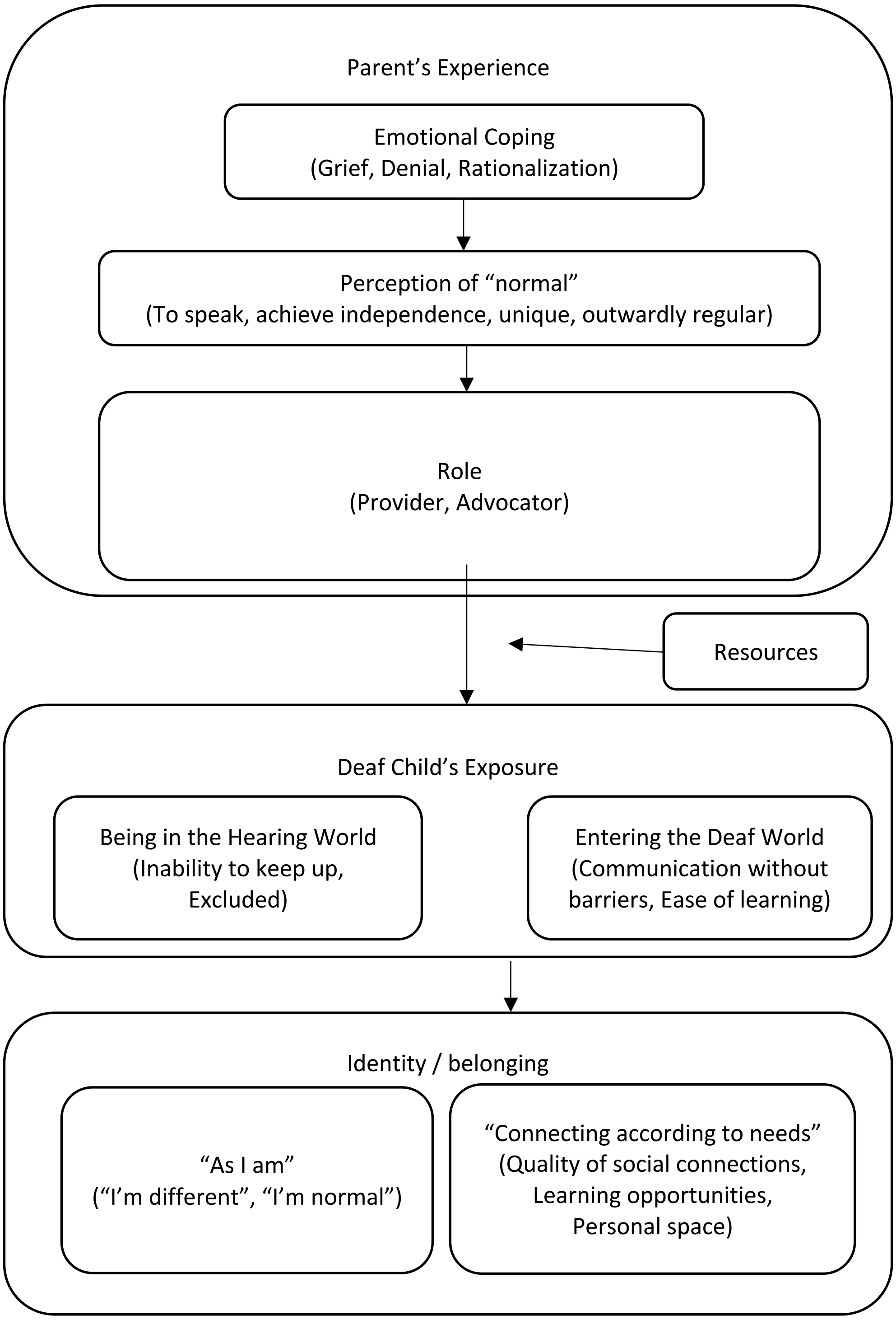
Research questions 2 and 3 intended to explore the environment of the deaf participant while growing up through the lens of Bronfenbrenner's ecological system theory. The themes that emerged from the interviews and observations concentrated on two layers – the microsystem (parents) and the exosystem (government social services and policies). Research question 2 focused on parents' experience (part of the microsystem), where the themes of parents' *emotional coping, perception of "normal",* and *parental role* emerged. These emerged themes were similar to reports of other research in Malaysia (Chong & Hussain, 2022; Wong et al., 2019). Parents' response revealed their perspective of deafness from the medical model of disability, providing evidence to the statement that Malaysia is still slow in transition to the social model of disability (Lee & Low, 2014).

Research question 3 explored the social support system provided by the government for deaf people. Parents' responses focused specifically on the exosystem, revealing themes such as *awareness of needs, deaf-friendly communications, support for financial independence, essential education,* and *better implementation.* Parents' responses indicated a high reliance on the government for social services and assistance, demonstrating that the welfare model of disability is still deeply rooted in Malaysia. This mentality explains Chong and Hussain's (2022) findings on why deaf people in Malaysia still see themselves as PWDs.

Figure 4.1 provides an overview of the themes mapped to the conceptual framework. Figure 4.2 was constructed to better illustrate how the themes and subthemes of research questions 1 and 2 relate to the microsystem and deaf person.

Figure 4.2

Overview of Themes and Subthemes of the Microsystem and Deaf Person



A more detailed description, explanation, and discussion for each of these three sections – (1) the experience of the deaf person growing up in a hearing family, (2) the experience of hearing parents bringing up a deaf child, and (3) the resources provided by the government, are presented accordingly in the sections below.

4.3 Research Question 1(a): Experience of Deaf Participants

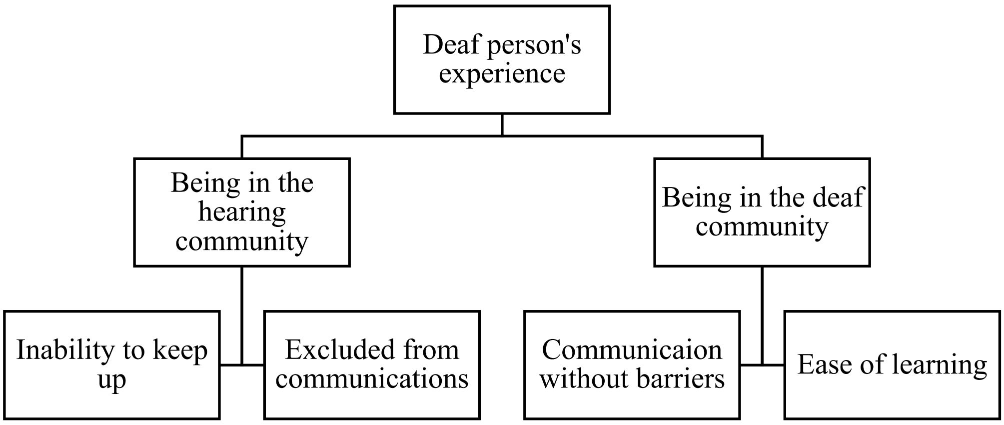
The first research question explored the life experiences of deaf participants and their expressed identity. This section will report the themes that emerged from the deaf participants' narratives of their experience living as deaf people. The following section, 4.4 Research Question 1(b), will continuously explore how deaf participants' experiences influence their expressed identity as deaf people in Malaysia.

Most deaf people are born into hearing families (Sutton-Spence, 2010) and are surrounded by a hearing environment. As deaf children grow older, their exposure is extended outside the family environment. They would meet other members in society such as teachers, classmates, etc. Through these interactions, the deaf child discovers more about themselves and the bigger world around them. How is life like for a deaf person? What are the experiences living as a deaf person in Ipoh, Malaysia?

Two themes emerged from the narratives of the deaf participants about their life experiences. They shared stories and incidences of how it was like being in the hearing community and the deaf community. Figure 4.3 displays the subthemes of deaf participants' experience.

Figure 4.3

Subthemes of Deaf Participants' Experience



4.3.1 Being in the Hearing Community

Apart from interacting with hearing family members, deaf participants also interacted with other members of the hearing community. Some of the shared experience of being in the hearing community includes "inability to keep up" and "excluded from communications".

4.3.1.1 Inability to Keep Up. The subtheme of the *inability to keep up* emerged from the narratives of two deaf participants (Deaf Participants 2 and 4) who were sent to a regular mainstream primary school. Both had better hearing abilities compared to the other four. Deaf Participant 2 had a cochlear implant. Deaf Participant 4 has moderate hearing loss and uses hearing aids. Their parents wanted to give them a chance to learn in a regular mainstream school rather than to be sent to a deaf school. These two deaf participants experienced a communication breakdown due to their hearing impairment, which interfered with learning in the hearing class. They were unable to keep up in the hearing environment, which caused them to feel pressured because of their inability to keep up with their hearing peers.

Deaf Participant 2 went to a hearing school to study. She could not keep up in class due to her hearing impairment. She shared:

> I really could not hear or understand what the teacher was saying. So, I stopped and moved to a deaf school. (Deaf Participant 2)

According to her mother, the teachers at the school did not know how to teach her. Deaf Participant 2 was also unable to learn adequately because she could not hear or understand what was going on in the class. Hence, as her mother stated, “It was a waste of time for her to be in the hearing school”. She left this school and was placed in a deaf school where she could learn better.

Although Deaf Participant 2 had speech therapy and cochlear implants that would help her to adapt to the hearing environment better, she was just not able to cope with the regular school's education system without any special assistance in communication. The teachers were not trained to handle a special needs child in the regular class either. Since the child could not cope, her mother removed her from the environment before experiencing too much stress and pressure to perform.

Deaf Participant 4, on the other hand, went through a traumatic experience learning in a hearing classroom. She was studying in a regular class for primary 1 and 2. However, as she advanced to primary 3, she could no longer keep up. The following is the account of her experience being in a hearing school:

> It was very difficult. I couldn't hear or understand what my teacher was saying when she spoke while writing on the board. Also, I didn't have a friend to help me. During Primary 1, I had a friend who always sat next to me. She would help me. But in the year after, we were in different classes. I lost her; I didn't have any close friends to help me with the interpretations of what was going on in class. It was very hard for me in Primary 2. (Deaf participant 4)

On another occasion, Deaf Participant 4 described the stress and fear she felt in class for not being able to keep up. Without an assistant to cue her on what was going on in the class, Deaf Participant 4 was lost. The teacher did not cater for her hearing needs. The communication breakdown also caused her to experience a lot of pressure to keep up. She exclaimed:

> I was scared that if I couldn't answer the questions because I couldn't hear or understand, I would be punished for that. I was afraid. That was the hearing school's pressure. So, when the teacher got all of us to stand up and answer the questions one by one, I was afraid because I couldn't hear, answer, or understand. I was scared because I couldn't understand. I was scared. I felt that I couldn't, and I was really scared. I wanted to go back to the deaf school. (Deaf Participant 4)

As Deaf Participant 4 conveyed this story, the researcher felt the stress and fear she projected through her expressions. She used the word 'scared' at least six times in sharing this incident.

Deaf Participant 4 also felt stressed about performing – answering the correct answer in a clear speech in front of the class to avoid embarrassing herself. The stress increased when she could not follow or understand what the teacher was asking. She was put in a position of possible self-humiliation if she were to give a wrong answer and with poor speech in front of the whole class. She risked being laughed at and ridiculed. This caused her trauma of speaking in front of others. This constant situation of risking being humiliated and teased by others caused her to want to be away from the hearing environment and return to the deaf environment, where she felt safe and free from the pressure to meet the expectations of performing according to the hearing school's standard.

Deaf Participant 1, who was staying with hearing students in the hostel, also expressed similar pressure being with hearing people. It was the pressure to keep up with ongoing information. In her account, she shares:

> When I was sent to that school with hearing people, I was quiet; there were a lot of questions, and I was very tired. (Deaf Participant 1)

She expressed in sign language that she was being "put aside" because of the communication barriers and being deaf. Although she signed the word "tired", her facial expression seemed to indicate a sense of frustration and that she had "given up" on trying to change the situation. She was "tired" of all the questions people directed to her, which she struggled to understand and communicate. There was also an expectation by her hearing peers for her to follow the verbal conversations immediately. She could not perceive and process the information just as fast as her hearing peers. It was very frustrating for a deaf person to be expected to keep up with communication without being able to hear. This breakdown of communication and disconnection frustrated her and made her want to go back to her deaf school community.

4.3.1.2 Excluded from Communications. Communication with the hearing community through hearing and speech is challenging for someone who cannot hear. Without the skill to read lips or speak, deaf persons are easily excluded from spoken communications. It is not surprising to hear deaf people's frustrations trying to communicate with the hearing community. Deaf Participant 2 expressed not only a sense of frustration in communication but also a hopelessness of effective communication, which left her excluded from the communication. She shared:

> When people call me and speak to me, I can't hear. I can't understand them. Even in lectures or talks, when the person speaks, I cannot hear. I

> don’t understand what they are saying. (Deaf Participant 2)

Participant 1 also had a similar experience when being among hearing classmates. She shared:

> There was a lot of pressure staying in the hostel as I was asked a lot of questions but couldn’t understand. They only spoke, no signing. I was put aside because I was deaf. I was tired of being in that situation. So, I left. (Deaf Participant 1)

The inability to join in verbal conversations with no accommodations for her left Deaf Participant 1 excluded from conversations, which she gave up and left the hostel.

When asked for suggestions on what a hearing person can do to help the situation, Deaf Participant 2 answered, “I don’t know. Nothing. Just go your separate ways. Join the Deaf.” Out of frustration in communication, Deaf Participant 2 seemed to have given up trying to connect and be part of the hearing community. Perhaps she felt powerless to change the hearing environment to suit her communication needs. She acknowledged her limitations and the challenge of communicating with hearing people. Feeling hopeless and helpless, her solution was to surrender, trying to connect with the hearing community and resigning to being only in the deaf community where communication has no barriers.

Deaf Participant 4 also felt excluded from conversations with family.

Though she tried to participate, she was pushed aside and left out, unable to join in the conversation with her hearing family. She states:

> Is it better that when my relatives speak, they can include me? I always need to ask my sister what they said, but she replies to me, 'Aiya aiya, Nothing. Nothing. Never mind'. I feel hurt and left out. I want to be able to be part of the conversation. But they tell me that I do not need to know. But I am family. I want to know what is going on so that I can develop and improve. But you put me aside as a deaf person? (Deaf Participant 4)

This scenario of being excluded from family communications is like the documented phenomenon term "dinner table syndrome", as observed in the experiences of deaf people (Hauser et al., 2010; Meek, 2020). The "dinner table syndrome" has been used as a metaphor for all types of conversations that are not completely accessible to deaf people in hearing groups. Conversations are so fast that deaf individuals find it difficult to identify the speaker and decipher the message of the conversation. Meek's research revealed how deaf people miss out on communication with hearing family members and their sense of conversational belonging or exclusion within the family. Deaf Participant 4 strongly expressed the same themes in the interview. Other than the daily conversations with family members during gatherings, she did not want to join Chinese New Year family gatherings anymore. The sense of exclusion was so strong as a child that she often cried alone.

Although Deaf Participants 2 and 4 reached out and tried to communicate with hearing family members or friends, over time, there was a sense of defeat, failure and giving up trying. If the hearing counterparts do not try to accommodate or include the deaf person in conversations, deaf participants reaching out would be in vain. In repeated observations by the researcher over the years, the deaf participants accepted the non-communication and congregated among themselves when they were in a bigger social context with hearing people. During the interviews, Deaf Participants 1, 2, 3, and 6 were adapted to the hearing situations and did not think or express much about it. They were neither positive nor negative about not being able to communicate with the hearing community. Deaf Participant 4 had more expectations to connect with hearing people. She perceived a lot of hurt and disappointment from trying and eventually also perceived this "exclusion" as a form of rejection. She once asked the researcher, "Do the hearing people love us? Why don't they connect or include us?"

There are hearing people who may unintentionally exclude the deaf person from communications, and their actions may have resulted from ignorance, fear, or cluelessness about how to communicate and include a deaf person in their conversations. As Meek (2020) stated, the essence of his study – deaf participants were "loved yet disconnected". Hearing family members love them, but the family table syndrome happens too often - leaving them disconnected because of the inaccessibility to conversations. Hence, to bridge this gap, creating awareness about the needs of the deaf among hearing members and using communication strategies (e.g., raising hands to get attention before communicating, using pidgin sign language) during conversations would be helpful to include deaf individuals in conversations.

4.3.1.3 Summary. Overall, it is difficult for the deaf participants to keep up with verbal communication. The continuous exclusion from ongoing communications has left deaf participants frustrated and isolated from the hearing community. The impossibility of keeping up with communications without accommodations has likely deterred deaf participants from further interactions with hearing community members. They seem to adapt to this unchangeable social situation by leaving the hearing community and congregating among themselves as a deaf community. Since they were being excluded by the hearing community, they formed their own group to meet their own needs as deaf people.

4.3.2 Being in the Deaf Community

Most deaf children grow up in hearing families (Mitchell & Karchmer, 2004), and they only encounter other deaf children when parents expose them to activities and schools with other deaf children. So, when deaf children enter the deaf community, they discover a different world, and they try to make sense of who they are and where they belong. From being exposed to the hearing community and the deaf community, they have a comparison between two different worlds and experiences. One world with sound where they are the exception, while the other world is without sound, where there are others just like them. The six deaf participants were asked about their experiences being in the deaf community, which community they felt a sense of belonging to, and why. Themes such as “communication without barriers” and the “ease of learning” emerged from the data.

4.3.2.1 Communication without Barriers. In the interviews with the different participants, there was a repeated theme of the importance of communication. In their experience of being in the deaf community, deaf participants pointed out how they felt connected and included because there were no communication barriers. Sign language, which is visual, connects them. They could easily mingle and understand each other with a common visual language. Deaf Participant 1 shared:

> I studied in a full deaf school, and I enjoyed that. It was good because you can play and get along well with each other. There was no issue with communication, as you can understand the signing. I prefer being with the deaf. It’s better because looking at the sign language to communicate is easier. (Deaf Participant 1)

It is because of a common visual language that enabled them to connect and have deeper conversations. Deaf Participant 2 pointed out how she preferred to be with the deaf community because of the ease of communication:

> Actually, I don’t mix with them (hearing people). I am very quiet. I don’t speak to them. I would choose the deaf because I feel happy that we can have good fellowship. With the hearing people, I can’t understand them. It is difficult to know what they are saying. (Deaf Participant 2)

Communication through sign language not only made connections but also created opportunities for deaf people to find social and emotional support from one another. Being understood through clear communication with each other gave them the deeper human connections that they need in life to cope with challenges. Deaf Participant 2 shared about her best friend who was deaf and how sign language enabled them to connect deeper and fostered good social and emotional support when it was needed. She shared:

> I have a close (deaf) friend; we are always together… We are very close, always together, sharing, chatting, and learning things together. She is the first person I would go to for support when I face problems. We, the deaf, can encourage and understand each other. (Deaf Participant 2)

From researchers' participation observations, during fellowship time after the program, outgoing Deaf Participant 1 happily went around to different deaf people to initiate all sorts of conversations (e.g., updates, current events, food). Reserved Deaf Participant 2 joined the existing conversation by listening in and responding to the deaf person's dialogue. Deaf Participant 3, who was isolated from deaf people for five years, observed signed conversation from where she sat. Maintaining eye contact with the speaker with occasional nods and facial expressions showed that she was listening and engaging in the conversation. Deaf Participant 4 freely initiated conversations with the hearing signers and deaf individuals in the group. When Deaf Participant 6 came for events, he selectively chose male friends to interact with. Deaf Participant 5 was generally not interested in communicating with this deaf community and hardly joined the social events.

From these observations, the deaf participants became alive in the deaf community as they were free to express and mingle, as compared to being among the hearing community where they avoided awkward situation or kept to themselves. As sign language is visual, it is open for all to see and to participate in the conversation by taking turns to continue its “story telling”. It was like an “open campfire storytelling” situation.

Overall, from the expressions of deaf participants in the interview and through the researcher’s participatory observations, it conveyed the importance of communication without barriers, where deaf participants felt free to communicate and connect. It was needed for emotional and social support. For these deaf participants, such connections undoubtedly had to be through sign language, as they could not hear or speak effectively to hold deeper conversations with the hearing community without straining to understand. (View Appendix F for participatory observation checklist summary).

4.3.2.2 ***Ease of Learning.*** Being in the deaf community always includes the use of sign language. Sign language is a channel for the ease of communicating information visually. Deaf Participants 2 and 3 pointed out how being in the deaf community that uses sign language for communication helped them a lot in learning. Deaf Participant 2 shared her experience meeting other deaf people for the first time and how it inspired her to learn:

> When I was in Primary 1, I met deaf people. They were signing. I was really surprised to see people signing. But I didn't know how to sign. They started to teach me with their hands. I learnt how to spell and sign. I improved my signing skills and started to understand and be more aware of things. (Deaf Participant 2)

She seemed intrigued and discovered a new way of communicating with other people without having to listen or speak. She moved from a stressful hearing community and entered a deaf community. Deaf Participant 2 was happy to be in an environment that understood her communication needs and where she could learn. Due to the ease of understanding others and expressing herself through sign language, she felt connected, and it immediately opened up her curiosity to learn.

Deaf Participant 3 also expressed similar experiences being in the deaf community. Mixing with her deaf classmates and with a teacher who could sign, she was happy to be able to learn. She stated:

> I like to mix around with the deaf because I can learn, and the teacher can teach us. The teacher uses sign language in class. So, together with the deaf, I can learn better. (Deaf Participant 3)

Sign language was not used for communication in the hearing world. Hence, communication of information and learning was a challenge for the deaf participant. The ease of learning through sign language was certainly a plus point for the deaf person.

4.3.2.3 Summary. Compared to the hearing community, where deaf persons are not able to keep up and are excluded from communication, being in the deaf community provided a more welcoming environment with sign language that eased communication and learning. Sign language is visual, and it provides the opportunity for deaf people to observe (e.g. listen in on conversations by seeing, not audibly listening) or join in on conversations for social and learning purposes. It is through observing a conversation that deaf persons can learn incidentally (Calderon & Greenberg, 2012). In the hearing community, deaf persons are not able to listen to conversations for incidental learning (Hauser et al., 2010). Hence, the use of sign language is important for communication and connection among deaf people.

Although the deaf community is more attractive to the deaf participants for its ease of communicating and learning, there are some limitations of remaining in the deaf community alone for development. Communication for social connections is great in the deaf community, but the quality of learning within the deaf community alone is limited. In the Malaysian context, the deaf community is underdeveloped. The majority of the deaf community members may not be as proficient in education and language. Their literacy and comprehension of written languages are questionable. Hence, if knowledge from among the deaf members is limited, what quality of knowledge and learning will there be for other deaf members who are observing conversations for incidental learning? The depth and breadth of knowledge would be limited to the pool of people who can obtain that information. In order for the deaf individual and community to grow, knowledge has to be imported from the hearing world into the deaf community. In this sense, the Malaysian deaf community is not established enough to be independent from the hearing world.

It is a dilemma for the deaf because though they can get more knowledge from the hearing world, they do not have full access to it because of their poor literacy and language comprehension. Sign language will be helpful, but in Malaysia, most information and knowledge are not accessible in sign language. Sign language interpreters and hearing users are few and far between (Lau, 2017). So, the deaf community, to a certain extent, has to depend on hearing people to obtain knowledge for growth. However, deaf people struggle to understand, communicate and learn in the hearing world without sign language.

In order to close this gap between the hearing and deaf communities, both deaf and hearing members of the community need to meet in the middle. Hearing people can learn sign language to connect to the deaf (e.g. parents learning signs to communicate with children), while deaf people also need to improve their learning and literacy. In this way, the deaf individual and community can develop, benefitting from the best of both worlds.

4.4 Research Question 1(b): Identity of Deaf Participants

The second part of research question one explored the expressed identity of deaf participants, which is formed through their experiences living as deaf persons in Malaysia. In the hope of understanding the deaf participants' journey of discovering themselves, the researcher asked the question: "How did you know you were deaf?". The intention of this question was to explore participants' perceptions of their own identity as a deaf person. The researcher had an assumption that deaf participants were indeed different from the regular person. The researcher expected the deaf participants to have already established a sense of identity, as stated in Glickman's social identity theory (Glickman, 1996). The researcher also assumed that it was a journey the deaf participants were aware of, and hence expected the deaf participants to share a clear narration or an "eureka moment" on realising that they were different from the hearing people and what it meant to be deaf.

On the contrary, the deaf participants responded to the question by giving facts on when and how they found out that they had a hearing loss rather than an incident that made them realise they had different hearing abilities or had felt distinctively different from the hearing people. For example, this is what the two deaf participants said:

> In the past, my mom knew that I would be deaf. My sister told me that my mom wanted to abort me as a fetus. When she fell ill with measles, she checked with the doctor about what to do. My mom thought that I would be handicapped because of this sickness. But the doctor said that everything was okay. At most, the baby might not be able to hear. (Deaf Participant 4)

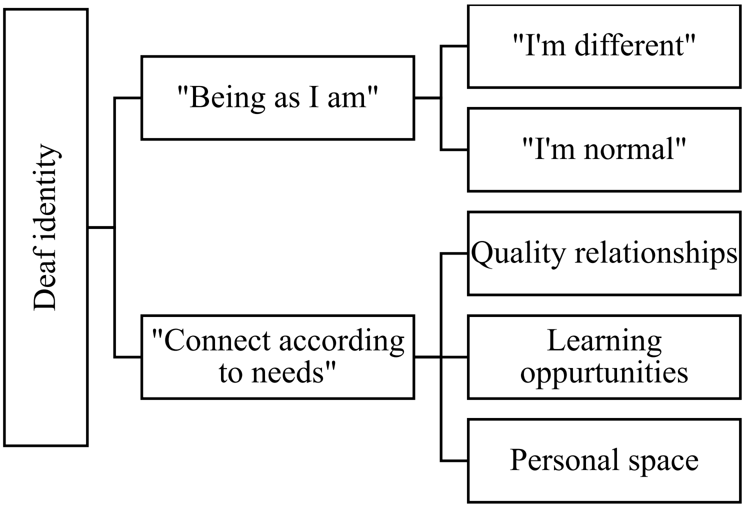
> I don't know, but when I was a baby, I was sick. My mom told me that I was deaf. I was about 8 to 14 when I realised that I was deaf. I'm not sure.

I don't remember. (Deaf Participant 6)

The researcher assumed that deaf participants would respond similarly to what she had read in literature or what she had heard about deaf identity from the Deaf awareness programs and movements in Kuala Lumpur, the capital city of Malaysia. Hence, during the interviews, the researcher asked different questions in the hope of drawing out their experiences and stories of what they thought of themselves as deaf people. The responses of the deaf participants were not what the researcher had expected: they would identify themselves proudly as *Deaf* – an exclusive, distinctive linguistic minority group. Nonetheless, data from the interviews, observations, and field notes reveal interesting results. The thematic analysis revealed two main themes related to deaf participants' perceived identity – *being as I am* and *connecting according to needs.* Figure 4.3 below captures the essence of the two themes.

Figure 4.4

Themes of Deaf Participants' Identity



4.4.1 Being as I am

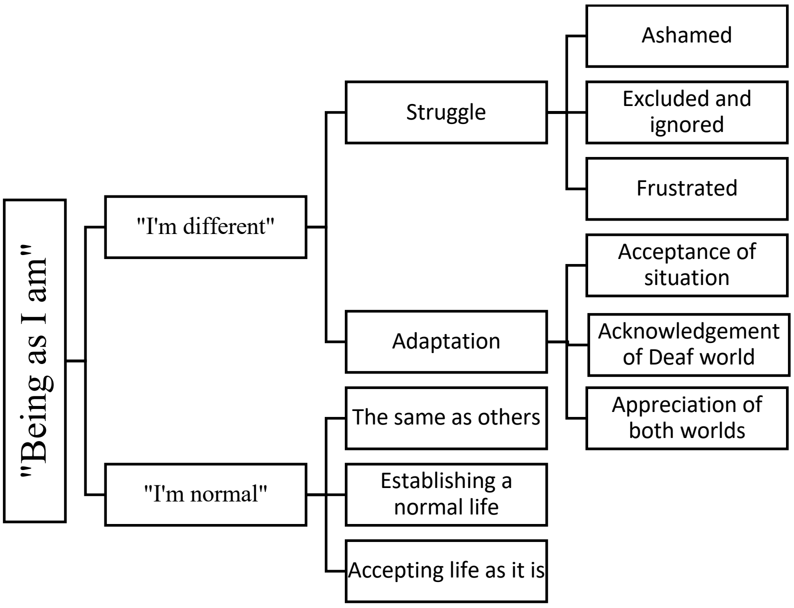
Before the interviews, the researcher had some pre-understanding and pre-education about deaf identity from the urban deaf people in Kuala Lumpur. The element of Deaf culture is one very important aspect from the perspective of the urban deaf community in Kuala Lumpur (Malaysian Sign Language and Deaf Studies Association (MyBIM), 2014). There is a strong emphasis on embracing Deafhood and BIM. According to (Glickman, 1996), this is the culturally Deaf identity. However, in the exploration with the deaf participants in Ipoh, they expressed a diversity of deaf identities, which do not fit into any categories in Glickman's four deaf identities models. Rather, it seems that the identities expressed by the participants are the concept that their identity is fluid (Leigh, 2009; McIlroy & Storbeck, 2011) and uniquely bicultural (Ohna, 2004).

The overarching theme "being as I am" that was given as a description of deaf participants points to accepting oneself as they are. This is comparable to the second wave of deaf politics, whereby deaf identity is understood from a postmodernist approach (Davis, 2002). The identity of deaf individuals is not segregated into merely two categories – deaf or Deaf. Rather, the concept that identity is fluid and diverse according to the postmodernism approach explains that individuals have their unique narrative and personal interpretation of what being deaf means to them – "deaf in my own way" (Ohna, 2004). Hence, identity is not limited to two categories.

There seemed to be two types of experiences that deaf participants narrated under this theme of *being as I am*. Deaf Participants 2, 4, and 6 experienced struggles living as a deaf person. They discovered how different they were from others and eventually accepted their differences as a deaf person. On the other hand, Deaf Participants 1, 3 and 5 expressed the experience of being deaf as a very normal part of life. The section below describes all six participants' experiences that expressed how they perceived themselves as *being as I am*. Thereafter, the researcher summarised her observations of the deaf participants' subscribed identity. Figure 4.5 below shows the subthemes that emerged from the data.

Figure 4.5

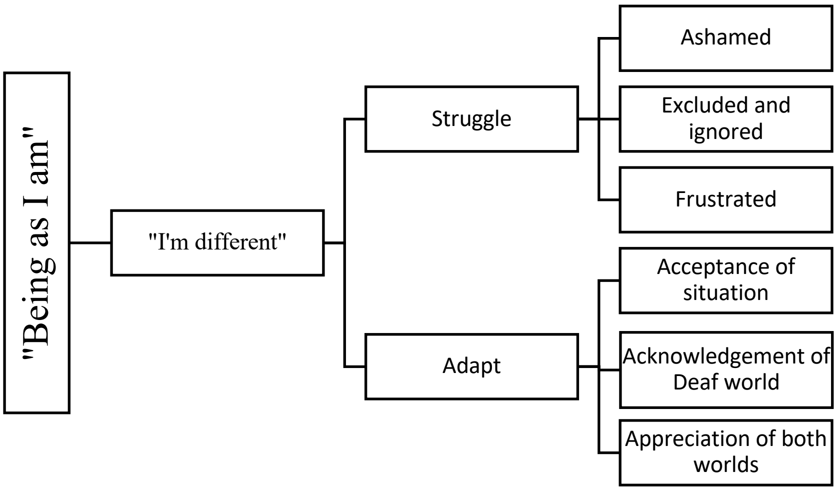
Subthemes of Being as I am



4.4.1.1 I'm different. The subtheme *I'm different* emerged from the data as participants described their experience struggling to fit in the hearing community, which resulted in feeling ashamed and frustrated. They then learnt to adapt themselves by accepting the situation, acknowledging the Deaf world, and appreciating both worlds.

Figure 4.6

The Subtheme Development of "Being as I am"



Some of the deaf participants' experiences in the hearing community had been unpleasant as they were expected to perform and communicate like a hearing person. They were not able to catch up with what was going on in the hearing environment. There was pressure to speak in front of others, with the risk of being laughed at in public for their poor speech abilities. They were excluded from conversations. These unpleasant experiences from the hearing environment leave the deaf participants unable to fit in due to their differences being deaf people. The subthemes that emerged from the data showed the negative emotional experiences of deaf participants – *ashamed, excluded, ignored,* and *frustrated.* These emotional responses were evidence of struggling to fit in.

4.4.1.1.1 Ashamed. From the observation and interviews with Deaf Participant 2 and her mother, the data revealed Deaf Participant 2 felt ashamed to speak. Her mother believed that being able to speak was essential for the success of survival in the hearing world. Hence, Parent 2 put in a lot of resources and effort to give her the opportunity to develop her hearing and speaking abilities. Deaf Participant 2 felt the pressure to speak, especially when Parent 2 'complained' to the researcher in front of her deaf daughter about her stubbornness to speak – "I asked her to speak, but she doesn't want to. She can speak, but she doesn't want to".

The deaf daughter responded with a silent "I don't want to, and you cannot make me" expression and remained silent (in speech and in sign). As a researcher, I sensed that the deaf child wanted to say something more but gave up because her mother would not understand from her point of view why she did not want to speak.

Later, in a separate interview with the Deaf Participant 2 alone, she shared that she was okay to speak and would speak a bit to her mother, but she did not like to speak because her voice was “not nice”. She was ashamed of her voice and the sound that it produced. Perhaps she had had a bad past experience of speaking – where she either saw the negative reaction of others (e.g., teasing, laughing at her) or how speaking had made her feel (e.g., stressed, anxious, fearful, embarrassed). These are assumptions of how Deaf Participant 2 might have felt as she did not want to talk more about this topic to the researcher.

From the researcher’s observation of the relationship between the deaf daughter and hearing mothers, Deaf Participant 2 seemed to rebel against speaking when her mother pressured her into it. But when she was out of the pressure, she spoke for her mother’s sake. When there was pressure to fit into the hearing community, this deaf participant silently rebelled against speaking and only wanted to mingle with the deaf community. Perhaps there was an underlying resentment towards the hearing community for how it made them feel less about themselves because of their hearing disability.

Deaf participant’s shame for speaking is not an uncommon account among deaf people. Deaf people with poor speech have often been bullied and made fun of, which may lead to increased psychological distress among deaf people (Cheng et al., 2019). Viewing deafness as a cultural identity, where not speaking but using sign language, was one way how deaf people safeguard themselves from feeling ashamed for not being able to speak like hearing people.

4.4.1.1.2 Excluded and Ignored. Deaf Participant 4 had her own share of negative experiences being in the hearing community, which made her feel excluded and ignored. She had been excluded from family communications, laughed at for her poor pronunciation and speech abilities, which she used in public, declined written communication by the doctors who insisted on speaking with her hearing husband, etc. Her parents expected her to speak, listen and earn just the same as a regular hearing would, but without any assistance for her hearing condition. They seem not to view her deafness as a disability or a difference, maybe because her hearing loss was moderate (hard of hearing). Her parents were uneducated, but with the help of friends and the government, she was sent for speech therapy and to regular mainstream school. First, she was immersed in the hearing culture, then exposed to the deaf community.

While being immersed in the hearing world for the first 8 years of her life, and consequently, working with hearing colleagues and marrying a hearing husband, she expressed unfair treatment and painful incidents she experienced as a deaf person living in the hearing community. These experiences often left her feeling excluded from social circles that she desired to be part of. These situations are likely to make her wonder who she is and how she fits in with society.

In school,

> I couldn’t focus or understand what the teacher was saying. I was scared that if I couldn’t answer the questions, I would be punished. I couldn’t hear the question. I was afraid and pressured. So, when the teacher got all of us to stand up and answer the questions one by one, I was afraid because I couldn’t hear, understand, or reply. I was really scared. I wanted to go back to the deaf school. (Deaf Participant 4)

At home with family,

> It is better that my relatives when they speak, they can let me know. I always have to ask my sister what they said; they reply to me, ‘Aiya Aiya, nothing, nothing. Never mind’. I feel hurt and left out. I want to be able to be part of it. But they tell me that I don’t need to know. I want to know what is going on so that I can develop and improve. But you put me aside as a deaf person? (Deaf Participant 4)

At the restaurant,

> We sat down in one of the stalls to eat. The aunty asked what drink we would like to order, but she didn’t know that we couldn’t hear. “Oh, this group of people cannot hear. You don’t know how to order your drink? Cannot hear, cannot speak?”. The way she said it was taunting. It felt like bullying. She didn’t give us a paper to write on for communication. She just kept saying, “This one cannot hear and cannot talk.” It was taunting. It was hurtful to us deaf people. She said loudly in front of everyone, ‘If you have a voice, speak lah’. It was very hurtful. (Deaf Participant 4)

At the hospital,

> My husband and I went to the hospital because I had some sickness, and I wanted to communicate deeper. My husband was out there waiting for me. And the doctor met with me and talked a bit. But our communication difficulty is this: I wanted to write to the doctor to communicate with me. But the doctor didn’t want to communicate with me, so they asked me who the person outside with you was. I replied, “My husband.” He asked, “Is he hearing or deaf?”. “Hearing,” I said. The doctor requested, “Can you call him?”. I felt hurt. (Deaf Participant 4)

Deaf Participant 4 was treated differently as a deaf person, although she tried to integrate with the hearing world. Her experience at the hospital made her feel incapable of independently managing her own medical condition. The experience at the restaurant was hurtful as her communication needs were ignored, and she was made fun of. The exclusion was emotionally and psychologically damaging. Her experience is not in isolation, as Leigh (2009) also pointed out the common themes in deaf people's lives, including isolation, tension, and struggle.

4.4.1.1.3 Frustrated. Deaf Participant 6 is likely to have had a personal crisis as a deaf person but did not elaborate much about it. The researcher drew a conclusion through the observational and interview data of both deaf participants and hearing parents. Deaf Participant 6 experienced a lot of frustrations, especially when communication needs were not satisfied. The constant frustration of communication is likely a personal struggle with himself – why he is this way and how he fits in society. His father relayed how his son went through this crisis during his teens:

> He (my son) asked questions about why he was like this (deaf). When he was young, he didn't realise (his difference being deaf), but later, when he was older, he did. So, we told him, "You were born like this". Initially, I don't think he accepted it. (Parent 6)

His father also shared how his deaf son was frustrated with communication barriers between them and the limited avenues for deeper discussions. This narrative below illustrates the frustration of Deaf Participant 6:

> My son always asks me about the news when I come home. But I haven't read the newspaper, how do I know what's on the news? He would say to me, "Why don't you know?" and then grumble a bit. After that, he would come up with a list of the words from the newspaper that he doesn't understand. I can't understand what he spelt. I can't read his fingerspelling. It's so fast. He starts to get angry. He can't speak but makes a certain noise. I, too, sometimes get angry at him. There is frustration in communication. I want to explain something to him, but I don't know how to fingerspell it. I write to him; he doesn't understand the words. (Parent 6)

Deaf Participant 6 was bad-tempered and got angry due to frustrations of not being understood, according to the father. Similarly, in the interview with Deaf Participant 6, he also expressed frustration with the deaf and hearing community. The deaf community was viewed as having a lot of problems, and he wanted to keep a good distance from being misunderstood.

4.4.1.1.4 Summary. Deaf Participants 2, 4 and 6 revealed struggles to fit into the hearing community as deaf persons. They felt ashamed, excluded, ignored, and frustrated. These negative emotions expressed were signs that they were likely to be struggling with themselves and society – why am I like this? Why am I treated differently from others? Who am I? How do I fit into community? The unresolved inner struggles were expressed in emotional turmoil.

Eventually, Deaf Participants 2, 4, and 6 slowly accepted their conditions. Finding acceptance of being deaf seems to be based on their exposure to sign language and being with other deaf people like themselves. Deaf Participants 2, 4, and 6 had exposure to sign language in kindergarten. Deaf Participants 2 and 4 had experienced being in a regular hearing primary school but transferred back to the deaf school when they could not keep up with the class. Being connected to other deaf people and using sign language helped the three participants to accept themselves as deaf people without having the expectation to behave or perform as hearing people. They have expressed acceptance of themselves in their unique situations through *acceptance of situations, acknowledgement of the deaf world, and appreciation of both worlds.*

4.4.1.1.5 Acceptance of situation. Deaf Participant 2 felt relieved learning sign language as it helped her to understand the world around her. In her words,

> They (deaf friends) started to teach me with their hands. I learnt how to spell and sign. I improved my signing skills and started to understand and be more aware of things. (Deaf Participant 2)

Since then, she has developed a preference for the deaf community over the hearing community because of the ease of communication. Her mother expressed concern that her deaf daughter withdrew from mixing with (hearing) people. She isolated herself at home and only communicated with deaf friends via video calls and directed her focus on the deaf community and sign language.

Over the years, her mother has also accepted that her deaf child may never speak as regular hearing people do and has stopped pushing to test her speech development. Her mother was satisfied with the fighting chance to provide her daughter with the best possible opportunity in life to excel. Deaf Participant 2 has also arrived at a comfortable state of being herself. Enjoying the love and unique communication and relationship with her mother, she has accepted life the way it is.

Deaf Participant 2 expressed a desire to be included in conversations with her hearing colleagues at work. When asked how she feels as a deaf person in such a situation, she said, “I can’t hear or understand what they are saying. I am not able to join them”. This may have made her feel left out and not part of the group. However, she was very happy to connect and be in the presence of her hearing colleagues during lunch invitations. She said, “I feel I belong with the hearing people; we go out for lunch together”.

When Deaf Participant 2 was asked again nine months after the interview how she viewed herself as a deaf person, she said, “I just can’t hear and understand conversations with hearing people. I can’t join. But I want to. I enjoy connecting with the deaf because I can understand.” Though she might have struggled in her younger days with the expectation to hear and speak, she seemed to have accepted her situation and is comfortable and connected both in the hearing and deaf community. When asked: would you rather be hearing or deaf?

She replied: “I think it is the same. I can accept being both”. She has arrived at a point of accepting her circumstances as a deaf person.

4.4.1.1.6 Acknowledgement of the Deaf World. Deaf Participant 6 stated in the interview that he realised he was deaf when he was between 8 and 14 years old, though he did not recall much about it. Deaf Participant 6 also came to an acceptance of who he is as a deaf person. One factor that helped him accept himself as a deaf person was his acknowledgement that there were other people like him and that it was a norm to use sign language for communication. His father (Parent 6) relayed how his son (Deaf Participant 6) coped and accepted his deafness:

> When he was in school, there were a lot of people like him. Then, he realised that he was not the only one. There was more exposure, like watching the TV news, which had some sign language. And, like now, there is the Internet. So, I think he has already accepted all these things some time back. (Parent 6)

By seeing that he was not the only one who was different from a deaf person, he seemed to accept that this was the way of life for a deaf person. His frustrations with communication and access to information somewhat lessened, and he acknowledged that there were alternative ways to meet these needs without making him feel ‘less’ or ‘different’. There were other deaf people who also used sign language, and hence, being deaf the way he was accepted as the norm for him. Having deaf role models at a young age may decrease the struggle and frustrations of living as a deaf person.

4.4.1.1.7 Appreciation of Both Worlds. As for Deaf Participant 4, she, too, has come to a unique position of accepting herself in both the hearing and deaf community. Being in the hearing community put pressure on her to hear and speak, though she was not totally against it. However, it was tiring for her to consistently experience the stress and pressure of connecting with the hearing world without proper hearing abilities. In both hearing and deaf communities, she has found a way to adapt and appreciate both worlds.

Deaf Participant 4 appreciated the deaf world. The deaf world was an alternative place to escape from such pressure, where she could freely express herself as a deaf person. She connected well with the deaf community, actively served in deaf organisations (e.g., Deaf Sports Association), advocated for deaf concerns through social media, and frequently hung out with deaf friends.

Interestingly, although she went through such traumatic experiences, she still longed and tried to connect to the hearing world, especially her hearing family. She did so through speech, lip reading or writing. She connected well with the hearing people at work. In fact, she taught her colleagues sign language and trained one of them to be good enough to help with some sign language interpreting during work meetings. She used her hearing aids, lip reading skills, speech, and writing with confidence to interact with the hearing world and did not shy away from it.

> Usually, I would write. I will start speaking and then write; after knowing me, I will sign. They will get used to my speaking, and I will seldom write. If they can understand my speaking, it is fine. First, I will start to

> write, then speak because they will already know me and understand. If not, they will always start focusing on other hearing people to interpret for me. I wanted them to get used to my voice. (Deaf Participant 4)

She also appreciated the knowledge the hearing culture could offer her for personal development. She shared:

> When I was in Form 1, I started to regret not continuing my studies in the hearing school. I feel that I have lost. When I returned to the deaf school and mixed up with the deaf, I stopped speaking. I started to lose my speaking skills. I couldn't speak a lot, and I didn't always understand because there was not much practice. I can only understand what my family is saying, but with other people, I don't understand what they are saying. It was right for my teacher to say that I should continue to stay in the hearing school. I wanted to develop in the hearing world. I was patient in mixing with the hearing, and with them, I can develop a sense of connection so that I can improve. When I was with the deaf, the standard was lower, even in reading, and it was difficult for them to advance. So, I slowly had to learn, slow to learn. (Deaf Participant 4).

Connections with family:

> I want to speak to my family because they are hearing. When I moved to Penang during Form 3, I didn't speak much, and I forgot. When I came back for the holidays, my mom spoke to me, and I had no idea what she was saying. And she was trying to communicate with me about how to respond. My mom was, "How can you forget to speak?". Maybe it was because I mixed up more with the deaf that I forgot how to speak. My mom was kind of disappointed. Then I continue to. I forgot a lot. But when I came back here (home) and worked, I started mixing with the hearing staff, and they used the spoken language. With my mom speaking, I picked up again on how to speak.

Deaf Participant 4 appreciated what the hearing community could offer her – connection to family and access to knowledge for self-development and took the initiative to reach out. Through the observation by the researcher, she thoroughly enjoys herself in the deaf community, where she can freely express herself non-verbally with people who understand the challenges of living as a deaf person in this community. She comfortably went in and out of the hearing and deaf communities, according to her access to social and information needs. Although she did not explicitly say which 'identity' she subscribed to more, her love for her family, longing to be connected to the hearing colleagues, and access to information indicated an appreciation of both the hearing and deaf community. This description is similar to the fluid bicultural Deaf identity concept that the researcher referred to (McIlroy & Storbeck, 2011).

4.4.1.2 I'm Normal. Deaf Participants 1, 3, and 5 expressed that being deaf was a normal part of life. Deafness did not hinder them from being themselves and living a normal life like other regular people. They were treated like regular people, and hence, the perceived differences between themselves and hearing people were insignificant. They were aware of their deafness, and it did not leave any impact on emotional distress. Deaf Participant 5 was living with very little social contact with people and just accepted life as it was. The themes that emerged under *deafness as a normal* part of life include *the same as others, establishing a normal life, and accepting life as it is.*

4.5.1.2.1 The Same as Others. Deaf Participant 1 merely said, "I feel (it was) fine". She seemed to be surprised at my question as if there was supposed to be a difference. Her verbal and non-verbal expressions seemed to indicate that she did not think she was any different from her hearing peers. In fact, in the interview, she said, "I was hearing when I went to kindergarten (age 5-6)". She believed that she was ‘hearing’ in kindergarten, while her mother clearly mentioned to the researcher that she was clinically diagnosed as deaf at age two. She believed she was ‘hearing’, but at the same time, further down in the interview, she made a comment that indicated that she might have known that she was different in hearing abilities when she played with her hearing playmates, but it did not bother her.

> There was a lot of playing, and I enjoyed it a lot, mixing it with different friends. We could chit-chat and talk to each other. My friends are hearing, they talk to each other, but I understand because we played together, so that was fine” (Deaf Participant 1)

The environment in their childhood did not present situations that obviously reflected their differences or made them feel isolated. As children, be they hearing or deaf, engaging in play in kindergarten, there was no pressure to perform or to be put in a system to meet certain expectations or achievements. The expectation to be or achieve was not applied to the child at a young age. Hence, the child was not put in a situation where their difference in ability would be shown, nor was there an expectation to perform or behave in certain ways. So, there was no measurement to divide the children according to their abilities (e.g., hearing/ speech). Hence, no distinction was made or imposed on the children in kindergarten.

From the sharing of Deaf Participant 1, the focus of the child in kindergarten was play, and the type of communication, whether it was verbal or non-verbal, did not matter if the message was conveyed. There was no expectation to communicate differently than she did. She was free to be as she was, and hence, her difference in hearing ability was perceived as insignificant and considered ‘different’ from the rest.

An accepting environment does not impose expectations on how one should be, nor does it reveal the negative effects of hearing impairment, nor does it highlight the difference a deaf person may have. Hence, the ‘difference’ between me and them was not distinct. Deaf Participant 1 may not have perceived being any different from her hearing peers as a child; she held on to the same perception when she was older (primary school and up till today). Though she did indicate that she knew she was deaf and different from the regular people, it did not bother her. Her family was very accepting of her as a person. Her mother and sister embraced her, and they had a good relationship and communication. She stated, “I think everyone is the same. There is no difference. I feel it is normal”. She seemed to look at her hearing impairment as just a part of her life experience, but it did not affect the way she viewed herself negatively. She was aware of her hearing impairment, but her deafness did not become her primary identity.

From this case study of Deaf Participant 1, her accepting family members and good relationships with them created a healthy environment for the deaf child to feel belonged. Previous research emphasized the importance for establishing good communication and connection with the deaf child for mental health and development, which Parent 1 had successfully established for her deaf daughter (Deaf Participant 1). The belongingness to her hearing family members, helped her to establish a healthy identity, which was not the Deaf dominant cultural identity.

4.4.1.2.2 Establishing a Normal Life. Like Deaf Participant 1, who regarded her deafness as something normal, so did Deaf Participant 5. He expressed the same sentiments throughout the interview – that having less ability to hear did not affect him as a person. His father (Parent 5) treated him as normally as possible and did not let deafness be a barrier to communication, belongingness, and access to information. So, growing up in such an accepting family helped Deaf Participant 5 live life the same as any other person.

In his words, "It was normal to me". When I investigated further what he meant by 'normal', he just repeated the sign "normal" and looked at me as if saying, "Normal is normal; what is there to explain? He continued to have this perception about himself since childhood and up to his current adult self. This was observed in the interview with his father (Parent 5), where his father described a lot about past experiences bringing up his deaf son. It gave me the impression that Deaf Participant 5 perceived himself to be the same as everyone else. There was nothing special, nothing different about him when compared to others. He was normal, being able to achieve all the typical milestones in life –

he had a good education, was independent, maintained a job, got married, and started a family. Hence, life was normal to him, and his deafness did not get in the way. He chose his friends judiciously. If hanging out with deaf friends would cause trouble, he would stay out of the way. He valued safety over connections with people. So, it seemed that for him, his life was the same as any regular person's; it was “normal”. What differences had he as a deaf person?

To further support this line of thought, when he was asked how he knew he was deaf, he stated, “I didn’t know that I was deaf. It was normal to me” (Deaf Participant 5). He used the word “normal” six times, indicating that life was normal. On a scale of 1 to 10 (1 indicating poor life satisfaction and 5 indicating good life satisfaction), he said, “I think it would be a ten. I’m very satisfied with life. Communication is good.” When the researcher was trying to ask questions regarding the challenges of being a deaf person, he replied “no challenges” twice at different points in the interview. This gave the impression that he was very comfortable and satisfied with himself as a deaf person. He preferred not to mix with the deaf; that was his choice. If he wanted to speak or write or sign for communication, that was his choice, too. And he was not bothered by what other hearing or deaf people thought of him. He basically looked out for his own concerns – his family and career. Friends, whether it was hearing or not, did not matter to him.

The impression the interviewer received from Deaf Participant 5 was that deafness was not an issue in life. He was deaf and could sign well. He decided how he wanted to live his life and achieved everything a regular person would in life. That was a normal life for him. Deaf Participant 5's view of deafness (pathology vs cultural) and deaf community does not seem to fit into any of Glickman's identity theory (Glickman, 1996). Perhaps Deaf Participant 5 has adapted and managed his life so that he did not experience such significant differences that made him establish a certain view on deafness and the deaf community. He was just 'being as he is' – regardless of what views or theories people had towards him. This concept seems to be in line with the current second deaf identity politics that views the diversity of deaf people however they are – "deaf the way I am" (Davis, 2002; Ohna, 2004). More about this concept will be discussed in the summary of this section.

4.4.1.2.3 Accepting life as it is. The last code that made up the subtheme is *deaf as normal* and *accepting life as it is.* The observations and interviews with Deaf Participant 3 and her mother revealed how Deaf Participant 3 perceived her deafness. She accepted life as it was for her. Even though she was isolated for half a decade before she rejoined interactions with other deaf people, she seemed to not express any distinct view about deafness and belonging to the deaf community.

To better understand Deaf Participant 3's life situation, here is her family background: Parent of Deaf Participant 3 was poor, uneducated, and stayed in a small town with limited resources for her deaf child's development. She had no idea what to do when her daughter was diagnosed as hearing impaired. She could not really articulate how she felt about her daughter's deafness. Nonetheless, Deaf Participant 3 was given hearing aids, trained to speak, sent to a deaf school, and learnt sign language.

However, she grew up isolated in the hearing world, where there was a communication breakdown with hearing family members. Her mother struggled to communicate with her. And when she graduated from deaf school, she came home and worked for her parents. There were no deaf friends in close physical proximity. Her deaf ex-classmates were staying far away from her, and she did not own a phone to connect with the deaf community. The hearing community did not interact with her. She stayed and worked at home. She was isolated from both the hearing and deaf world. When asked whom she preferred to socialise with, she responded:

> I like to mix around with the deaf because I can learn, and the teacher teaches us. The teacher uses sign language in class, so with the deaf, I can learn. (Deaf Participant 3)

But that was the time when she was in school. When asked further if she had hearing friends, she said, "none". When asked about current deaf friends, she replied, "There are no deaf people around here. My deaf friends have married and moved far away. We are not in touch". She was isolated from the deaf community, and there was a communication breakdown with the present hearing contacts. She was willing to embrace anyone who was willing to connect to her

– be it hearing or deaf people.

In our initial contact in 2015 with the deaf community in Ipoh (1.5 hours away from her house), she was socially awkward and had strange behaviours. The deaf community found it hard to relate to her. The deaf community started to avoid her because of her weirdness in communication and behaviour. For example, she would fingerspell every sign she used, even though everyone understood her sign. Other deaf members had little patience communicating with her as she fingerspelled every word in the sentence. She would also ask the same questions repeatedly in her attempts to connect. On a separate occasion, she locked herself in the room that she was sharing with three others. She was oblivious that her roommates had the same access to the room. Perhaps, due to her isolation, she forgot how to relate to others, even though she longed to be connected.

Deaf Participant 3 was socially isolated for a minimum of five years. It did not matter which group she belonged to as long as she was accepted and connected. She might not have a reference group (be it a hearing or deaf community) to compare to and, hence, did not consider questions about identity as a deaf person. She was just being herself as she was in her isolated environment and accepted life as it was. According to Glickman's identity theory, which listed out the four progressive stages, the researcher could not accurately place Deaf Participant 3 into any of the four categories. Rather, the identity of

Deaf Participant 3 is likely to be categorised as a ‘culturally marginal identity or culturally captive identity’ in Holcomb’s seven categories of deaf identity (Holcomb, 1997).

4.4.1.3 Observations. Deaf participants neither knew how they turned deaf nor realised that they had hearing issues. They were told they were deaf, but what did it mean to them? They were given facts, but how did they interpret what it meant to have hearing disabilities? It was later when the child grew up and entered society, that the environment revealed the effects of deafness. This, in turn, led the child to interpret and give meaning to their experience as a deaf person. What did it mean to be a deaf person in the community that they live in? Although deaf participants did not explicitly say what it meant to be deaf, they expressed the different challenges being in the hearing and deaf community. These experiences reflected who they were and where they felt they belonged, which revealed their unique identity as a deaf person in their world.

The three deaf participants (Deaf Participants 1, 5 and 6) expressed neutral experiences in the hearing world. ‘Neutral experience’ is described as no significant traumatic incidents that have caused some negative reaction against the hearing world. These three participants were from parents who viewed their deaf child as unique in his/her own way and accepted the child as they are. Parents viewed them as normal while their deafness was only being different from others, not a disability that needed to be fixed.

They were not forced or pressured to behave or communicate like a regular hearing person. All three of them did not go through surgery to attempt to restore or increase hearing abilities. Either the child's hearing loss was not severe enough for the surgery (Deaf Participant 5), or parents could not afford it (Parent 1), or there was concern about the new advancements in restoring hearing (Parent 6). Parents provided hearing aids and speech therapy for the child. The deaf children were later sent to study at the deaf school, from primary to polytechnic college. Deaf Participants 1, 5 and 6 were not forced into the hearing community's expectations and were given the freedom to develop and be themselves. Parents put much effort into making their deaf children feel accepted and that they belong in the hearing family. Parent 6 stated:

> As parents, just provide for him. Send him to school. Nothing special or different that we went through. Initially, we pity them, and to me, we just treat him as normal; communication with him is normal, but we must understand that he is a bit different in the sense that they lack one sense. In the other sense, they are better. Different character. (Parent 6)

Although Parent 5 did not explicitly say how he tried to make his son feel he belonged, this was shown in his actions. He always took the son out wherever he went, planned exposure trips, and was there for him. Parent 1 was always with her daughter, sharing in conversations, taking her along for trips and activities, bringing her into her mother's social circles, and even allowing her daughter to chat with her hearing friends. There were close bonds between hearing father and deaf son (Parent and Deaf Participant 5), hearing mother and deaf daughter (Parent and Deaf Participant 1).

Hence, there was an acceptance of the hearing community by the deaf participants, and they embraced their experience with the hearing community as it was. There was no strong pressure to perform and no reason to want to escape from the place they were accepted and felt they belonged to their hearing family, which was the hearing world that they knew.

The bond between hearing mother and deaf daughter was very close (Parent and Deaf Participant 1). Even though Deaf Participant 1 did not say directly how she felt she belonged, the research saw her interactions with her hearing mother and sister. There was playful teasing with the sister and carefree conversations with the mother. Certainly, there was a strong sense of connection and belonging with the family. No wonder Deaf Participant 1 said, “I like mixing with hearing people”.

Deaf Participant 5 was a man of few words (signs). However, he explicitly stated that he felt belonged to his hearing family. And during the interview, he came with his father. The way they relate to each other shows a very close bond between father and son.

Deaf Participant 6 was always included in every family outing and activity. His father described how his son expressed his fear and frustration of certain situations to the father. This seemed to show how comfortable the son was in expressing his vulnerable feelings in the family without being judged. It showed a sense of assurance and security being in the family.

All three deaf participants were also exposed to the deaf world and were able to connect well with other deaf people. Deaf people were their preferred community because they enjoyed connecting and being deaf people chatting (Deaf Participant 1); it was normal to them (Deaf Participant 5), and for the ease of communication (Deaf Participant 6).

It seems that it was not important for them to make a strong distinction between self and others in terms of their deafness, as they did not make a very strong claim on choosing one group that they exclusively felt belonged to. Deaf Participants 1 and 6 expressed an uncertainty of which group they felt they belonged to. In fact, they seemed to be torn between the benefits of being in both worlds.

> I mix more with the hearing people. Cause the hearing people can teach me. And I can teach them SL. I am curious when I see deaf people sign. But I feel more comfortable with the hearing. But yes, I like both. I don't know which to choose. I think both are fine. Both are okay. I am fine with both. I don't have a preference. I prefer being with the deaf. It's better. But if you have hearing, join us, they are really good at explaining to us. But it is easier when you look at the sign. So, let's say the hearing is good at signing; then it would be good that they mix with us. (Deaf Participant 1)

> I prefer to be with the deaf. But with the hearing, meaning that you can

> have a lot of friends. But the deaf... I mean, the hearing and the deaf are quite segregated. Because they can always hear, they always speak Chinese; they don't use English very much. So, I feel that it is better to be with the deaf. Because… it is quiet and peaceful and there are no problems. But the deaf has a lot of problems. Because there is peace, and if there is any problem, it is their problem. Deaf do have their problems. (Deaf Participant 6)

Deaf Participant 5, on the other hand, was not bothered about which group he belonged to.

> I prefer to be with deaf friends. But because of the arguments and conflicts, I prefer to have nothing to do with them and mind my own business. So, I don't really meet them. Even if they come to me, I'll go my own way. If you call me late at night for a chat session, sorry, I won't do that. Because I can't hear, I prefer not to go out so late at night. I would also rather save some money as it is expensive to go out to eat all the time. I prefer to go out with my family to go shopping or sightseeing. But if friends call me out at 11 pm, sorry, I won't join them; it is too far away. I would rather rest at home. (Deaf Participant 5)

The deaf participants seemed to embrace their deafness as being different and unique without needing to be defined by the expectations and treatment of society. They experienced the deaf world, used sign language did not have a strong reaction against the hearing world, and yet also enjoyed the hearing world.

Among the four proposed identities of Glickman, this seems to fit closest into the description of "marginal culturally" deaf identity, whereby a person is not sure about their feeling about their deafness (Bat-Chava, 2000). However, these participants seemed not to be bothered by how they felt about their deafness. They have come to an acceptance of their unique situation and their own way of life, having their own definition of what it means to be deaf. Although it seems to fall under the marginal cultural deaf identity where they are uncertain about their feelings about their deafness, this too does not seem to fit into their description of their experiences as a deaf person. They were happy with their unique experience of life as a deaf person.

While interviewing the deaf participants, they all seemed to be happy where they were as deaf people. Deaf Participants 2, 4, and 6 seemed to have some earlier struggles and frustrations with the hearing community but have accepted and adapted to their current unique situations. Deafness was “accepted”, and they have “adapted”. Other Deaf Participants – 1, 3, and 5, did not project an identity crisis and seemed to be contented with who they were as deaf people. Deafness was “normal” to them and part of life. They perceived themselves as not being very different from other hearing people.

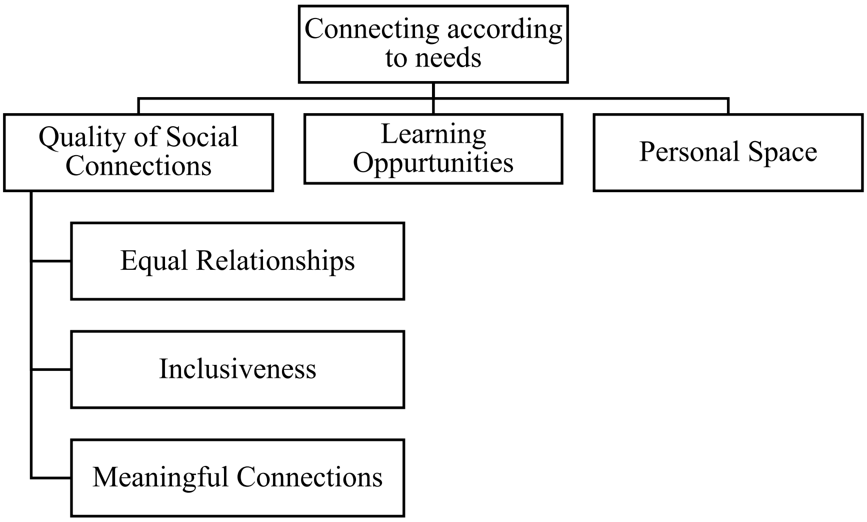
Deaf participants in these two groups - “struggling to fit in” and “normal part of life”, expressed in the interviews that they were “being as I am”. When asked about their experience being deaf or how they felt when with others (deaf and hearing communities), they all seemed to have already come to a place of contentment with who they were and what life was like for them. They were treated well by family, colleagues, and people around them and have learnt how to adapt to life in their surroundings. So, when the interviewer asked them questions about what it was like to be deaf, they were a bit perplexed, with facial expressions that seemed to say in Malaysian slang: “How is it like to be deaf? Like this loh. What is there to ask?”.

4.4.2 Connecting According to Needs

When comparing the experience of deaf participants in both the hearing and the deaf world, it was interesting to note that each deaf participant had their own preference on which community they preferred to connect to. The researcher thought that deaf people would automatically be inclined to want to be with the deaf community because of the use of sign language that provides an immediate connection for socialising and learning. However, the deaf participants seemed to indicate a changing preference of which community to connect to according to their needs. The deaf participants expressed their connecting preferences according to the *quality of social connections, learning opportunities* and *personal space.* Figure 4.7 below shows the subtheme of connecting according to needs.

Figure 4.7

Subthemes of Connecting according to needs



4.4.2.1 Quality of Social Connections. It was interesting to note the deaf participants' connecting preferences. Deaf Participants 1, 2 and 4 expressed feeling stressed being in the hearing community and inclined towards connecting to the deaf community because of the ease of using sign language for communication and learning. However, she switched preferences when the hearing community members considered and catered to her needs as a deaf person. The deaf participants expressed valuing social connections that are equal and inclusive and connections that are meaningful.

4.4.2.1.1 Equal Relationships. Deaf Participant 2 was happy when she shared about her experience studying with hearing classmates. This was especially true when there was a perceived equal relationship between the two persons. An equal relationship refers to having a mutual exchange of help. It is about equal power to contribute and not always having one dependent on the other. Both Deaf Participants 1 and 2 shared an experience to illustrate this point:

> I have a close friend in class. She would always help me. If there was any miscommunication, she would write it down so that I get the right and clear communication. She helps me, and I help her. I taught her how to sign and fingerspell. She learns well. (Deaf participant 2)

> I mix more with hearing people. This is because the hearing people can teach me, and I can teach them Sign language (Deaf Participant 1).

Deaf Participant 2 did the same thing when she started work. She happily taught her hearing colleagues sign language and was glad to contribute in that way. She seemed to be pleased with the "learning together" approach.

> When I first entered the workforce, I looked for a hearing person, and she became my friend, and we worked together. She wanted to learn sign language, so I taught her the alphabet. She continued to learn, and I taught her at work. She enjoyed it, like it. So, working was good. There was an exchange of information and learning together for proper communication. (Deaf Participant 2)

Deaf Participant 2 appreciated the mutual exchange of help and learning together. Perhaps this kind of mutual exchange of contribution gave her a sense of equality in the relationship. There was something that she could contribute and offer to the hearing world and not have to always be on the receiving end. Being Deaf may require special assistance in communication when present in hearing communities, which sometimes may make the deaf person feel dependent. So, when there was a mutual exchange, there was a give-and-take, which made the relationship more equal and made her feel useful. Hearing people who were willing to learn sign language removed one of the communication barriers. This creates a deaf-communication-friendly environment in which the deaf person may choose to connect. However, if there was a communication barrier, it is likely that the deaf person would prefer to stay in the deaf community.

This is also supported by the participatory observation analysis whereby Deaf Participants 1 and 2 were happy to communicate with both deaf and hearing friends in Malaysian sign language. Pidgin sign language and writing were used with hearing people relatively new to the group by Deaf Participants 1 and 3. Deaf Participant 4 preferred to spend her time interacting with deaf friends in Malaysian sign language. Deaf meetings were the time they communicated without concerns about the language barrier as the deaf people were the majority, and the usage of sign language was dominant in the meeting.

4.4.2.1.2 Inclusiveness. Whether it was the deaf community or the hearing community, the deaf participants seemed to choose their preference to connect depending on how included they were. Deaf Participant 2, who prefers to be with the deaf community, made mention of "feeling belonged" to the hearing but only in certain incidents. In the earlier conversation, she was "complaining" about how stressful she felt being with the hearing and preferred to hang out with the deaf. Yet, in this incident, she indicated an appreciation and feeling of belongingness when her hearing colleagues included her in lunch outings and considered her needs. She shared her experience:

> I feel I belong to the hearing because we go out for lunch together… The hearing people are concerned about me. They would ask me out for a meal, and sometimes, they would help me order food. We sit down together for a meal. When I need help to speak, they help me. (Deaf Participant 2)

She was included and her needs considered, and this made her feel she belonged to this hearing group. If the hearing community did not include the deaf person in their conversations and presence, the deaf person would not be able to connect and, hence, prefer to connect with other groups (e.g., the Deaf community) that would include them. Deaf Participant 6 expressed this idea of inclusiveness and how it affected his preference for connection. He states:

> I prefer to be with the deaf. But with the help of the hearing, you can have a lot of friends. The hearing and the deaf are quite segregated because they (hearing people) can always hear. They (hearing people) always speak Chinese; they don't use English very much. So, I feel that it is better to be with the deaf. (Deaf Participant 6)

Deaf Participant 6 was a bit torn between choosing deaf or hearing friends. There was an impression that he wanted to connect with more hearing friends, but because he was not able to join conversations with hearing people, he chose to be with the deaf. There were obvious communication barriers. First, it was about not being able to hear the conversation; therefore, not being able to join in. Second, it was also about the type of language used. Deaf Participant 6 was more familiar with Malay and English in writing and perhaps able to lip-read some spoken words. However, the main language used for communication was Chinese, and Deaf Participant 6 was totally left out and not included in this hearing group. Hence, there was a preference to be with the deaf community, with whom he shared a common language for communication. All in all, this seems to indicate that when deaf persons are included, and communication needs are catered for, they would like to be connected to that group.

4.4.2.1.3 Meaningful Connections. Some deaf participants indicated in their interviews that they enjoy making connections with others and establishing friendships. It did not matter whether they were from the hearing or the deaf community. However, it depended on how connected they felt. Deaf Participant 1 was undecided about which group she preferred to connect to because she enjoyed being with both hearing and deaf people for different reasons. She stated:

> I am curious when I see deaf people sign, but I feel more belonging with the hearing because I enjoy being with them…; it is better to be with all the deaf; it's just different… I like both (hearing and deaf friends). I don't know which to choose. I think both are okay. I don't have a preference. (Deaf Participant 1)

In earlier parts of the conversation, she said she enjoyed being with the hearing because she could listen to different stories and learn from their experiences. She also enjoyed being with the deaf because communication was so free and easy to express and understand. According to the participatory observations, she mingled with both hearing and deaf and had conversations about various topics such as family, friends, current happenings, deaf-related activities, and food. She had conversations on at least three different topics in each observed meeting. She seems to enjoy learning about different things from the conversations. Hence, it is not surprising that she would be torn between both worlds, so she embraced both communities, as each community gave her different experiences. Despite everything, she felt connected to the people in both communities. She enjoyed the presence of friends, regardless of hearing status.

Deaf Participant 4 also enjoyed connections with people, but she preferred the deaf community over the hearing community. Her reason for a preference for the deaf community was not only because of better communication but also because the deaf community was smaller and a close-knit community. It was unlike the big casual hearing community. She shared:

> I felt that I liked being with the deaf, as it was easy to connect and sign. It was difficult to be with the hearing because not all of them knew how to sign. Not everyone is my friend. For example, you may have 60 students in a class, but I don’t feel I belong to everyone. For the deaf, I feel I belong; the class is smaller, and I feel closer. I like to be with the deaf. (Deaf Participant 4)

From these statements, despite the different preferences, the deaf participants appreciated a connection with people with whom they could be close and with whom communication was not a barrier. They felt meaningfully connected.

By trying to understand what connections were considered meaningful, the researcher observed how Deaf Participant 2 related to both hearing and deaf persons. This is one incident that was observed by the researcher: In the presence of hearing people, Deaf Participant 2 kept quiet and was not her usual bubbly self as she usually was in the deaf community. She pulled back and disengaged herself from interacting with the hearing people around her.

One hearing person came up to Deaf Participant 2 and the researcher, wanting to communicate and show concern to Deaf Participant 2. However, instead of directly approaching Deaf Participant 2, the hearing person turned to the researcher while pointing to the deaf participant who was standing in front of him and asked, “What is she doing now? Working? Studying?”. Both the hearing person and Deaf Participant 2 looked to the researcher, waiting for an interpretation of their conversation. The researcher interpreted the message into sign language for the deaf person. She responded in sign language with simple and short answers. The hearing person continued to look at the researcher for the response of Deaf Participant 2 before proceeding with the next question. There were about four more questions and responses before the conversation came to an end.

There was no direct eye-contact between the hearing person and the deaf participant throughout the conversation. Questions and answers were kept short by the deaf person. The hearing person asked the interpreter about the deaf person and seem to merely want information from the deaf person. The deaf participant offered minimal information and showed less interest to continue the conversation. She did not reject being questioned but answered snappily, showing less interest when there was no connection through eye contact.

The researcher wondered why Deaf Participant 2's response to this hearing person was different than her response to the researcher as a hearing person. In the participatory observations, Deaf Participant 2 had interactions with friends and strangers who were either hearing or deaf. She used Malaysian sign language, pidgin sign language, and writing (when needed) to communicate in the deaf meetings. This showed that she did not have a problem communicating with hearing people, be it a friend or stranger.

The researcher later came to know through a key actor in the deaf community that deaf people are used to this type of one-sided conversation – where there is no direct communication; thus, they could not make meaningful connections. They felt it was pointless to carry on the conversation. While people showed interest and concern on the surface, they were not truly interested or concerned. If they were, they would at least look at them in the eye and try to communicate directly with them, even if they had no sign language. So, usually, they would show respect to the other person by answering their questions and keeping it short so as not to burden or trouble the interpreter. They prefer to have meaningful connections with people who want to have a genuine two-way conversation with them.

4.4.2.2 Learning Opportunities. The deaf participants had a preference for when to connect and to which community, according to their personal needs. One deciding factor in connecting to a certain community is the learning opportunities provided by the community. Different deaf participants showed a preference to connect to the deaf or hearing community based on what they could learn from that community.

Deaf Participants 1 and 3 preferred to connect to the deaf community because they could learn easily with good communication through sign language. The deaf participants enjoyed learning about things in a communication mode that they were able to comprehend. They could learn a variety of topics through teachers and friends without a hindrance in communication. They shared:

> I like being with the deaf because you can chat about different stuff. (Deaf Participant 1)
>
> My teacher uses sign language in class. So, I learned with other deaf people. (Deaf Participant 3)

Nonetheless, they also noted the limitations of learning from the deaf community and the benefits of learning from the hearing community. Deaf Participant 1 stated further:

> I mix more with hearing people. Cause the hearing people can teach me, and I can teach them Sign language. I also like to mix with hearing people because I want to learn from their stories. So, if I could join them, I could learn. If they join us, they are really good at explaining (things) to us. (Deaf participant 1)

She appreciated the learning opportunities that the hearing community could offer her, especially if language was not an issue. For learning opportunities, she would like to connect with the hearing community. As for Deaf Participant 3, in the participatory observations, she spent more time interacting with hearing people as she sometimes struggled to fit in with the deaf community because she uses more writing, pidgin sign language, and exact Malay or English to communicate. As the majority of the deaf people rather use Malaysian sign language, she is often left with the hearing people, and she takes the opportunity to learn about the current happenings of the week.

Overall, it seemed that learning opportunities is a pulling factor for a deaf person to connect to a certain community. It is plausible that once there is no communication barrier, it does not matter which community the deaf person learns from. It still reverts to the need for proper effective communication for the deaf to learn.

4.4.2.3 Personal Space. Although the deaf participants preferred the deaf community probably because of the visual communication mode, Deaf Participants 5 and 6 acknowledged the problems within the deaf community and opted not to be deeply involved in any communities that were seen to be more trouble than it was worth. Personal space was important to them, and they avoided complications and drew their own boundaries to protect their personal space. Deaf Participant 5 shared:

> I prefer to be with deaf friends. I don't have hearing friends… I don't mix with deaf friends. I keep to myself. Because of the arguments and conflicts among the deaf, I prefer to have nothing to do with it and mind my own business. So, I don't really meet them (deaf people) … I'm on my own (Deaf Participant 5)

Deaf Participant 5 preferred to avoid both communities so as not to get entangled in the problems and complications of either community. He mentioned four times in the interview that he would rather keep to himself, whether it was going out with friends, avoiding conflict, handling his own issues, or just living his own life. Personal space seemed to be important to him, and he decided who and which community to be allowed into his life. Interestingly, Deaf Participant 6 shared a similar opinion. He, too, did not want the complications of being in the deaf and hearing world and cut himself out from both communities. He stated:

It is quiet and peaceful to be with the deaf. But, if they have a problem,

> it is their problem. Not mine. (Deaf Participant 6)

He preferred to stay out of potential problems and any unnecessary additional stress. Both Deaf Participants 5 and 6, who were males, preferred to be on their own. They chose who and which community to be part of their world. This is how they guard their personal space. Although they did not explicitly mention what problems they saw in the deaf and hearing communities, from the researcher's observation and experience in the deaf community, one common issue was miscommunication, which could lead to uncontrolled and unfixable gossip.

4.4.3 Observations on Deaf Identities

In the literature of deaf studies, much focus has been given to the identity of deaf people from the perspective of social and cultural models. In the social and cultural model, deafness was seen as a linguistic and cultural difference, not a pathological condition that needs rehabilitation. There was an emphasis on experiences, Deaf identity, Deaf culture, Deafhood, and sign language (Bedoin, 2019; Johnson et al., 1994; Ladd, 2005a, 2005b; Monaghan, 2003; Reagan, 1995). The cultural model emphasises the experiences of Deafhood - stressing possibilities rather than focusing on the deficits (Ladd, 2005a). The researcher also learnt about Deaf culture through her sign language interpreter's course and Deaf friends in Kuala Lumpur, the capital city of Malaysia. There was a strong emphasis that deaf people in Malaysia have a Deaf culture because of their experience being deaf. Hence, the researcher brought in certain assumptions about deaf people when she interviewed her six deaf participants in Ipoh, Malaysia.

The two main assumptions that the researcher brought into her study were that (1) the deaf participants had an awareness of their Deafhood and (2) the deaf participants identified as Deaf – a cultural identity. The researcher expected deaf participants to confirm the narratives in the literature review about their culturally Deaf identity. The researcher also expected the deaf participants to present a clear narrative of when and how they felt about their deafness and their belonging to the Deaf community. However, observations and results from this study revealed otherwise.

The deaf participants did not have a cultural Deaf identity as defined by the American and European Deaf studies. Although they were from Deaf schools, had sign language skills, and had accepted their deafness as part of their lives without shame, they did not hold strongly to any particular social rules of the American Deaf culture, nor did they show great concern about Deaf education. They seemed to function from the social welfare model of disability rather than the cultural-linguistic model.

To illustrate the researcher's point that the deaf participants did not seem to know or subscribe to the American Deaf culture and identity (as defined by Glickman, 1996; Ladd, 2005a), the researcher's observations and field notes are shared here. Assuming that deaf participants were culturally Deaf, they would have an understanding of the crucial Deaf issues that gave them the Deaf cultured identity (e.g., the social-cultural understanding of deafness, “healthy paranoia” towards hearing people, the importance of advocating for sign language, devaluing of speech and use of hearing aid, the ability of Deaf people to control own lives) (Ladd, 2005). However, when the researcher asked for their story of what life was like growing up as a deaf person, only Deaf Participant 4 responded with her stories that indicate a ‘Deaf culture’ as described by Ladd (2005). Other deaf participants could not answer and gave very brief answers like “okay”, which was irrelevant to the question. Hence, the interviewer asked more specific, short, close-ended questions to draw out information, hoping that the participants would eventually share significant stories of their lives as deaf people.

One interesting observation in the analysis of the deaf identity of participants is that their positive or negative experiences in the hearing or deaf community had an influence on their deaf cultural identity (as defined by Ladd, 2005). It seems that the more negative the experience was with the hearing community, the more themes of concern about the deaf culture emerged in the narration of the deaf participants. This discussion will review each of the deaf participants’ experience and possible D/deaf identity.

When the researcher asked for their story how life was like growing up as a deaf person, only Deaf Participant 4 conveyed many painful stories of feeling excluded in the hearing world while being drawn and feeling a sense of belonging to the community of deaf people and then embraced both hearing and deaf communities. She seemed to have experienced the four stages of deaf identity development with a wealth of emotions (e.g., despair, confusion, anger, "in love with Deafness," and self-acceptance and group pride) according to Glickman (1996) and is currently in the last stage of bicultural identity. She also showed strong alliances with the community of deaf people, which she would also be identified as Holcomb's (1997) Deaf-dominant bicultural identity.

Deaf Participant 2 was not able to provide a clear narration of her experience of being deaf. However, by asking different questions, the researcher managed to extract her life stories. She had a fair share of pressure and negative experiences in the hearing culture. She was rehabilitated to function like a regular hearing person - had a hearing cochlear, underwent speech therapy, etc., but failed to fit in the hearing culture. In her narrative and her mother's stories, she did struggle with the hearing culture and rebelled against it (e.g., not wanting to speak, only resorting to signing, not willing to mix with hearing people, and only interacting with deaf people). Her mother wanted to provide the best opportunity for her to develop herself to the best of her potential. When she had done all that she could, and there was no more improvement in the child's development, she eventually let go and accepted her deaf daughter as she was. Deaf Participant 2 embraced both hearing and deaf culture, though she had a stronger preference for being with deaf people. According to Glickman's (1996) theory, she too seemed to have experienced the four stages of identity development and is currently at the bicultural identity.

As for Deaf Participant 1, the interviewer had to use many specific short, closed-ended questions to draw out her experiences as she responded with a simple “okay” to open-ended questions. She did not have a clear “Deaf narration” as the researcher expected. Nonetheless, she related more positive experiences with the hearing culture (e.g., family) and very few negative ones. As both the hearing and deaf community had positive experiences, Deaf Participant 1 mingled well in both cultures, choosing the community she would like to participate in to meet her social or learning needs. She seems to fit into the bicultural identity (Glickman, 1996). However, she did not seem to experience the first three stages, which are hearing, marginal and immersion identity.

The other three participants (Deaf Participants 3, 5, and 6) did not have any opinions or stories to share about their experiences as a deaf person. Deaf Participant 5 and 6 regarded their lives as normal as everyone else and had nothing to say about how different it was being deaf. Both male Deaf Participants 5 and 6 chose not to mingle with the deaf community, though they were comfortable interacting with them, and both went to deaf schools. They also were not keen to socialise with hearing people unless they were family members or colleagues. They chose to isolate themselves to have their own personal space in life. Their view on deafness and the deaf community was rather neutral. They do not seem to fit into the stages that Glickman (1996) proposed accurately. They do not have a particular view of deafness as pathological or cultural, nor do they think much about the Deaf community. Deaf Participants 5 and 6 are likely bicultural as they indicated being comfortable in both cultures. However, they were not bothered about socialising, separating themselves from both communities and keeping interactions to a minimum. Hence, this Deaf cultural identity model does not seem to make sense to them. Their perceived identity is out of this cultural model.

Lastly, Deaf Participant 3 was exposed to deaf people in schools, then isolated from both hearing and deaf communities for five years before she was reconnected to the deaf community. She did not highlight any specific negative experience with the deaf or hearing world but rather looked forward to any kind of social interaction. She did not seem to develop a Deaf cultural identity, according to Glickman (1996). Like Deaf Participants 5 and 6, she did not have a cultural or pathological view of deafness and a neutral opinion about the Deaf community. She did not seem to make a distinction between deaf and hearing people. She responded mostly based on her needs. She felt comfortable in both cultures. However, both the hearing and deaf community did not feel comfortable with her, and hence the limited social interactions. Hence, she does not seem to fit into this model.

Table 4.3

Summary of the Experiences, Cultural Preferences, and Possible Deaf Identity of Deaf Participants

Deaf Participant	Dominant experience		Culture preference			Deaf identity
	Hearing	Deaf	Hearing	Deaf	Neither	Glickman (1996)
1	Good	Good	√	√		Bicultural
2	Bad	Good		√		Bicultural
3	Neutral	Neutral	√	√		Bicultural
4	Bad	Good		√		Bicultural
5	Neutral	Neutral			√	Bicultural
6	Neutral	Neutral			√	Bicultural

Table 4.3 above is the summary of the deaf participants' experiences, cultural preferences, and possible deaf identities as perceived by the researcher. The six deaf participants did not explicitly tell the researcher what their identity was, as they did not know much about the different identities. The identities are given by the researcher according to what the researcher perceived through the expressed opinion, behaviour, and emotions of the deaf participants towards deafness and the Deaf community. Outsiders may give deaf people an identity based on theories for the purpose of understanding and meeting their needs better. However, participants of this study either did not have a strong sense of deaf cultural identity or were ignorant about it. This result is similar to Chong and Hussain's (2022) recent study on the deaf leader in Malaysia. They, too, reported that deaf people generally were not entirely confident that they belonged to a linguistic minority and had a culturally Deaf identity.

An important question to ask is: Is establishing a cultural Deaf identity necessary for healthy well-being among deaf people in Malaysia? What is the Malaysian Deaf culture, and how would it differ from the Western model of Deaf culture? According to Turner in Ladd (2005a), there is an assumption in analysing the Deaf culture; the Deaf culture is a universal concept, whereas the idea of a national Deaf culture does not exist to most writers. Hence, the Deaf culture in Malaysia should be explored in depth, rather than assumed that the Ipoh or Malaysian Deaf subscribes to the same values and cultures as the Western Deaf culture, and then clearly define what and which "cultural identity" it refers to.

4.4.4 Discussion

One important point to note in this study's results is that the categorisation of the two groups (Deaf and hearing community) by the participants was different compared to Glickman's deaf identity (1996). Glickman categorised the two groups into the hearing community and the Deaf community, which is divided according to the hearing or Deaf cultural values of the group (e.g., advocating the importance of sign language and deaf education, devaluing of speech and use of hearing aids). However, the participants of this study seem to identify with groups, not according to the categorisation of Deaf or hearing cultural/community values but according to the inclusivity (acceptance and accommodation) of the group. This difference in group categorisation explains why participants' deaf identity was difficult to define clearly, according to Glickman’s deaf identity categorisation (1996). The unclear group categorisation led to unclear social identification and less social comparison.

Tajfel’s social identity theory (1978) provides a framework to explain the identity development process of participants in order to understand how a participant's deaf identity has been developed further. From the results, participants generally expressed the *inability to keep up* and *feeling excluded* when they were in the hearing world that operates through sound and speech. When they were in the Deaf world where sign language was used, they were able to *communicate without barriers* and had *the ease of learning*. The nature and characteristics of both communities set the challenges that the deaf participants will face when they are in that community. However, the expressed identity or group membership by the deaf participants, such as being as I am and connecting according to needs, revealed that their sense of belonging depended on factors other than the two categorisations of the Deaf or hearing community. It depended on what each group could offer them to accommodate their needs – *quality of social connections, learning opportunities, personal space* and an acceptance of who they are – *different* or *normal.*

Hence, according to Tafel’s social identity theory, the social categorisation for this group of participants was not the category of Deaf or hearing culture but according to the group’s characteristic of being accepting and accommodating to their needs. Using this new social categorisation (acceptance vs non-acceptance), participants then identify with the group’s values and may make comparisons with the group they feel belonged to (ingroup, being included) and the other less accepting group (outgroup, being excluded). This forms their social identity.

However, because the nature of this categorisation is based on the acceptance and accommodation of the group, this social identity can be very fluid depending on the inclusive nature (not interests, similarities, values, or achievements) of the group they join. Hence, participants may choose to go in and out of the group and not have a very strong social identity or group membership with a specific group. The group membership is based on the inclusivity nature of the group.

The findings of this study relating to the identity of the deaf are different from those of the deaf respondents in Chong and Hussain's Malaysian study, where identity was categorised into two groups – PWD or linguistic minority/culturally Deaf (Chong & Hussain, 2022). It was important to distinguish the identities as the Intersectionality Model supports the idea that a person's identity consists of more than just one aspect (e.g., gender, age, sexual identity, etc.). The Intersectionality model was employed to clarify identity based on categorised groups. However, the deaf participants from Ipoh in this study perceived their identity in terms of specific characteristics rather than predefined categories.

4.4.5 Conclusion

In conclusion, research question 1 explored the experience and identity of deaf participants. Contrary to what the researcher expected, deaf identity to be similarly defined and expressed as in the Western concept, results revealed that deaf participants felt that they belonged to groups that would be inclusive – accepting them of who they are and accommodating their needs. A social identity that is based on the status and experience of being deaf or based on the values of a cultural-linguistic minority was not expressed as of utmost importance or priority among the participants of this Malaysian study. Their identity as deaf persons, or their sense of belonging, was based on the groups that were inclusive and accepting. The results of this study affirm the government's direction of moving towards inclusiveness as in the United Nation's SDG 4 (ensuring inclusive and equitable quality education) and SDG 8 (inclusive employment) (United Nations Department of Economic and Social Affairs, 2023).

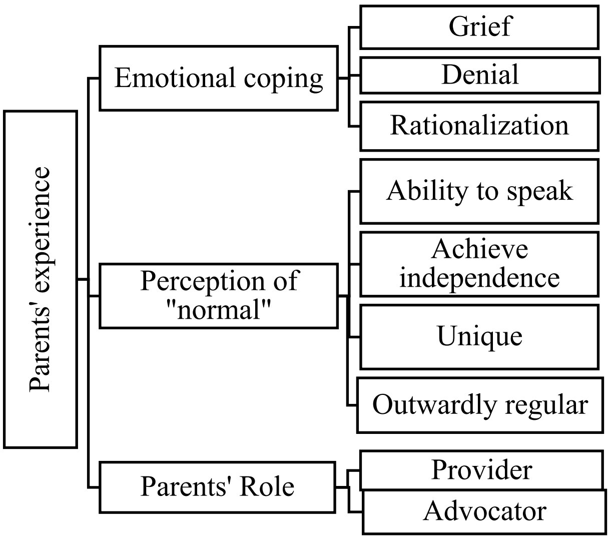
4.5 Research Question 2: Experience of Hearing Parents

"How did you find out about your child's hearing loss? What was it like to bring up a deaf child? Can you share with me what happened?" the researcher asked each parent participant. "It was such a long time ago", Parent 5, a father responded. There was a moment of silence, and then he smiled and shared the joy of the birth of this long-awaited child after eight years of marriage. Mothers (Parents 1 and 2) and fathers (Parent 6) shared the same sentiments – a look of reminiscing the past, a smile of thankfulness, a quiet laugh to themselves. What a pleasant and heart-warming sight to behold. They have journeyed thus far, and now, their deaf child is all grown up. This moment gave the researcher a sense that she was about to hear of a special journey parenting a deaf child. Stories of the grief and hope, the challenges and kindness of others, came pouring out one by one. Themes such as parents' emotional coping, perception of normal, and parent's role emerged from the narratives through the interviews.

Figure 4.8 is a summary of the themes and subthemes that emerged from parents' narratives. The subsequent sections below describe the formation of each subtheme.

Figure 4.8

Themes of Parents' Experiences

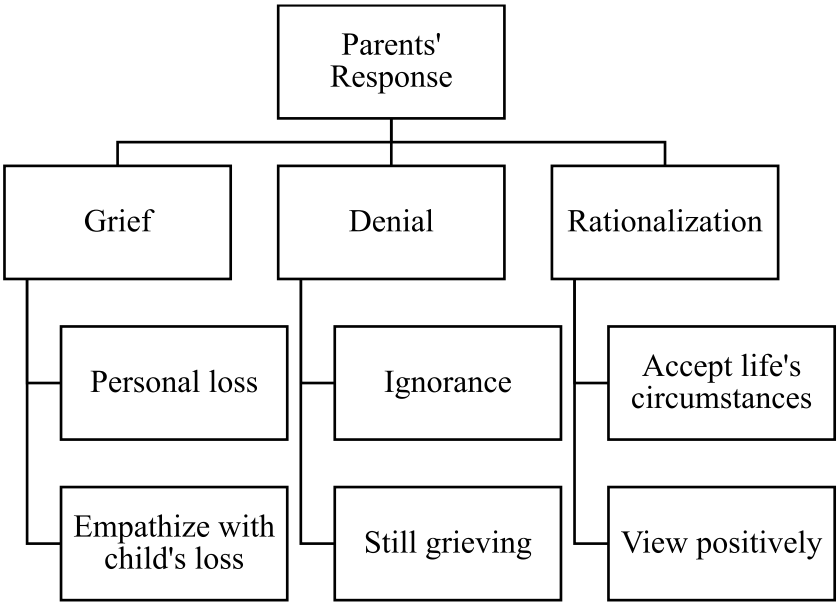


4.5.1 Emotional Coping

Parents were asked in the interview about their thoughts and feelings when they received the diagnosis of their child's hearing loss. Parents recollected their experience and conveyed it to the researcher. All parents seem to display some feelings of sadness and a sense of loss, though their expressions and coping strategies vary from each other. Each parent expressed and coped with their loss differently. They grieved for different reasons, too. The themes that emerged in parent's narratives of coping include grief, denial, and rationalisation. Figure 4.9 displays the codes and subthemes of the parents' coping strategies for receiving the child's hearing loss diagnosis.

Figure 4.9

Subthemes of Parents' Emotional Coping



4.5.1.1. Grief.

The six parents expressed some form of grief for the loss of their child's hearing. Four out of six parents shed tears during the interview as they recalled the moment the diagnosis of their child's hearing loss was received. They grieved for their personal loss and empathised with the child's loss.

4.5.1.1.1. Personal loss.

Two mothers (Parent 1 and Parent 2) openly shared their emotional devastation upon receiving the doctor's confirmation of their child's hearing loss. There was a sense of personal loss to think that their deaf child would not be able to call them "mommy". Parent 1 shared her experience:

> When she was diagnosed, the doctor said that it was 130 dB of hearing loss. At that time, I was crying very badly（哭到要死）. After the wax removal, it was 80-90dB hearing loss, which was much better. If not, can you imagine that your own daughter would not be able to call you 'mama'? That feeling would be terrible. It would be so hard to take. (Parent 1)

The Chinese term that Parent 1 used to express how she felt in Mandarin was "哭到要死". In transliteration, it meant she "cried till she could have died". This expression revealed how devastated she was and how much she had cried upon hearing her daughter was profoundly deaf. However, when the second diagnosis revealed better hearing results, it provided her with some relief. However, in the initial state, when she thought her daughter had lost all sense of hearing, she was devasted thinking that she would never hear her daughter call her "mama". It meant a lot to Parent 1 to be verbally called "mommy".

Interestingly, Parent 2 also shared a similar concern of being called "mommy". Parent 2 did not cry over the possibility of never hearing her child's voice calling her "mommy". However, she demonstrated a lot of effort to make sure her daughter could call her "mommy". It was to the extent that she accepted the calling of "mommy" in the Malay language "ibu". It was not her mother tongue, but "ibu" was easier for her daughter to pronounce. This is what she said:

> I taught her to say "mummy" so many times. But she couldn't pronounce "m" clearly. So, I said: Never mind, you can say "ibu". Even (for her) to learn to say the word "ibu", I had to make her repeat one thousand times - ibu ibu ibu ibu… And I had to teach her syllable by syllable - "I" (that sounds "ee"). It's not so easy to teach her. For just a simple word, you had to teach it so many times. But we continued to do so until she could call me "ibu". (Parent 2)

It meant a lot to Parent 1 and Parent 2 to hear their child call them "mother" – 妈妈 ("mama" in Chinese) or "ibu" in Malay. Perhaps being called "mother" was a typical expectation when one enters motherhood. Hence, when a child could not call "mommy", it was viewed as a sense of personal loss of an idea of what was expected in motherhood. The mothers had to accept a new reality of their motherhood – being a mother to a special needs child. Hence, the reaction of Parents 1 and 2 towards their deaf child not being able to verbalise "mommy" was a way for parents to process, acknowledge, and grieve over this loss.

According to Kurtzer - White (2003), this parental grief over the loss of what should have been (e.g., typical healthy baby and motherhood) could be one-time grief followed by acceptance of the circumstances or perpetual grief where parents are reminded throughout the developmental milestones of the child's life.

Another personal loss that the parents demonstrated was not being able to share their passion for music together as father and son. Father (Parent 6) expressed some disappointment and sadness about this lost father-son experience. This was his first reaction when he found out about his son's hearing loss:

> I'm the kind of guy who takes things as they are. My first reaction was that he could not enjoy music. I like to listen to music, but he cannot enjoy music. (Parent 6)

There seemed to be some disappointment of not being able to bond with his son through his passion of music. Yet, he knew that he had to accept that there was nothing he could do about it. He did not want to enjoy something his son could not share in. So, in consideration for his son - that his son would not be left out, he stopped playing music in the house. However, he admitted that he secretly listened to music in the car.

4.5.1.1.2. Empathized with Child's Loss. Other than grieving over personal loss, parents also empathised with the child's loss. When parents were asked how they felt when they received the diagnosis of their child's hearing loss, Parent 3, a mother, flatly stated:

> I was very sad because she couldn't hear, which meant she could not learn. (Parent 3)

After stating that she was very sad, there was a moment of silence before continuing, "Because she couldn't hear, that meant she could not learn". She looked visibly sad that her daughter did not have the "assets" needed for learning. Her concerned and sad response was as if her deaf daughter still had this difficulty today. She might be grieving today for the loss of what her daughter could have. This is like the 'perpetual grieving that Kurtzer-White and Luterman (2003) observed in parents with PWD children. However, the perpetual grief that parents reported in Kurtzer-White and Luterman was for the loss of their own dreams and expectations, while this parent in Malaysia expressed perpetual grief for the daughter's loss.

Parent 1 also empathised with her child's suffering. Deaf Participant 1 was born with a hole in her heart, which was the first major concern. Upon finding out that the hole in her heart had healed, she received news about her daughter's hearing loss. She felt for her child's hearing loss and said:

> I really cried because it was such a pity; her heart was okay, but now, her hearing had a problem. (Parent 1)

Parent 5, a father, expressed a lot of empathy towards his son's hearing loss. He did not admit feeling sad about his son's hearing loss, but he expressed emotionally through tears when he shared how he advocated for his son's needs.

Whether it was about organising exposure trips, his concern about the quality of education for the deaf, or the financial assistance for their livelihood - he expressed frustration with the lack of resources to meet the special needs of his son. He did not look down with pity on his son but empathised with the challenges his deaf son had to face in life due to his hearing loss. Out of love and empathy, on behalf of his deaf son, he responded and stated in frustration over various concerns:

> They already lost something. Give them back something. Not the thing that they lost. Give them the benefits that they are entitled to. (Parent 5)

4.5.1.2. Denial. The other parent participants displayed some signs indicating denial of their child's hearing loss. They brushed it off in ignorance, while the spouse of the parent participant seems to be silently grieving and has yet to fully accept the child's hearing loss to this day.

In the interview, Parent 4 did not answer the question and brushed it off with the current perception of his independent deaf daughter. However, in the interview with the deaf child, she relayed the story she heard from her sister about the discovery of her deafness while she was still in the womb. Her mother wanted to abort her because of the possibility that she would be disabled. The doctor persuaded her mother to continue with the pregnancy by saying that the baby was healthy and, at most, the baby would be deaf. The Deaf Participant 4 relayed the story in the interview:

> My mom knew that I would be deaf. My sister told me this story: my mom wanted to abort me as a baby before I was fully developed in my mom's womb. She went for a checkup with the doctor when she fell ill with measles. My mom thought that I would be handicapped because of this illness. The doctor said that everything was okay, but, at most, she might not be able to hear. The doctor advised my mom against abortion. She accepted it and continued with the delivery. My mom has a brother who is deaf, my uncle. My mom saw the problems he had, and she didn't want to have to go through it with me. Hence, thought it would be better to abort me. It was unacceptable to the doctor, and he told her that she had to continue with the pregnancy. And so, I was born. (Deaf Participant 4)

Her mother did not want to deal with a child who would have special needs due to disabilities. Participant 4 would be her fifth child. Her mother had a brother who was deaf, and relating to that experience, she did not want to go through the same challenges and trouble with her own child. In addition, they were from a financially poor family with four other children. To bring up another child with special needs in that financial situation would be a difficult challenge. Hence, the first response was to abort the baby.

This story was relayed by the elder sister of Deaf Participant 4. Both father and mother (Parent 4) did not mention or comment about this incident. This is probably a private and embarrassing matter to disclose to anyone outside the family, especially in the Chinese culture. Hence, the parents did not talk about the matter. The researcher did not verify this story with her other family members as it is a sensitive and private family issue. However, there are similar stories to

Parent 4 that the researcher has heard from her circle of family and friends. The same concern was about being able to handle a child with disabilities on top of caring for a large family with poor financial conditions.

From the way Deaf Participant 4 was brought up by her parents, it seemed that her parents might still be in denial that she had a hearing disability, which required some special needs assistance. For example, her parents did not follow up on her hearing ability despite the earlier diagnosis of a possible hearing loss. She was finally diagnosed with hearing loss at age 6 when she did not respond to clapping games with friends. However, the parents did not provide any other alternative ways of communication except through speech, although Deaf Participant 4 struggled with verbal communication. The researcher also observed that the parents and Deaf Participant 4 interacted with each other. They spoke to each other like regular people, with very few or no gestures to assist with lip reading.

It was almost as if their parents assumed that she was like everyone without any special need for communication and learning. They also implemented the same expectations on the deaf child (now an adult) to earn and support the parents financially. This is a typical Chinese culture of expressing filial piety. Were the parents aware of how the deaf are more disadvantaged in the working world? However, it was also likely that they saw no reason for different expectations of their children. Nonetheless, could these observed behaviours from the interview be evidence of a silent denial of the child’s hearing loss – to not acknowledge her disability and hence not provide for her special needs when she was a child? Or they merely had little knowledge about how to manage someone with deafness?

Other than the seeming ignorance of the hearing loss of Deaf Participant 4, two spouses of the interviewed parents seem to be in denial about their child’s hearing loss. They were unable to accept the child’s condition and shy away from the public when it relates to their child with hearing loss. The researcher received this impression in the interviews from Parents 5 and 6 that their wives had a hard time dealing with the grief of their child’s hearing loss. When Parent 5 was asked about their wife’s reaction, he paused and then said firmly, “She had to accept. No choice”. He did not want to elaborate, and the researcher did not ask further as she sensed it was a sensitive topic that the participant wasn’t comfortable with and wanted to avoid talking about it.

His response to this question gave the impression that his wife might still be grieving and have yet to accept her child’s hearing loss. He did not want to comment on his wife’s response but solely pushed it down, saying that it had to be accepted, whether she liked it or not. His wife does not know how to sign and was not actively involved with the husband in learning sign language – the language to communicate with her deaf son. The father did everything related to the child’s well-being (e.g., hearing check-ups, speech therapies, sign language classes, and education). While sharing his journey bringing up a deaf son, he did not mention his wife at all. The only time he mentioned his wife was when the interviewer asked how she responded to her son's deafness and how she communicated with her son. This father also displayed strong messages about 'accepting' the child the way the child is because it is a fact and it is reality. He expressed it this way:

> Let's say the son is fat; we cannot think that he is thin. It is a fact that he is fat. You cannot run away (from the facts). Black is black. White is white. You cannot say black is white; white is black. If someone says black is white, he wants to make you happy, that's all. True facts - you have to be realistic. (Parent 5)

On a separate occasion, he indirectly expressed frustration with people denying their child's deafness and questioned why one goes to church for healing when the reality is the child is deaf. He viewed seeking miraculous healing as a denial of the situation. Hence, these two incidents made the researcher wonder if he had a transference defence to counter his wife's response to their deaf son. He might have forced the truth of reality on his wife, and she might not have accepted it. It is unsure if the wife of Parent 5 is still grieving or unable to accept her son's condition. However, it is highly possible that during the early years of the deaf child's life, she was struggling to accept her son's hearing loss.

The wife of Parent 6 also seemed to be very sad and maybe still grieving over her son's loss of hearing. When Participant 6 was asked 'how did your wife take the news?', he could hardly answer the question. He paused, trying to find the words to say, mumbled something inaudible, then continued to give facts of what happened.

> My wife took it quite………hm……. Emotionally. So, that was the process. We went down and took him to a special nursery school run by some nurses, people who were experienced with special needs. (Parent 6 wife)

When he paused in between his sentences, his facial expression showed he went back in time and remembered how his wife responded. For a moment, he looked like there was a big emotional burden and sadness that he did not know what to do about and did not want to talk about. Perhaps it was his wife's personal grief that he did not want to expose to outsiders. It is common in Chinese culture that private matters between husband and wife, or within the family, should not be made known to outsiders. To embarrass one's spouse is to embarrass oneself.

It could also be that this matter was a lost cause. Parent 6 was helpless to change the situation or his wife's response to the situation. Hence, there was no point to bring it up. While listening, the researcher sensed that his wife did not take the news well, and she may still be dealing with this sense of loss. According to Parent 6 in the interviews, his wife did not want to go for sign language classes and relied a lot on her husband (Parent 6) to take care of their deaf son's needs.

Wife of Parent 6 also seemed to not be involved directly in matters related to her deaf son, without her husband. For example, the researcher first approached the mother to be interviewed. She declined, saying she needed to ask her husband first and that she didn't know what to say. Eventually, she declined the interview twice, and her husband (Parent 6) willingly shared his experience parenting a deaf child.

In summary, some parents seemingly are in denial, whether it is expressed through ignorance or the inability to accept the child's hearing loss. This denial has resulted in the parents being less involved in the child's life. The child's special needs (e.g., communication) will not be met if parents do not accept the child's hearing loss condition. Secondly, parents who cannot accept the child's hearing loss are not able to manage the caregiving of the child, and the role and responsibility are passed to the other parent. In this case, it is the mother not being able to accept and manage the child's condition. Hence, the fathers became the main care giver. It is clearly seen that the inability to accept the child's diagnosis has an effect on the caregiver and the quality of help they give to the deaf child.

4.5.1.3. Rationalization. One of the ways parents coped with their child's hearing loss, was to rationalize and accept the situation. Parents looked at reality and tried to accept the child's condition by accepting life's circumstances without having to blame anyone. They also tried to view their child's condition positively – looking at what the child can do, rather than what they lack.

Parent 2 rationalised that her daughter's condition was due to circumstances out of her control. With the doctor's support and advice, Parent 2 could quickly accept her child’s hearing loss. Parent 2 shared:

> Once I knew she was deaf, I was so sad. I hugged the doctor. Dr. XX was so good. She is currently in Hospital Y in Ipoh. She is still there. She is very good. The doctor was very good with me. Okay lah, I accept it (my child’s hearing loss). On both sides (of the family), nobody was deaf. It is not genetic. Most of them (deaf children) stay in Jalan Pasir Putih and Lahat area. There was some kind of chemical pollution. (Parent 2)

She concluded that it was the unfortunate circumstances that caused her daughter to be deaf. She believed that her daughter’s deafness might have been related to the chemical pollution in Lahat. Lahat has a history of mining activities (Ahmad & Jones, 2013) and it is also an industrial factory area (Federation of Malaysian Manufacturers, 2020). However, there is no solid evidence to verify that there was chemical pollution in Lahat. Regardless, Parent 2 accepted life’s circumstances.

Parent 5 rationalised the reality of the situation. He saw the importance of looking at the facts and accepting reality. He rationalised that if it is a factual truth, then it is a fact he had to accept whether he liked it or not. He used the facts of reality as a guide to rationalise how he ought to respond to his son’s hearing loss. He shared:

> We already had to accept it. We sort of knew... when we were with the child... we called, but he didn’t respond. We knew that something was wrong, but to what degree? … We had to accept the fact. (Parent 5)

Perhaps he strongly emphasised in this response the acceptance of the child's hearing loss because he had met many other parents of deaf children who were in denial about their deaf child's condition, which did not help the child in their development. This response also seems to be a way of quickly moving forward to help the child rather than focus or dwell on the emotions and circumstances that cannot be changed.

Parent 4 rationalised that his daughter's hearing loss was not a unique situation. He made comparisons with others and concluded that there were many others who were in the same predicament and could still succeed in their careers. He tried to normalise the situation and looked at the positive side of things. He said:

> She's not the only one like that. There are many other people who are deaf, too. She can't hear, but she can do everything else. What she sees, she does, unlike others who are blind. There are a lot in Ipoh, and some are teachers. (Parent 4)

Although Parent 4 was rationalizing how common his daughter's condition could be, there was a hint of caution if this parent was possibly ignorant or in denial of his daughter's hearing loss. Rationalizing to ignore the special needs of the child would not be beneficial, although rationalizing was a way for parents to try to deal with the reality of the situation.

4.5.1.4. Observations. An overall observation of all six parents is that one parent took the main role of looking into the needs of the deaf child. It would usually be the mother as the main caregiver, and the father would be the main financial provider. When mothers were involved, fathers seemed to be quite distant or absent. Parent 1's husband was busy working. She mentioned that she had to do everything herself and never mentioned her husband's involvement in teaching or interacting with the deaf child. Similarly, Parent 2's husband was also busy working, and she had to do the caregiving mostly on her own, though she did mention involving her husband in major decision-making (e.g., cochlear implant). However, she seems to be more exertive in these decisions, while her husband is assented to the recommendation.

When the mothers were not able to cope with it, the fathers had to step up to be the main decision-makers and caregivers of special needs for the deaf child. They looked into every aspect of the child's needs while their wives seemed to remain less involved or dependent on the father's decisions regarding the deaf child's needs. This was evident in Parents 5 and 6. For Parents 3 and 4, both fathers and mothers seem to not be involved, in denial or at a loss of what to do to help the child. They did the basics of providing for the child's needs.

The two fathers (Parents 5 and 6), who were the main caregivers of their deaf child, were not exempted from the sense of loss. They, however, expressed it differently. They were practical and realistic and did not give as much time to express their emotions. Perhaps they had to be strong for the sake of their wives, who were emotionally unable to accept this reality. Perhaps, as men in an Asian culture, they were expected not to show emotions.

These observations provide insights into the thoughts and emotions of parents' coping in the journey of parenting a deaf child. Counselors, social workers, teachers, and medical staffs are the frontliners of providing support. These gender differences of expression and roles are important points for the social workers to be sensitive to and aware of when giving advice or support.

4.5.1.5. Summary. Parents in this study responded to their child's hearing loss diagnosis in three main ways – grief, denial, and rationalisation. The emotions they felt are like what literature has documented in Ross' stages of grief – shock, anger, bargaining, sadness, and acceptance (Kubler-Ross, 1969). However, the parents did not provide evidence that grieving was a process and that they had to go through each stage of grief. Parents 1 and 2 were shocked by the news, while parents 5 and 6 suspected the hearing loss and were better prepared to receive the diagnosis. Parent 4 and the wives of Parents 5 and 6 seem to indicate denial of the child's condition and could not provide the support and involvement needed.

All parents expressed sadness over the child's loss, but none showed signs of depression. Parents 1, 2, 5, and 6 accepted the child's condition very quickly after diagnosis and were fully focused and involved in the early intervention for the child's development. Parents 3 and 4 accepted the diagnosis, but they were either helplessly dependent on what was given or uninvolved in the child's development.

All parents in this study except Parent 3 did not express a 'non-finite' loss, where parental grief for families living with a disability is believed to be throughout the lifespan (Bruce & Schultz, 2001). Whether it was non-finite or infinite grief for the loss, their sorrows were not because of the differences between parents' own idealised child and reality, but rather because parents grieved empathetically for the loss and challenges that their deaf child will face in life. The focus of Malaysian parents was on their child's loss rather than their own 'dreams' for the child.

Kurtzer-White and Luterman (2003) emphasised that parental acceptance is a necessary prerequisite for a successful hearing-impaired child. This study affirms this statement. The quick acceptance of Parents 1, 2, 5, and 6 enables them to focus on the practicality of what can be done. Unhelpful thoughts were not entertained, while rationality and practicality overruled the parents' next course of action. Another possible reason for parents' "once-and-for-all-grieving" is that they had no choice but to rise to care for their vulnerable deaf child. It might be the survival instinct. "Grieving" for what cannot be changed had no value to survival, and hence, they focused on being as involved as possible to ensure their child with hearing loss has the skills and opportunities to survive and have a fulfilling life.

As for Parents 3 and 4, although they may have partially accepted their child's condition, they may have lacked the resources, support, and skills needed to help their child succeed. Deaf Participant 3 is isolated and lonely, while Deaf Participant 4 have experienced emotional rejection in the family. There might have been a gap between diagnosis and support for these two cases (Kurtzer-White & Luterman, 2003).

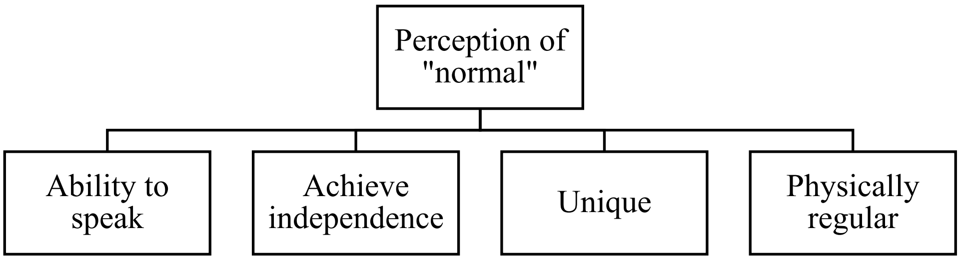
4.5.2 Parents' Perception

From the parents' narratives in the interviews, a common theme of their perception of 'normal' emerged. The perception parents currently have of their child's 'normality' revealed how they might have cognitively adapted to the reality of the child's condition. Parents viewed their child to be 'normal' if they able to speak, be independent, physically regular, or considered unique. This adaptation and acceptance of the child's hearing impairment are essential for the success of the child (Kurtzer-White & Luterman, 2003) as the perceptions of their deaf child impact the next course of action taken to assist the child's development.

In the interviews, every parent used the term "normal" at least once in sharing their experience bringing up the deaf child. Interestingly, the same term "normal" that parents used in the interviews was defined differently by the parents. The fact that parents used the word “normal” seems to indicate that parents made comparisons between their deaf child and what everyone else was expected to do or be like. From the interviews, parents have described and emphasised “normal” in different aspects – to be able to speak, to be outwardly regular, to achieve independence, and to be unique in their own way, just like everyone else. Figure 4.10 describes the subthemes that emerged in parents’ narratives regarding their perception of “normal” for their deaf child.

Figure 4.10

Subthemes of Parents’ Perception of “Normal”



4.5.2.1. To Speak. Parents acknowledged that their child was not exactly like other children in terms of development, specifically speech development. Parent 2 expressed a lot of concerns over this matter as she viewed this hearing and speech impairment as a disability that needs to be overcome for a regular life. She expressed her desire for her child’s normality:

> I want her to be a normal person. She only wants to mix around with the deaf. She doesn't want to mix with normal people because she can't talk. (Participant 2)

To speak was the main emphasis and deciding factor of what it meant to be 'normal' for this parent. She used the word "normal" fifteen times in the interview – normal language, normal people, normal school, normal life, and all these related to the context of using speech as the main mode of communication. When asked for her definition of 'normal', she commented:

> Just to be able to talk to people. It's okay if it's not so clear, but I still can (be able to) talk and communicate with people. That's all. I do not want her to be intelligent or anything (I don't expect her to be intelligent), but that she can survive on her own (independently), I am satisfied with it. (Participant 2)

Parent 2's perception of 'normal' is to be able to communicate with people through speech. The ability to speak was considered an important ability to connect with the hearing world for better survival (learning, career, social relationships). So, not being able to speak was seen to be abnormal because one would naturally be excluded from the hearing society and not be able to connect, develop, and survive independently in the hearing world. In other words, if one had normal speech, they would have normal social connections with other people and, therefore, be able to survive independently.

Throughout the interview, Parent 2 kept coming back to the importance of speech. She expressed pride and joy when her daughter successfully spoke after cochlear implants, speech therapy and intense private personal daily exercise. She also expressed disappointment when her daughter refused to use her speaking abilities to communicate and excluded herself from hearing people. Parent 2 also compared their hearing son and said that “he is normal, but she is not normal”, which led to the mother’s protectiveness of her daughter’s social exposure and activities. This protective behaviour was out of fear for her daughter’s safety in a world she cannot communicate with.

With the emphasised view of the importance of speaking, Parent 2 strived hard for a fighting chance to restore her child’s hearing ability through cochlear implants and speech therapy. This was in the hope that her deaf child would be like everyone else—to speak and communicate just like everyone else. This parent’s perspective of the deaf person is the same as the medical model in understanding deafness (Baines, 2007), whereby the hearing loss should be restored.

4.5.2.2. Achieve Independence. When parents did not emphasise the need to communicate through speech and hearing to survive in the community, parents perceived their child to be normal and merely different in communication methods. It was just a different way to achieve the same goal of independence. Parent 5 viewed his child as ‘normal’ regarding the child’s ability to be independent like everyone else.

He (his son) usually behaves and is very independent. He only cannot

> hear. But for what he lost, his other senses increase in sensitivity, like his visual observations. His eye is very sharp. So, to me, he is very normal. We can interact, and he is better than me in technology. (Parent 5)

For Parent 5, deafness was not viewed as a barrier to the child's independence. This parent saw no lack in his deaf child to live like everyone else. Though he had limited ability to speak, this deaf child successfully achieved independence in life (e.g., secure job, got married and has a daughter) and was more successful than his father in certain areas (e.g., technology savviness). Hence, Parent 5 viewed his deaf child to be just like everyone else. Communication other than speaking was accepted and seen as normal. It is just a different way of communicating that needs to be more acknowledged and accepted by the majority of society. This perspective aligns with the Social Model of understanding deafness, where deafness is viewed as a different ability, not a disability.

Just as Parent 5 viewed 'normality' as achieving independence from everyone else, so did Parent 2. However, Parent 2 related the success of being independent largely to the ability to speak. Parent 2 expressed:

> I know that one day, I will leave her (leave this world). I just want her to be able to have her job, survive, and meet her own needs. So, I want her to talk so that it is easier for her to communicate (through speech). I want her to be an average person. (Parent 2)

Communication via speech was seen as the main channel and key to achieving independence in the hearing world by Parent 2. Hence, Parent 2 pushed her deaf daughter to speak. As for Parent 5, he accepted his deaf son's unique communication method, which did not solely rely on speech but a blend of written communication, gestures, etc. Deaf Participant 5 is living proof that surviving and being independent in the hearing world is possible without depending entirely and solely on speech. The living testimony of Deaf Participant 5, who is independent with a secure job, got married and started a family, challenges the perspective of Parent 2, who placed utmost importance on speech for survival. This showed the different perspective of an alternative lifestyle and communication mode for survival and independence of a deaf person.

4.5.2.3. Unique. While parents navigate through what "normal" means to them through a comparison of different aspects, parents accept the uniqueness of their child, as of any other child. The child's differences are embraced as the child's uniqueness, and uniqueness is normal. Therefore, the deaf child is seen and treated as normal by the parents. Parent 6 expressed and demonstrated this perception in the following narrative:

> So, as parents, (we) just provide for him and send him to school. Nothing special or different that we went through. Just initially, we pity him. But to me, just treat him as normal. Communication with him is normal, but he must understand that he is a bit different in that he lacks one sense. The other senses are better. Each has their own character and personality... Sometimes, we treat him… we don't want to say as a special child; though they (people) give him some advantages, we treat him as normal. (Parent 6)

This father viewed his deaf son as “normal”, and parenting was “normal”, nothing special or different. Yet, at the same time, he acknowledged that there was some difference in how his son interacts and behaves because of the lack of hearing. This difference is unique, just as each person has a unique personality. In this sense, there was not much of a comparison but an embracing of the child as he is.

4.5.2.4. Physically Regular. Other parents acknowledged that their child’s hearing ability may cause some differences in development. However, when compared with children with other disabilities, parents view their deaf child to be “normal” and not disabled. Parents compared and commented that their child only cannot hear but is completely “normal” physically and behaviorally - just as abled as everybody else is.

The deaf child was considered “normal” with the absence of any severe mental and physical handicaps and irrational behaviours (e.g., biting people). Parent 1 stated:

> She is normal. Her problem is only hearing. She is rather good; she doesn’t need anything, unlike other kids who salivate and bite people and all sorts of (behavioural) patterns. (Parent 1)

The child was “normal” as he behaved like other children:

> I feel he is normal. Wherever I go, he comes along. He behaves normally and is very independent. (Parent 5)

The child was deemed “normal”, as in being abled body. They could see, walk, and do things - just as physically abled as everyone else. Parents made a downward comparison with other disabled children (e.g., blind) and saw how “normal” and abled their child was:

> She is only deaf; she can use her hand and everything. For me, she is better than some of my friends’ children who can’t walk, and they have to carry them until they are 20 years old. They are disabled children. (Parent 2)
>
> She only can’t hear, but she can do everything else. What she can see, she does. She is unlike others who are blind. (Parent 4)
>
> It is only hearing; what if they were blind? They have two legs. (Parent 6)

Compared with other children with physical and mental handicaps, parents viewed deafness as the least severe of the disabilities. On the outward appearance, the deaf child is “normal” physically and behaviorally, like a regular person. Hence, on a spectrum of disabilities, the deaf child may seem to be more like regular children than they are to children with other disabilities. However, deafness is an invisible disability, which, if proper assistance and support are not provided in the early stages, can result in poor mental, cognitive, social, and behavioural development. It is easy to neglect the special needs of the deaf individual because among the PWDs, from the physical appearance, the deaf are considered to have little need for assistance. While among the regular society, they struggle with their disability to hear and communicate socially and develop cognitively.

The researcher attended a one-day conference organised by a local hospital about the special needs of children. Interventions discussed were focused on motor and cognitive development, learning independence, and self-care skills. When the researcher asked about interventions for deaf children, the answer was simple and a matter of fact – “get medical assistance for hearing restoration and speech therapy”. When asked about developmental interventions, they suggested sending them to sign language class as they have only communication issues. However, they had no contact when asked for further information on the sign language classes offered. They took the researcher’s contact as a reference for future sign language classes.

Relating to the incident stated above, the interventions recommended were based on the medical model view. There was little emphasis on the balance needed from the social model. Hence, deaf children can easily fall through the cracks because they are not getting the assistance needed for development. They are considered “normal” - not disabled, among the other visible disabilities. Yet, they are regarded as “not normal” with regular children due to their special communication needs. Interventions that consider the deaf person’s special developmental needs would help the child develop more holistically. Ignorance or neglect of consideration of the deaf child’s needs may result in poor development in various aspects - mental, social, cognitive, emotional, linguistic, and behavioural. Hence, it is important to give attention to the interventions needed for the holistic development of deaf individuals and not allow these people with invisible handicaps to fall through the cracks.

4.5.2.5. Discussion on Cultural Perspective. Malaysia is a multicultural and multireligious country. Pre-dominantly, the ethnic Malays are Muslims, the Indians are Hindus, the Chinese are Buddhist, and the indigenous people have their own cultural animistic beliefs. There are pockets of Christians, atheist, and freethinkers among the different ethnics in Malaysia. These religious beliefs have an influence on a person’s perception towards disability in society.

Since this study’s participants were from a Chinese Buddhist background, we will focus on the influence of Buddhism on the perception of deafness. From the general perspective of a Buddhist, “to be born with a disability is very widely considered a negative condition, indicating 'bad karma'. It is not seen as a reward, or as promotion to a higher condition (though to be born human, even with a disability, is a better condition than being born as an animal or an insect)” (Miles, 2013).

Although the broader teachings of the Buddha include human relationships, kindness, and compassion, the understanding of ‘karma’ may have influenced some of its members to assume that people with disability “deserve” due to failures from their past lives. In some cases, it was the parent who felt that the ‘karma’ was on her because she did something wrong in her past life and hence gave birth to a child who was deaf. Another mother indicated in a private conversation by quickly stating and then rejecting the idea that her child was deaf because of her wrongdoing and bad karma. The quick defence against ‘bad karma’ as the cause of her child’s deafness seems to reflect that ‘bad karma’ was one of the common ideas people have placed on her.

Although parents vary in the depth of their Buddhist beliefs and practices, parents seem to give a different perception of their child’s deafness, contrary to the ‘negative’ cultural beliefs about deafness. Parents have accepted the child’s deafness; some have absorbed the blame for the child’s deafness. Parents seem to have taken on the role of a protective layer to shield the child from the unkind view of society towards them and their deafness. This has given the deaf child a secure and positive view of who they are as a deaf person in society.

4.5.2.6. Summary. Parents would like their children to have as normal lives as possible - to be just like everyone else. Parents define “normal” according to the area of focus of what they believe makes a person “like everyone else”. Whether the parent chooses to restore the deaf child’s hearing to be “normal” or accept the child’s differences and uniqueness, parents desire to create an inclusive environment for their deaf child to feel they belong, just like everyone else.

It was also observed that parents’ perception of deafness influenced the parents' choices for the child's development. Parents who view deafness as a disability tend to focus their efforts on hearing and speech restoration for total inclusion into the hearing world (e.g., Parent 2). Parents who viewed deafness as a difference made the necessary minimal effort for hearing restoration and concentrated their effort on establishing a communication system and expanding opportunities for learning (e.g., Parent 5). Parents who viewed their child's deafness from the surface, where there was no difference outwardly, tended not to acknowledge the child's special needs for communication (e.g., Parent 4).

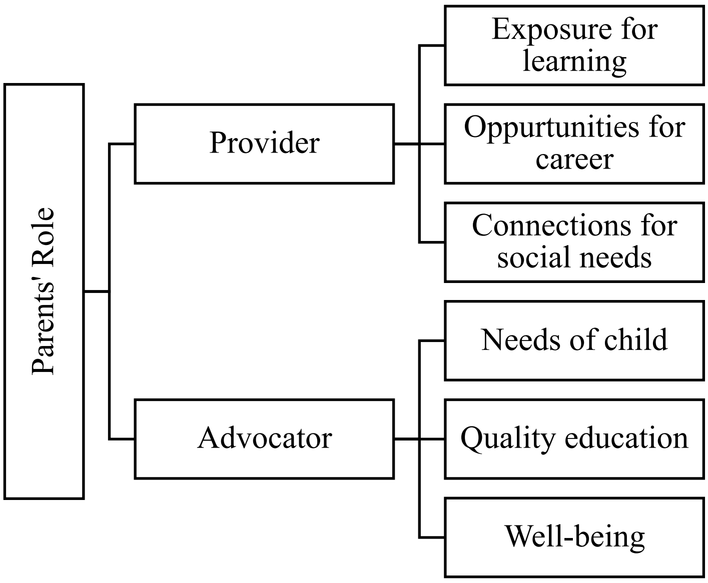
4.5.3 Parents' Role

The first research question explored parents' experience and role in bringing up their child with hearing impairment. Other than parents' emotional coping and perception of their child with hearing impairment, the third main theme that emerged from the data was parents' role.

The two subthemes of parents' role that emerged from the parents' narratives are parents are the provider and advocator. Parents played the role of providing exposure for learning, opportunities for career, and connections for social needs. Involved parents with leadership also became advocators for their own and other deaf children. Figure 4.10 below shows the subthemes of the parents' role that emerged from the interviews and observations.

Figure 4.11

Subtheme of Parents' Role



4.5.3.1 Provider. Children with hearing loss may not have the same opportunity to learn as children who can hear. Regular hearing people learn about the world through sound and speech. Hence, children with hearing impairment are at a disadvantage in learning as they cannot hear. They depend on their parents to provide them with the necessary environment and exposure. From the interviews, parents described how they were trying to provide exposure for their child's development.

4.5.3.1.1 Exposure for Learning. Parents tried different ways to provide exposure for the child's learning. One parent tried to create a learning environment at home, while most parents sent them out of the home for more exposure. Parent 6 attempted to do both. He tried to create curiosity in his deaf child to learn by setting up the environment with books.

> In my house, we have the children's encyclopedia. I leave it on the table. But the mother always keeps it. I will put it back on the table. Let my son see it. Then, he would start reading. (Parent 6)

When this attempt at self-learning was insufficient, Parent 6 reinforced learning by sending his deaf son to tuition class. Parent 6 shared:

> But I feel that my son's language is not as good as expected. We do give him tuition. He has a typical hearing teacher who comes over to our house to give English tuition. We also send him to XXX (a famous tuition centre that allows students to learn various subjects at their own pace). (Parent 6)

This was Parent 6's way of providing exposure to the world's knowledge for his son. Other parents selected schools that were suitable for the child's learning needs. All parents (except Parent 2), by default, sent their deaf child to the deaf school to learn. Parent 2 wanted to give as much exposure and opportunity for her deaf child with a cochlear implant to learn. Hence, she first sent her to the mainstream regular school. It was upon finding out her deaf daughter was not learning anything that she changed her to the deaf school.

Parent 2 tried to give her daughter the most suitable exposure to learn. This is her narrative:

> I sent her to a normal school…The teacher said that she couldn't teach her and that it would be a waste for her to continue to be there (in the mainstream school). The teachers didn't know how to teach her. So, I transferred her to a deaf school. (Parent 2)

> Other than providing exposure to learning knowledge through books and school, parents also focused on providing exposure to the child's independent living. Whether it is learning independence in daily events or through a one-time-off event, parents try to provide the exposure to learn them. Below are examples of parents' effort to provide exposure to go out on her own. If she wants to go out to buy things, I'd let her go. Let her communicate with other people and not be protective over her interactions. Because it involves money, I'd ask her to count her money. I know that other people won't cheat her; let her learn and have the experience of buying things on her own. (Parent 1)

> Brought deaf youth to Pangkor for an exposure trip. We do not allow the parents to follow. If their parents are there, they will be distracted. We want them to be independent. (Parent 5)

> To gain more exposure, he enrolled in the hostel. He got a place in the hostel, which is good for him. I want him to be more exposed, to be by himself. So, we sent him to the hostel. (Parent 6)

One parent felt that deaf children should be exposed to more than just regular daily activities. Parent 5 felt it was his responsibility to provide more exposure for his deaf son. However, during his time, there were no available resources. He eventually initiated and pulled in his own resources for the sake of his child's development. He organised exposure trips for his son and deaf classmates and got people involved along the way.

> We took them to Cameron Highlands to stay overnight. We did not allow the parents to follow. If their parents are there, they will be distracted. We want them to be independent. We made another trip to Pangkor Island, just for one night. Before we reached there, we tried to get a discount from the ferry. They said we were not informed. We paid and went across, then the taxi came. We have children, and they are all deaf. Some of them are very poor. The taxi drivers were so kind, they gave us a free ride … (participant was emotional and shed some tears) ... so our itinerary included - playing with them, teaching them, let them enjoy themselves. So, the taxi the next day, we went to a hotel, which is managed by an ex-badminton player; they gave us a free lunch and a taxi to take us around the island. (Parent 5)

Parent 5 was one of the earliest parents to start such initiatives. His deaf son was about ten years older than the other deaf participants. So, other parents and their deaf children benefited from Parent 5's pioneering efforts to provide exposure for the child's development. Parents 1, 2, and 6 with their children were among those who benefited. Parents 1 and 2 merely had to get in touch with the YMCA and join in what was already provided. Parents 3 and 4 were not educated and did not know what to do to assist the child's development. They did not assume the role of expanding exposure for the child's learning.

4.5.3.1.2 Opportunities for Career. Even when the child has completed tertiary education, parents continued to play the provider role by seeking resources for their child's career development and survival. For her deaf child to have better career prospects, Parent 2 helped her daughter through college and tried to obtain job opportunities on behalf of her daughter.

> After SPM, I sent her to college to complete a diploma in graphic designing. Then I sent her to a few companies to do work (graphic designing), but it didn't last long. Only lasted for 2 -3 months before the company said "no" as they couldn't communicate with her. (Parent 2).

Parent 6, on the other hand, search for possible opportunities for his son's further career. He honestly shared his concerns about his son's career development and how he tried to look for resources to provide the skills needed for his career development.

> I tried to get him to join the government. It would be good if you joined the government. That is why I keep pushing him in English. If he is good at English, he can be a teacher for deaf students. At least at the primary school level. Which is what I think is good for him. We do give him tuition, with a normal teacher at home for English, and we also send him to XXX (a popular tuition centre in Ipoh). (Parent 6)
>
> I don't have any business for letting him run. So, we have to do something about it. Find him something he wants to do. Maybe open a coffee shop for him, or a café. We showed him Starbucks, the special outlet run by the deaf (in hope) to get him interested so he can work there or do some cooking… whatever is possible. (Parent 6)
>
> His mother wants him there to work instead of staying in the house. Since he likes cooking, maybe he will experience and pick up cooking. Anyway, I brought him there to have a look, but he didn't like it, and he said that I had bluffed him. Anyway, later, he knew that some of his friends were working there. For example, his classmate was there. So, he went there to work for a couple of months washing dishes. (Parent 6)

Parent 6 still puts in efforts to think and search for opportunities to help his son's future career development. It is interesting to note that parents still play a role in seeking and providing opportunities for their deaf adult child.

As for Parent 3, they have a family food business. After their deaf daughter completed her basic education, they recruited her to help out with the family's business instead of continuing to work outside. They were worried for her safety as a young woman. Although Parent 3 did not say anything about the plans for her deaf daughter to play a bigger role in the business, they wanted to make sure that she had something to do in life.

4.5.3.1.3 Connections for Social Needs. Parents also had a role to play in providing for the child's social needs. Parents were either the deaf child's main connection, or they were providing a connection between others and their deaf child. They want to provide a conducive environment where their deaf child will feel connected and belong within the family or society. Due to the child's inability to hear and to connect to people through sound, parents find different ways to bridge connections for the child. Parents played an important role in bridging the gaps in communication to help their deaf child and other family members interact with each other.

Of the six pairs of hearing parents and deaf adult children, only two parents (Parents 1 and 6) expressed their role as the connector between deaf children and family members. The other pairs were silent about their involvement in connecting the deaf child with other family members. Parent 1 played an active role in creating family communications with her deaf child and other children. She tried to bridge the gap in communication among her children. She shared her daily interactions with her children in the car during pick-ups and drop-offs:

> There were traffic lights. A lot of them! So, it was during that time that I chatted with her (deaf daughter). And she listened to me. I would say with my mouth covered, “(daughter’s name), call me”. Then she would say “mummy”. “(daughter’s name), call your brother!” when her brother was in the car, “gor gor”. “XX, call your sister “mei mei”. But she was cheeky; she didn’t want to call her sister. And her sister gets upset about it. (Parent 1)

Parent 1 attempted to get her deaf child to connect to her other hearing children while getting her to practice her speech. This mother created a situation to get all her children involved and interact with each other. When the researcher went to interview Parent 1 and her daughter, I observed the interactions between the deaf daughter and her hearing sister. They were connective and playful and seemed to have a close bond with each other. Perhaps the effort and example of the mother to bridge communication and intentionally include her deaf daughter in the family has resulted in good connections between the two sisters.

Parent 6 seemed to be the main connector within the family between the deaf son and his mother. Parent 6 stated:

> My wife... she... not that she is not interested (in sign language classes). She is a bit wary about learning these things, so she learns from me. (Parent 6)

So, Parent 6 learnt sign language and taught his wife, so that she could communicate with their deaf son directly. The father’s role was a connector within the family. It seemed that when family members found it difficult to communicate to with the deaf child, the parent would play the role of connecting and bridgingmmunication.

Parents also indicated that it was important for their children to be exposed to other people for social interaction. This was especially highlighted by the mothers of deaf daughters (Parents 1, 2, and 3), while fathers of deaf daughters (Parent 4) or sons (Parents 5 and 6) did not display concerns about their deaf child's socialisation. The mothers tried to provide socialising opportunities in safe environments. This exposure to other people was a strategy of parents to reduce the disconnection and loneliness of the child. They wanted the child to feel like they belonged. They shared:

> I let her and encourage her to know or to be exposed to anything/everything. If not, she won't know anything. So, now she can be quite a busybody at times. She knows all my friend's contact; she wants to know everything. She knows all my friends and even says hi to my friends on Facebook and chats with them. (Parent 1)

> Please don't leave them at home; you have to bring them out and bring them around to mix with people. I went to cued speech in KL. It's good also. Cued speech is easier. I want her to mix around so she won't feel lonely. She is not alone. (Parent 2)

4.5.3.2 Advocator

Another role parents may play is acting as an advocate, where the parent voices out on behalf of the child for their needs. Only one parent was an active advocator – Parent 5. The other parents themselves either did not know much about their own deaf child's needs, and what to do (e.g., Parents 3 and 4), or they only managed their child within their own ability and context (e.g., Parents 1, 2, and 6). The role of an advocator that this father played included advocating for the child's needs, quality of education, and the child's well-being.

4.5.3.2.1 Needs of the Child. Only one participant strongly voiced out the needs of the deaf child, while the other participants did not demonstrate to play this role. Perhaps this is because Parent 5 was one of the eldest in the participant group, and during his time, resources were scarce. Hence, he had a stronger urge to advocate for the unmet needs of his deaf child. The other participants already had the opportunity to reap the benefits from the initiatives of Parent 5, who advocated for the needs of the deaf (e.g., school). He spoke to other parents on behalf of the deaf children:

> Then there was a mother from Sitiawan who came and said to me, "You know sign language and talk to them (deaf children)?" I told her that even if you do not know sign language, you can use body language. They do understand. Do you take your son out at night? Why not? What is wrong with that? You don't want them to stay home because they are deaf. She did not let her son out. When her son was standard two, the tuition teacher took them places, not the mother. Among the OKU (PWD), they (children with hearing impairment) are considered one of the mildest. Sometime later in the future, she started to take her son out. (Parent 5)

He was advocating for the deaf child to his hearing mother to give him the exposure and communication the deaf child needed to develop. He also advocated for the needs of deaf children in schools.

> I was told that it would be good if I joined the Parent Teacher Association (PTA). This is because, according to them, the headmaster disapproved of certain things we proposed. When I went in, I was the vice president of PTA. Then I found out a lot of things that the school should have done. I told the headmaster, "I see a lot of children without hearing aids. Does

> the government provide them?". They said, "They only give four sets." I asked, "Where are the four sets?". They replied, "There, but they are not wearing. They complain that it is noisy, no battery." (Parent 5).

He made it his priority to see to the needs of deaf children. First, he checked out the available resources in school and tried to find a solution to the issues. He bought batteries for the deaf children's hearing aid and felt strongly that the school should get a trained person from Kuala Lumpur to provide services and free checkups for the deaf child's hearing condition. He was the voice for the deaf children at the school. Parent 5 did not only voice out for the deaf child's hearing aid needs to the school, but he also took note of the lack of schools in Ipoh for deaf children. He advocated for the need for a deaf school in Ipoh for deaf children and fought to have a school in Ipoh. He shared his experience:

> I went to the education department. I said to them, "They don't have a proper school. Why don't they have one for their own, rather than to borrow classes from the normal school? We have a budget every year. But they don't make use of it? We have one place in XXX. It is next to another school. The land is very big, and they are going to build a school there." The next year, I went in and asked how the school was. The other school took over; they wanted the land. I just don't understand. If it was given to them, let them have it. (*Emotional).* The school XXX was the school we fought for. We made sure there was a school. By the time we got a school, my son was already studying elsewhere. (Parent 6)

4.5.3.2.2. Quality of Education. Parent 5 also looked into the quality of education the deaf children were given in class. One day, he went to check up on his deaf son's class. This is what he saw:

> The teacher was seated there with two legs on the table while the kids were playing. I asked if I was in the wrong place. What did they do? Go there at 8 am – 3 pm. But the teacher didn't do anything. He had two legs on the table, and the kids running around and playing. The teachers know Sign Language. I was sarcastic because I was very angry. How can they improve themself? They don't have (*emotional*)… (Parent 5).

This incident was very upsetting to Parent 5. He was emotional every time he spoke of the 'needs of the deaf' that were ignored or not met. He was advocating not only for his deaf son but for the other deaf children. He pointed out this class incident in the Parent Teach Association (PTA) meeting. He also succeeded in fighting for a school in XXX for deaf children. Apart from advocating for deaf children in schools and the government education sector, Parent 6 also looked into matters of employment salary later in life. Even as he spoke during the interview, he advocated for the deaf people's livelihood and earning a living. He voiced out his concerns on behalf of the deaf community:

> Look into the allowances. They (the government) talk so much for the lower-income group. OKU is also the lower income group, so why don't they look after them? Once registered with the government, the deaf person is given a few hundred. I'm talking about the whole group of OKU, not just the deaf. They should do something. This is the basic. Not that I'm saying we must give them a bonus. But I think they should look into concerns of the OKU. (Participant 5).

4.5.3.2.3. Well-being. Parent 5 demonstrated an advocative attitude especially when it was perceived that the deaf were placed in a disadvantaged situation or when there was a barrier to receive the help deserved. In the narrative of Parent 5, he conveyed a concern about the well-being of the deaf and PWD in general, demonstrating his advocative voice for the deaf to the researcher.

According to Parent 5, a form would need to be personally submitted to the social welfare department to request financial assistance. The requirement for the applicant to be physically present would mean that he would need to take a day off from work – losing a day's pay. He argued with emotions, stating that this requirement was unfair to expect of the PWD, especially if they had gotten all their documents in order and previous records in the system. He voiced out:

> But to me, they (PWD) are working. If they come to attend to this matter, their one-day pay will be deducted, and certain factories do not like it. The staff of the Social Welfare Department replied to me, "They want RM400 or lose a day's pay?" That was the answer that I got. I think that is unfair. If they've got a salary slip and it is properly signed, why must the person be there physically? They are already earning less, so maybe they will have to take one or half days of leave. But it's one day's wages. Don't you think that it is unfair? The social welfare officer could just check with the company if this person is working for them. It is that simple. They are already earning less than RM1,200 a month, and you are asking them to take half or one day off. That is unfair (*emotional*)... (Parent 5).

It seemed that this advocative attitude and emotions came from a place of empathizing the hardships and disadvantages the deaf person has in life. As his son was deaf, he took these matters to heart, not only advocating for his deaf son but also on behalf of the other PWDs.

4.5.3.3. Summary. While parents felt it was their role to be providers for the child's needs and development for survival (e.g., independent living, education, career, and social life), their decisions were made based on availability of personal and government's resources. Most of the parents' struggles were related to the lack of knowledge and resources. The lack of resources and struggles of parents were explored and its results reported in Section 3.5.

4.5.4 Discussion

Although parents were not explicitly asked what they thought of deafness, the researcher deduced their view of deafness from their response to the child's diagnosis, their perception of 'normal', and the parental role they played in parenting their deaf child. Parents seem to view deafness from both the medical and social model of disability, which is a good balance according to the International Classification of Funding, Disability and Health (ICF) of WHO (2023). Table 4.4 below presents an overview of how the themes from parents' interviews relate to the medical and social model of disability.

The medical model views deafness as a pathology or physical deficit. When parent views hearing loss as a physical abnormality, it is understandable why they grieve over their child's disability. Parent participants, particularly the mothers (Parents 1, 2, and 3) and wives of Parents 5 and 6, expressed grief when they received the news of the child's hearing loss. They grieved for their own personal loss and empathised with the child's loss. Wives of Parents 5 and 6 seem to be in denial and ignorant of the true situation or are still grieving and do not know how to relate to their deaf child. Parent 2 tried hard to medically treat her deaf daughter's deafness by trying Chinese medicine, acupuncture, faith healing, hearing aids, cochlear implants, and speech therapy. She viewed the ability to speak as being "normal", indicating that her view of deafness was a medical condition that needed to be fixed. All the other parents also sought medical interventions such as hearing aids for their deaf children.

Table 4.4

Comparing the Themes with the Medical and Social Model

	Medical model	Social model
View of deafness	Hearing loss as a medical deficit	Deafness become disability when social barriers are not removed.
Focus	Restore hearing	Remove social barriers to provide full accessibility.
Parent's response	Grief - Personal loss - Empathize with child's loss Denial - Ignorance - Still grieving	Rationalize - Accept life's circumstances - View positively
Perception of 'normal'	To speak	To achieve independence Unique Physically regular
Parental role		Provider - Exposure for learning - Opportunities for career - Connections for social needs Advocator - Needs of child - Quality education - Well-being

However, when medical interventions fail to restore hearing, parents change their views on deafness to the social model. This can be seen by Parents 2 and 5 rationalising by accepting life's circumstances and viewing their deaf child positively. Parents then played the role of providers to break down social barriers to ensure their child gets access to exposure for learning, opportunities for career, and connections for social needs. Parent 5 even advocated for his and other deaf children's needs, quality education, and well-being. Parents' perception of "normal" also changed to viewing their deaf child as being able to achieve independence, as physically regular as everyone else, and as unique as they are. These subthemes were indicators of the change in parents' view of deafness from the medical model to the social model.

Bronfenbrenner's ecological system theory states that the microsystem consists of people in direct contact with the deaf child (Bronfenbrenner, 2005). In this case, it is the parents who shape the deaf child's view of themselves—their own identity. Parents' view on deafness, whether medical or social, influenced their responses and their roles in bringing up their deaf children. The family life that the deaf child experiences becomes a part of one's identity (McIlroy & Storbeck, 2011).

Research question 2 revealed parents' experience in parenting their deaf child. How did the social system then help the parents raise their deaf children, and how did it indirectly affect the deaf child? These questions will be explored and answered in Research Question 3.

4.6 Research Question 3: Support by Government

The third research question explored the suggestions of both hearing parents and deaf participants for improvement in existing support systems for the deaf community. From participants' responses, one main theme emerged: the need for continuous support in five areas: (1) parents' awareness, (2) deaf-friendly communication, (3) financial independence, (4) essential education, and (5) better implementation. Figure 4.12 below displays the themes of the need for continuous support.

Figure 4.12

Themes of the Need for Continuous Support

The six pairs of parent-child participants had varied responses to suggestions for improvement for the social support system. Nonetheless, the themes that emerged from the data reveal the need for ongoing support for the deaf community. These needs include "awareness of needs", "deaf-friendly communications”, “financial independence”, “essential education”, and “better implementations”.

4.6.1 Awareness of Needs

The researcher was surprised that most of the participants, both deaf adult child and hearing parents, did not have any feedback on the support system. This theme of *awareness of needs* was given as participants were either *satisfied with support, and clueless of needs.* They seem to indicate there were needs to be addressed but they were unaware of them.

4.6.1.1 Satisfied with Support. The researcher expected parents and deaf children to know what needs were lacking as they faced parenting challenges bringing up a deaf child. To the researcher’s surprise, three of the six parents did not give any suggestions or indicate any “complaints” about what help or resources they lacked in their parenting journey. They seemed satisfied and thankful for whatever help they had received. They were not demanding nor expecting more than what they had received.

Parent 1 was the youngest mother and the youngest deaf participant in this study. From the interview with her, she stated that she had received the help she needed. From the day her child was suspected to have hearing loss until today, she has received various help. The hospital helped her with the medical issue of hearing loss. She was provided with contacts to the special needs preschool, where the teachers and fellow parents with special needs were supportive and helpful. There were sign language classes and social activities in YMCA during her daughter's childhood. In terms of education, her daughter had primary and secondary education, and now, she has a polytechnic education awarded by a special school catered for deaf students.

The only need she mentioned were personal ones – finances for hearing aids, time, and energy to spend more time teaching her daughter to speak and hear. However, whatever was lacking, she easily found a substitute – personal additional tuition classes and other exposure for learning, thus reducing expectations for her to speak. She adapted to the situation well. When asked for suggestions for improvement, she did not have anything to say. This gave the researcher the impression that she was satisfied with the help that she had received throughout this journey.

Parent 2 also did not comment or respond to giving suggestions as to what was lacking or needed in her journey of parenting a deaf child. Although she did indicate the challenges of obtaining needed services (e.g., speech therapy, cochlear implant surgery), she did not complain or suggest that these services should be provided in Ipoh. She did have good support from her doctor, financial help from the government, knowledge about the education choices for her child, and help from her neighbours. She stated how supported she felt:

> At the hospital, the doctor was so good to her (deaf daughter) and me. So, everything was convenient for me. They knew that I was a government servant, so they arranged suitable appointments for me because I was working. (Parent 2)

Although there were some inconveniences in obtaining affordable services in KL city, she was thankful for the help she had received and did not demand more. She did not give any suggestions on how to improve the support system. However, the researcher went through the list of help and services that she mentioned in the interview (e.g., support groups and sign language classes) to ask for her opinion. She merely stated what was available and did not indicate a strong need to improve or insist on having such services. For example, this was her opinion and what she stated about social support groups for deaf children and hearing parents:

> I think you have to mix with deaf children. And once a month, mix with the parents. For example, I have a group in KL, the cochlear implant group. Every month, mothers will gather and share their experiences. It was very good. (They shared about) how to take care of children, everything. I can learn. But it was in KL, so far. (Parent 2)

She did not demand this service that was non-existent in Ipoh at that time. She accepted this lack of resource and made do without. Overall, she seemed to be satisfied with the services, help, and support she had received and did not demand or expect more. Hence, there were no suggestions given when asked.

Parent 4, too, seemed satisfied with the help received from the government. There was financial support from the government. There were teachers and other parents who helped with the transportation for the child's speech therapy. He was of the perception that his deaf daughter was 'normal' like a regular hearing person and did not have any special needs. So, it was not surprising that he did not have any suggestions on how to improve the support system for the deaf community and was generally satisfied with all the help given.

The response of Deaf Participant 1 was similar. She had no comments – no complaints, no suggestions for improvement. This gave the researcher the impression that there were no immediate needs unmet, and hence, she was contented. Perhaps Deaf Participant 1 did not know what to suggest because she was content with her current life situation. Throughout the interview with her, she responded more to topics related to her immediate situations – friendship, fun, and communication. When asked about matters that relate beyond herself, such as suggestions for improvement in the support system for her deaf community, she did not know what to say. She was contented with her immediate context, which did not require her to think further about what improvement was needed. Hence, she did not have suggestions to help the deaf community.

4.6.1.2 Clueless of Needs. Like hearing parents, the other deaf participants (Deaf Participants 1, 3, and 5) did not have much to say when asked for recommended improvements to the social support system. The three hearing parents were generally satisfied with the support and help they received, while the three Deaf participants seemed to express that they did not know what support or services would be helpful for the deaf community.

Deaf Participant 5 was very honest in his response to the question. His response “I have no idea. I don’t know how to help develop the deaf community”. When probed further for his opinion about the current situation of the deaf community, he said that he did not think there were any problems, though he agreed that the deaf community needed support and help. He did not know how the hearing community could help the deaf community. He thought that whatever the government was doing to help was sufficient. He had no suggestions on how to improve social support.

From his response, he knew that the deaf community would need some support but could not pinpoint what was needed. Perhaps his response was as such because he had a very active father who fought and advocated for the needs of the deaf community. Deaf Participant 5 did not experience the need it had been provided for. So, he did not need to think deeply about the matter – needs and solutions. Hence, this may be the reason why he might not have any suggestions to improve the support system of the deaf community.

Deaf Participant 3 was not involved in the deaf community and hence did not know or had anything to suggest for improvement. She had been isolated from the deaf community since she finished school. Perhaps because she was isolated at home, she had learnt to live with whatever situation she was in -

accepting, not questioning, not demanding. Hence, she had no idea what to suggest to improve the support system for deaf people.

4.6.1.3 Discussion. Participants' responses to the enquiry for feedback in the support system showed that parents and deaf adult children had a low awareness of needs. They were satisfied with whatever help they received or had no idea what was needed for the development of the deaf. They depended on the government's provision. The government and Social Welfare Department provided support according to the medical-welfare model. Below is a list of support and assistance provided by the government, with parent's awareness of them.

Referring to Table 4.5 below, all parent participants were aware of the medical interventions that the government provided. Doctors recommended cochlear implants or hearing aids. The Social Welfare Department also provided some financial aid for this medical intervention (Deaf Participant 2). These actions of support by the government indicated an emphasis on restoring hearing abilities, which also reflected the beliefs and perceptions about deafness. It may seem that hearing disabilities were regarded only as a medical issue that needs restoration – a medical model of deafness.

Table 4.5

Parents' Awareness of Support Provided by the Government

Support system by Social Welfare Department		P1	P2	P3	P4	P5	P6
Financial assistance	Allowance for salary	√	√	√	√	√	√
	Business initiative grant						
	Transportation					√	
	Education	√	√	√	√	√	√
Medical	General treatment	√	√	√	√	√	√
	Hearing aids/ Cochlear implant	√	√		√	√	√
Education	Special/ integrated / inclusive education	√	√	√	√	√	√
Employment	Employment opportunity policy					√	
	PWD placement system					√	
	Code of practice to hire PWD in private sector					√	
	Business initiative assistant skim						
Social	Community-based rehabilitation program (one stop center, PDKnet)						
	Vocational training						
	Training / Counselling services						

Note: √ indicates awareness of the support given by the government.

To further investigate if the intervention for a child with hearing disabilities is confined to the medical model only, the researcher attended a seminar about special needs for children with disabilities held in one of the Ipoh hospitals in 2019. The main advice given by a specialist to a child with a hearing disability was to restore hearing and speech through medical devices (e.g., cochlear implants or hearing aids) and follow-up speech therapies.
When asked about interventions for children with hearing disabilities in the special needs centres, the answer given was that they were normal and only needed to learn sign language.

However, the specialist could not give the researcher a reference to where or how to learn sign language in Ipoh. This showed that there was a lack of other development interventions for children with hearing disabilities in Ipoh. It also reflected on the values the support system had about deafness – which is only the medical model perspective focused on restoring hearing and speech. There were no other alternatives for those who struggled and failed to restore hearing abilities. There was little consideration for those who fell into the cracks of not being able to restore hearing and speech. And there was a lack of resources to develop an alternative communication system, which is detrimental to the deaf child's language development.

The scenario described above is a preview of the current situation in Ipoh, where generally, Ipoh has remained and functioned only in the medical model of disability. Hence, there were few interventions other than medically related. Although Malaysia has a shift of philosophical paradigms, its implication and transition from the medical and welfare model to the social model has been slow (Lee & Low, 2014).

Nonetheless, there are a few concerns about providing interventions for deaf children from the medical model alone – (1) if parents cannot afford financially for these medical interventions, (2) the detrimental outcome of language acquisition and developmental delay, (3) having no alternative communication modes when hearing restoration fails. Hence, it is advisable to continue to develop other alternative interventions for the deaf child's development. For example, sign language should be introduced for the benefit of the deaf child's communication and language development, which are needed for learning and social connections.

4.6.2 Deaf-friendly Communications

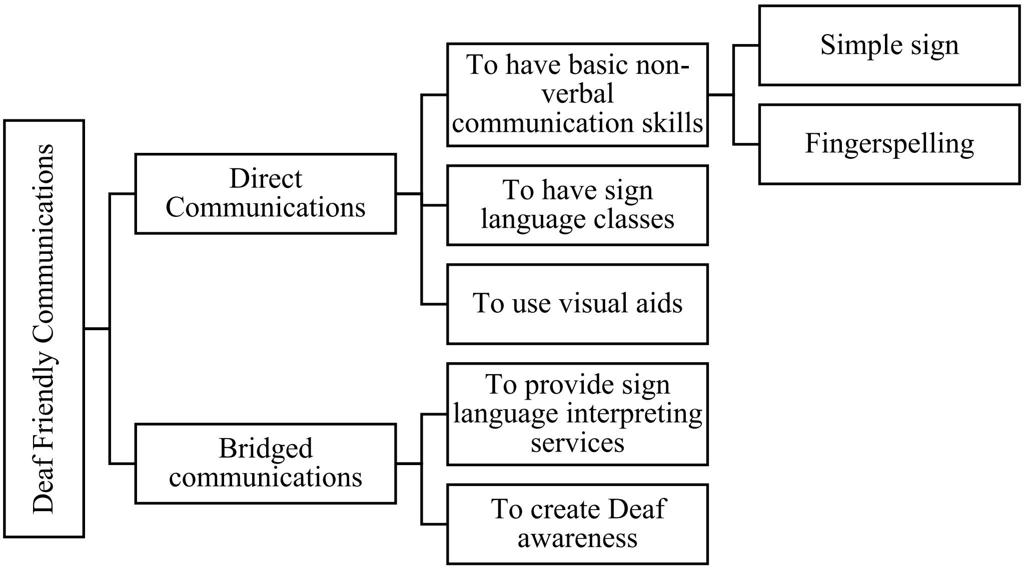
The other theme that emerged from the data was the need for deaf-friendly communications in society. This would be especially helpful if Malaysia were to move toward the social model of inclusivity. Among all the participants, Deaf Participants 2 and 4 expressed the most concerns about communication between the deaf and hearing community. This was not surprising as Deaf Participants 2 and 4 had more negative experiences in the hearing community;

as expressed by them in their narratives, they were expected to function and perform like regular hearing peers without any special communication support. (e.g., to follow hearing conversations without any cues). This feedback was similar to previous local research – the challenges being in a hearing environment (Khairuddin et al., 2018).

Deaf Participants 2 and 4 provided practical suggestions on overcoming communication challenges between the deaf person and the hearing community. A hearing father (Parent 5), who was also concerned about having good communication with his deaf son, also shared about the lack of resources for communication with deaf people. From the data, there were two subthemes that emerged – *direct communication* and *bridged community.* Figure 4.13 shows the codes of these two subthemes.

Figure 4.13

Subthemes of Deaf-Friendly Communications



4.6.2.1 Direct Communications. Deaf participants understood their limitations in communicating through speech and hearing. They know that they would not be able to keep up with spoken conversations without hearing but want to be included. To reduce this "dinner table syndrome" (Meek, 2020), deaf participants suggested direct communication through using basic non-verbal communication and visual aids.

It was interesting to observe that this group of deaf participants had only a little expectation for the hearing community to connect to them through non-verbal communication. They merely hoped that hearing people could learn some basic simple signs and the alphabet in sign language (also known as fingerspelling) for communication. They did not expect the hearing community to pick up the sign language fully or to master it, though that would certainly be a great help to them. They wanted direct communication and were willing to mellow- own their expectations to have such personal connections.

Deaf participants expressed a need for hearing people learn simple signs for direct connection and communication with them. Deaf Participant 2 encouraged the hearing people to attempt to learn simple signs so they could communicate. She shared her hope to connect:

> Hearing people see me sign but don't understand. They can help the deaf by learning simple signs. We can't hear, so sometimes, pointing will help. Yes, that's the one thing that I want the hearing people to learn so that we can communicate directly. (Deaf Participant 2)

Deaf Participant 2 shared that she would be contented if hearing people would attempt to learn the alphabet in sign language. Signing each letter of a word is called 'fingerspelling'. Fingerspelling would be a good starting point for developing further communication with deaf people. She stated:

> People can learn sign language (to communicate with us) so we can help each other. If you don't know how to sign, you can fingerspell (Deaf Participant 2)

Deaf Participant 4 was also of the same opinion and hoped that hearing people could just start learning the alphabet in sign language. She further made a comparison to other countries that embrace sign language and wondered why learning sign language was not treated as important as learning any language. She also made a comparison with the compulsory learning of the written Arabic language *Jawi* implemented in Malaysian schools for all races. She stated:

> In America, a lot of people learn Sign Language. But Malaysia, we don’t have that. Is that because we are poor? In America, people who are hearing can sign. But in Malaysia, not so. Why not just the basics like ABC? Not expecting the difficult ones. Just one simple sign. Everyone can learn ABC. Why not? Since now, it has been compulsory for everyone to learn *Jawi*. Why not do so for the sake of the deaf? Basic sign for everyone. So, at least, we can have basic communication. It is helpful for everyone to be able to communicate a tiny little bit, even if it is just ABC. (Deaf Participant 4)

A few years after data collection of this research, it was reported in the news that sign language will be introduced as a third language to the Perpaduan kindergartens in 2022, under the Perpaduan Kindergarten Early Childhood Education Plan 2021-2030. This implementation would reach 1,781 kindergartens and involve 38,000 students nationwide (Bernama Newspaper, 2021).

From various interactions with hearing people, the researcher received the impression that hearing people are overwhelmed with learning the full sign language – that it is too difficult. However, these two deaf participants voiced out a very simple proposal of just being willing to learn simple signs and the alphabet in sign language. They can continue to slowly pick up the rest of the language a step at a time without feeling overwhelmed. At the bare minimum, some form of face-to-face (not paper-to-paper) connection is made through simple signs and fingerspelling. This proposal seems reasonable for hearing people to pick up.

The deaf participants in this study revealed that they had little expectation of the hearing community to learn sign language for direct communication. They did not distinguish between the types of communications in which they wanted to be included. Was it for casual conversations or important communications such as an appointment with the doctor? If it is for casual socialising and connection purposes, this proposal for simple signing is reasonable. However, if it is for serious communication in decision-making, this proposal is insufficient to meet the needs of the deaf person. The deaf participants may seem to be unaware of the need for access to quality communications through sign language interpreters.

Nonetheless, in the global human rights movement for deaf people, the rights of sign language, its accessibility, and equal participation are some areas that the World Federation of the Deaf (WFD) are promoting. Equal participation includes "having equal access to participation in the personal, public, and political area as everybody else" (World Federation of the Deaf, 2023). If communications are related to important matters such as medical and legal, the right for equal access to information through a sign language interpreter is important for the deaf to make his/her own independent, informed decisions. However, this awareness is low in Ipoh (and Malaysia as a whole) among the hearing and the deaf community. There is not only a lack of sign language interpreters but also a lack of resources to learn sign language in Ipoh. Parent 5 of this study gives some context to the situation in Malaysia below.

While deaf participants hoped for simple direct communications for connections, a hearing father (Parent 5) also had the same intentions to connect. He went a step further and wanted to equip himself with proper sign language skills so that he could have good communication with his deaf son. He shared about his search for sign language classes in Ipoh and expressed the lack of this important resource for establishing communication with deaf persons.

Parent 5 was the eldest parent, and his deaf son was the eldest deaf participant among the other participants of this study. In the earlier days, he searched for sign language classes, and this is what he concluded from his search:

> When my son was young, in Ipoh, the only place you could learn sign language was in the YMCA. I went to the social department to ask if there were any other place that teaches deaf kids to sign or speak. They said 'no'. I was referred to Yayasan. So, I went there and met a lady. She told me, "Oh. We are not teaching any signs. We only do it for Down syndrome and cleft lips children, but not for the deaf". (Parent 5)

Sign language classes were not offered, and the "sign" used for communication was catered for the other special needs kids with various developmental disabilities. There were no classes offered for the proper learning of sign language. During his deaf son's primary school years, he found a school teacher to teach sign language and initiated gathering the deaf children and hearing parents to learn together. Many years later, when his deaf son (Deaf Participant 5) graduated from school, started work, got married and is now the father of a hearing child. Parent 5, who is now a grandfather, started his search to find sign language classes for his hearing grandchild, hoping that she could communicate well with her deaf parents. This is the conclusion of his search for sign language classes in 2019:

> Someone asked me if I knew anyone who could sign. I went to the YMCA and learnt that it (deaf club) had closed down many years ago. I'm thinking about my grandchild; I hope she can sign a bit with her parents so that they can have simple connections. I am still looking. It so happens that I can meet people like you (the researcher) who can sign. (Parent 5)

He has combed through the resources he knew and found "nothing whatsoever" as quote by Parent 5. He received the researcher's contact through YMCA and requested the researcher to conduct sign language classes for his grandchild in the near future. This is how scarce sign language classes are in Ipoh.

Other than simple signs, deaf participants suggested that the hearing community can use visual aids in communication if one has trouble with learning and using sign language or fingerspelling. Deaf Participant 4 suggested making the environment deaf-friendly by having pictures and written words on restaurant menus for easier communication. She shared a background story on why she suggested this:

> For example, when you go to the different stalls to eat, everything is in Chinese. I am scared. You may not be, but I am. I will not go to the Chinese stalls that use Chinese only; I will go to the cafes that have pictures and menus with English or Malay words. Because I cannot speak or communicate. I feel scared because of the Chinese words; I don't know

> how to order or say what I want. There was an experience; I used my voice. Everyone looked at me. It was very embarrassing because everyone turned around to look at me at how I spoke. I was embarrassed. It's the same experience with my other deaf friends. We don't want to go to the other stalls, we just go to the cafes, because it is easier to look at the menu and point. (Deaf Participant 4)

Deaf Participant 4 was ashamed to order verbally despite being able to speak some Cantonese (Chinese dialect). She would rather choose a more expensive place to eat than order from the hawker stalls that do not have menus. Hers was not an isolated case. The researcher observed this trend in the other Ipoh deaf persons. When asked a key actor in the deaf community, it was also confirmed as such. Using visual aids like pictures would make communication more deaf-friendly when there is a verbal communication barrier.

4.6.2.2 Bridged Communications. When direct communication with the deaf person was not available, the next best way to bridge communication was through a sign language interpreter. Deaf Participant 4 was the only one who strongly voiced this need. The other deaf participants did not express this need. Perhaps this is because they have family members to help them when interpretation is needed, while Deaf Participant 4 was living a very independent life and had elderly parents who depended on her. Hence, there was a greater need to interact with the hearing community But she experienced all sorts of communication breakdowns. She expressed the need for bridged communications as there was a lack of sign language interpreters and deaf awareness. She wanted equal access to information. Deaf Participant 4 shared her need for bridged communications, which can be achieved through a sign language interpreter. She expressed this need for interpreters in Malaysia:

> If you could have an interpreter or someone who knows Malay, they can help with the interpretation. Because, sometimes, it is difficult without an interpreter. (Deaf Participant 4)

Knowing that there is a lack of sign language interpreters in the country, she did not expect a face-to-face interpreting service but rather a remote sign language interpreting service through the phone. Below are extracts of her interview that reveled her hope for interpreting services:

> I hope people can interpret for us. Only to interpret. So, if there’s a call, I can’t speak. So, I can pass it to the interpreter, and the interpreter can help to communicate on our behalf. So, the deaf also knows what the phone call is about. (Deaf Participant 4)

> If we are at the doctor’s and there is a communication problem. Can we just use a video call interpreter on the spot? Maybe that is a new suggestion. (Deaf Participant 4)

She understood that there were few sign language interpreters available and gave a new suggestion of having a sign language interpreting service through live video calls. As of May 2023, there are no organised interpreting services available for the deaf community. However, there is one on-going project by Monash University that uses a phone application to request remote medical interpreting services (Monash University, 2023; Ragu, 2023).

The lack of sign language interpreters was clearly pointed out by Deaf Participant 4, who needed it for independent living. The lack of interpreting services was also reflected in the narration of Parent 5. He was actively looking for sign language classes but found himself being called to help with sign language interpretation. He only had basic communication skills with the deaf, yet the organizations he sought out for sign language classes, turned to him for help to interpret for police cases. He shared this experience:

> It so happened… the deaf lost his handphone. We went to police station to make a statement. They called Yayasan. Yayasan called me. I knew a bit of sign; So, I could help do a statement. But if this goes to court, I will surely lose because I am not qualified. Never mind. I just helped them with a statement. That's why I was to plicate station a lot of times. (Parent 5)

He had limited signing and interpreting abilities, yet he was sought after to help with making a police report. This showed a lack of available sign language interpreters in Ipoh. One may argue that this was the situation a decade ago, However, the situation persists until today. There were three hearing families in Ipoh who were looking for a sign language interpreter for official matters. They eventually found a sign language interpreter in the church. According to the interpreter, two of the hearing families were referred to him through a church pastor. The other family found a deaf person on Facebook who gave a reference to the sign language interpreter. Apparently, these families could not find any other available interpreters in their search through the NGOs. Only after much searching did they manage to find a sign language interpreter through the church in Ipoh.

Was the church the only place in Ipoh that offered sign language interpretation services? Perhaps there are other sign language interpreters around but they are not known. There is no compiled list or organization of sign language interpreters in Ipoh. It is likely that there are very few sign language interpreters in Ipoh. If any, they are likely to be layman who can communicate with deaf people but are not professionally trained. According to *Malaysiakini,* it was reported there are about 100 interpreters for a population of 32,000 deaf people in Malaysia (Lau, 2017). Increasing the number and quality of sign language interpreters is one strategy to move towards the social model of disability - providing equal accessibility and opportunities by breaking down social barriers.

The other strategy to work towards the social model of inclusion is to increase deaf awareness. This was one point that Deaf Participant 4 emphasized in her narrative. She had negative experiences being treated as a PWD and expressed this communication dilemma:

> My husband and I went to the hospital because I had some sickness, and I wanted to communicate deeper with the doctor. My husband was outside the doctor's office waiting for me. The doctor met with me and talked a bit. However, our communication difficulty was this: I wanted to write to the doctor to communicate with me, but the doctor didn't want to communicate with me this way. He asked me who is the person outside with you. I replied, "My husband." Is he hearing or deaf? I said, "Hearing." When the doctor asked me to call him, I felt hurt. So, I called my husband. The doctor talked to my husband, not me. What if my husband was working and I am the only one here? How? What if

> everyone is busy and I am the only here and you don't want to communicate with me? One challenge is to get an interpreter. The doctor didn't know how to communicate with me, which I wanted to write. The doctor called my husband and ended up talking to him instead, which make me felt hurtful. (Deaf Participant 4)

As much as Deaf Participant 4 wanted direct communication with the doctor, the doctor was not confident in communicating with a deaf person. Perhaps the doctor was not confident that important messages would get through, or he did not have the time or patience to communicate through writing or the doctor was not aware how a deaf person is capable to communicate independently through other means than writing. It was certainly easier for the doctor to communicate through a hearing person (e.g., hearing husband) to get the message across, though this made the deaf person feel overlooked and treated less as a PWD.

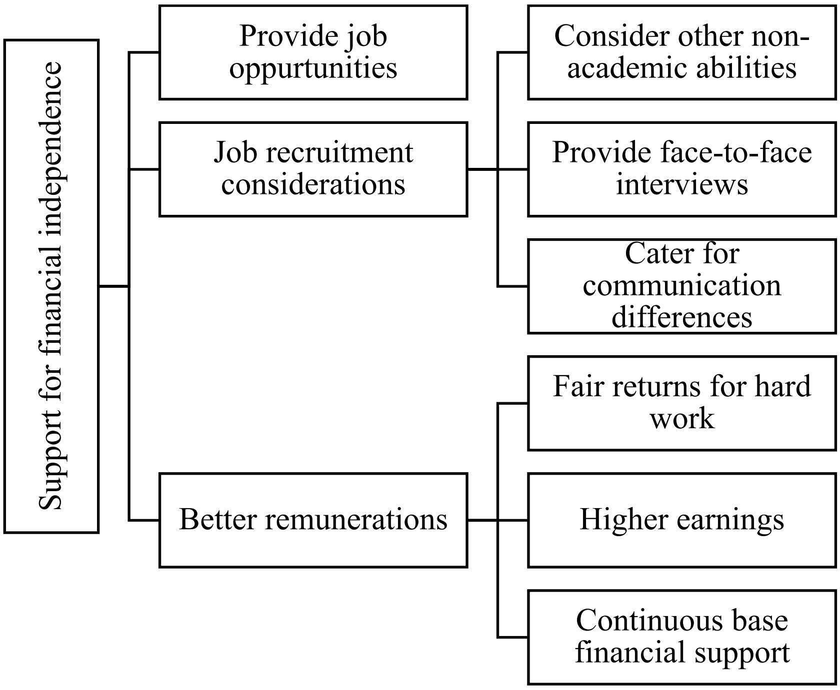
When no hearing person is able to play this interpreting role, the deaf person often is left helpless. It is not because she cannot communicate, but because of the doctor's lack of awareness of a deaf person's ability to communicate independently through other means like writing. Having said that, it is unfair to assume all deaf people are just as capable and independent as Deaf Participant 4. This might also be another reason why the doctor would talk to a hearing person rather than to a deaf patient. He might have had other experiences that caused him to behave that way. Nonetheless, there was a lack of awareness on how to communicate with deaf people.

4.6.3 Support for financial independence

The other expressed need for the development of the deaf community is to receive support for financial independence. Among all the deaf participants, only Deaf Participant 4 strived for better job opportunities and career advancement. She had to independently earn a living to take care of herself and provide for her ageing parents. Hence, there was more pressure to look for better jobs. In striving for better opportunities, she faced challenges obtaining job opportunities as a deaf person. The other deaf participants were either content with their current job (Deaf Participants 2 and 5) or being provided for by family (Deaf Participants 1, 3 and 6). In the interviews, Parents 3 and 5 expressed their concerns about the job opportunities for their deaf adult child. The interviews revealed subthemes – *providence of job opportunities, considerations in the job recruitment process, and better remunerations.* View Figure 4.14 for the details.

Figure 4.14

Subthemes of Support for Financial Independence



4.6.3.1. Providence of Job Opportunities. Parent 5 expressed a lack of job opportunities for PWD, even though the government's policies apportioned 1% of government job positions for PWD. He shared:

> 1% of government staff must be OKU. I went to the labor department a few years back to ask if there were any vacancies. There was none. My son registered, but no one called. Why didn't they call back to tell us that there was a vacancy? At least, give them a chance to be interviewed. And if they failed to get the job, it's okay. At least they tried and was given a chance to go for the interview. Since my son was 18 and until now (39 years old), he did not receive a single call from the labor office in Ipoh. There's no point registering. They are not doing their job. Until today, no government department has that 1% of the PWD workforce. It can be very simple - Let them be an office boy. At least, they have a job. They may not be very educated, but at least give them a job – photocopy, sweeper, etc.… just create a job for them. (Parent 5)

He strongly felt that job opportunities should be created or made available for PWD as this is consistent with the government's policies. It did not matter what type of job was offered, but rather, it was the providence of an opportunity to get a job, as expressed by Parent 5. The researcher cross-checked Parent 5's expectation of the government and found that his frustrations were valid. The Malaysian government has the One Percent Employment in Civil Service for Persons with Disabilities Policy (PP16/2010), whereby every agency was required to employ at least 1% of PWD, be it full-time, part-time, or contacted employment. The PWD may apply for a job through the online employment system, or through approved application methods set by the commission.

Deaf Participant 5 applied for the job and waited for a long time without any response until today. Parent 5 viewed this as a flaw in execution of the policy and was frustrated about it. He felt that the government was not doing what they ought to. Parent 5 was not the only one with such thoughts. A local Malaysian study reported that 56.7% (*n*=271) of PWD participants felt the government measures to help them get proper jobs were not enough. Some reasons for this dissatisfaction include the insufficient job opportunities for PWD in the job market (36%), discrimination during job applications (13.2%) (Tiun et al., 2013). A decade later, these concerns remained the same.

According to the One Percent Employment in Civil Service for Persons with Disabilities Policy (PP16/2010), the commission is responsible to consider these steps in the employment procedures: (1) to include an option to state the disability status, (2) to only impose minimal requirements according to the service scheme, (3) to ensure that the social welfare officers are one of the interview panels that is appointed, and (4) to implement reasonable adjustments in recruitment especially in the interview screening for the PWDs (Kerajaan Malaysia, 2010). From the experience of Parent 5, his son did not have a chance to be interviewed. There seem to be a problem in translating the policy into action.

Having said this, the issue of employment for the PWDs was highlighted in the media, especially during the COVID-19 pandemic crisis. In 2021, Senator Datuk Ras Adiba Radzi brought to light the need for the government and corporate sector to provide employment opportunities for PWDs to help them out of poverty. She attributed the issue of few employment opportunities for the PWD to the lack of awareness of the needs of the disabled, knowledge of how to support them, and opportunities given to them (Bernama, 2021). Other efforts, such as the provision of quota for PWDs, the Malaysian Short-Term Employment (MyStep) program under Budget 2022 was finally tabled in Dewan Rakyat at the end of October 2022. This is the focus to provide more job opportunities for those unemployed in 2023 (Harizah Kamel, 2021). Generally, the implementation of the policy and proper action has been slow.

4.6.3.2 Considerations in the Job Recruitment Process. Parent 5 pointed out the issue with government providing job opportunities. Deaf

Participant 4 tried her chance to get a job in the government sector and provided insights on the obstacles to deaf people securing job opportunities. According to her narrative, there was some discrimination in the recruitment process. She suggested employers consider the deaf person's other non-academic abilities, provide face-to-face interviews, and cater to communication differences in the recruitment process.

Deaf Participant 4 pointed out how deaf people were easily discriminated against for job opportunities because of their poor academic performances. She voiced a hope for employers to consider the needs of deaf people in their recruitment process. It is not uncommon for the recruitment process to use academic performance as one of the criteria for screening. Even though the majority of PWDs do not have a high level of education and trained skills they believe they would be able to perform tasks if given the opportunity (Tiun et al., 2013). Deaf Participant 4 felt discriminated against because she was not good at writing and could not meet the minimum academic requirement for the job. She expressed her disappointment in her failure to obtain a government job:

> I want to get a job in the government sector, but it is difficult to get an offer because of my grades. I searched for jobs in the government's section through their online applications. Their requirement is Grade C for the test (SPM), but I didn't get the grade that they wanted. I didn't do very well. It was difficult for them to consider me for the job because the criteria they required of me were my academic results. (Deaf Participant 4)

She also reasoned that it was not a viable option for her to re-sit examinations to obtain better grades at this age (mid-30s). It was as if past academic failure was a ‘death sentence’ in all her further career development. She did not have the energy and time to ‘correct that mistake’. According to the One Percent Employment in Civil Service for Persons with Disabilities Policy (PP16/2010), the government was supposed to impose only minimal requirements according to the service scheme. What government job did she want, and was she aware of the minimal requirement for the job? Deaf Participant 4 did not want to elaborate but pointed out that other skills should be considered in the job recruitment process.

Deaf Participant 4 gave another point about missing job opportunities because the online system had already discriminated against individuals based on their academic performance. Hence, there was no opportunity to appear physically in the interview to showcase their ability. She expressed the need for opportunities for a face-to-face interview:

> I was thinking of applying for jobs online. But I’ll be dismissed almost immediately because I did not meet the minimum required academic grade. I think that it is better that they meet the person for the interview straight away rather than an online application to screen through results as the first filter. (Deaf Participant 4)

The other obstacle for the deaf person in obtaining job opportunities is the challenge of communicating with the potential employer. Deaf Participant 4 shared her concern about missed job opportunities because of communication breakdowns:

> The deaf may be smart and good with their hands, but communicating is difficult. Writing is a struggle for many deaf people. In the interviews, the boss usually says, “No, I’m sorry. You are good at drawing and art, but it is difficult to communicate with you”. (Deaf Participant 4)

In conclusion, due to communication issues, deaf people are rejected for the job position at the initial interview. Potential employers may not be ready to cater for communication issues with deaf people.

4.6.3.3 Better Remunerations. Regarding earnings, Parent 3 expressed her concerns about how hard her deaf daughter worked and the payment she got. She hoped there would be a fair return for the hard work done or at least to receive higher pay for financial sustainability. She stated:

> Society should help them find a job so they can get equal pay. The pay is very low for them. She worked in the bakery in the past. She would get up at 5 am to prepare for work, wait till the shop opens, skip lunch and work to about 5 - 6 pm. And the salary was very low. So, you feel that there should be better paid job opportunities so that they can independently survive. (Parent 3)

Parent 3 expressed that wages should be higher for her deaf daughter so that she can be financially independent. She stated her daughter’s case:

> To help her to be independent, she needs a good salary. The pay is really low. She is only getting RM 750 per month for a 6 week of work. It was in Ipoh at that time (about ten years ago). The salary is a bit higher in KL.

> The government does give an additional RM 300 in financial support, but that isn’t sufficient for financial stability. (Parent 3)

Although it was said that RM750 was the amount one earned a decade ago in Ipoh, the salary rate is a little higher today. Most of them earned less than RM1200 per month, and they received financial support (allowance) from the government. The government encourages people with disabilities (PWD) to work and live independently. Hence, the Social Welfare Department provided an allowance of RM 350 a month for PWDs whose monthly salaries are below RM 1200, aged sixteen and above, and who are not staying in an institution that provides free food, clothing, and accommodation (Jabatan Pembangunan Orang Kurang Upaya [JPOKU], 2018). In 2021, the maximum salary limit for disabled workers allowance increased to RM1,500 (The Sun Newspaper, 2021), with the disabled workers’ monthly allowance of RM450 (Jabatan Kabajikan Masyarakat, 2023).

Another suggestion regarding getting better remunerations for the deaf worker is to receive a continuous financial support base. Parent 5 proposed that the continued received amount of RM350 (increased to RM450 in 2021) disabled worker’s allowance regardless of how much the PWD earn. He reasoned that it would be unfair to remove the RM350 of financial support, if the deaf person received a salary higher than RM1,200 (increased to RM1,500 in 2021) for the hard work they put in. Parent 5 stated, “Regardless of what they earn, as long as they are PWD, they are entitled to receive the financial support”.

He felt that having a limit on how much a deaf person earns to obtain allowances was unfair and that there should be a continuous financial support base for deaf people regardless of how much they earn. To him, the deaf have already been short-changed at the beginning of their career because of their hearing disability. The removal of financial support if one earns more than RM1200 demotivates a deaf person to work harder. In a way, it prevents the deaf person from wanting to advance in career. Parent 5 brought up a case in point:

> There is a lady working in Tasek; her starting pay was RM500, and now it's about RM1,000. The company wanted to promote her to supervisor, where her salary would increase to more than RM1,200. She declined. If the offer was taken, she would not get the RM400 of financial assistance from the government. If you do the math, if I earn RM 1,200 and get a RM 400 allowance, I would bring home RM1,600. Why do I want to be promoted to be a supervisor and earn a total of RM1,400, without the extra financial support of RM400? I will bring home less money if I accept the promotion. (Parent 5)

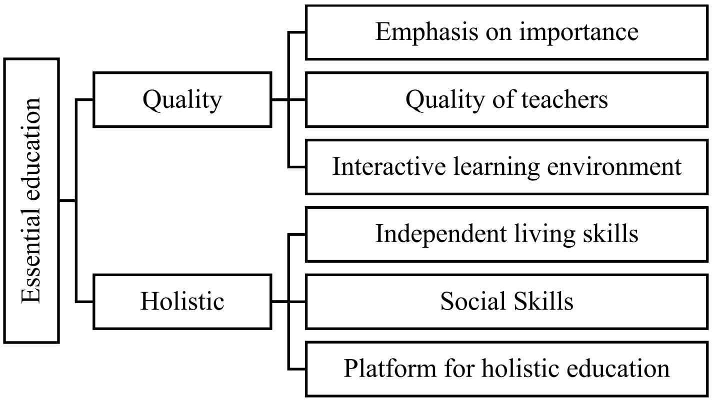
For this case, he rightly asked why a deaf person would want more responsibilities and stress for a non-significant increase of salary of RM 200 forfeiting allowance (RM1,200) when they could work less and earn just as much with allowance (RM1,400). Therefore, a suggestion to better remuneration for the deaf is to have a continuous base of financial support. However, the Social Welfare Department has stated clearly that the delivery of this assistance is based on eligibility and not on rights (Jabatan Kabajikan Masyarakat, 2023).

4.6.4 Essential Education

One of the other expressed needs for ongoing support is education. There were only three participants (Deaf Participant 4, Parent 5, and Parent 6) who highlighted the importance and needs of essential education for deaf children. Deaf participants of this study attended special schools for the Deaf (pre-school, primary, secondary, and polytechnic). The Majority of participants had no idea what else would be needed that was already given in the government education. However, three participants gave some feedback for improvement. The themes that emerged from the interviews are increased quality of academic and holistic education. Figure 4.15 displays the codes for each of the subtheme.

Figure 4.15

Subthemes of Essential Education



4.6.4.1 Quality of Education. There were no complaints from any of the parent participants except for Parent 5. Parents shared in the interviews that they did not know how to teach their deaf children and left it to the schools to do so. Parents 3 and 4 depended on the school fully for the child's learning. Parents 1, 2, 5, and 6 personally taught or provided other learning opportunities to enhance their deaf child's learning. Parents 1, 2 and 6 sent their deaf child for additional tuition classes. The parents have found ways to provide the necessary academic education for their deaf child. Hence, they did not have other suggestions of what else was needed in this aspect. However, Parents 5 and 6 made two points to increase the quality of education, emphasising the importance of education and the quality of teachers.

Throughout the interview, Parent 6 highlighted the importance of education. He placed a high priority on learning by sending his deaf son to many English tuition classes so that he could have a good command of English, especially in reading, writing and comprehension. He stated his point with an emphasis on education:

> The most important aspect is education. Everything depends on education. If they have a good education, they can do whatever they want. They would be able to write and read because of education. When they are good in language, they can see the whole world. (Parent 6)

His son went to a polytechnic school to study after secondary school, as "it is more for his exposure and for his learning", said Parent 6. After completing the diploma, Deaf Participant 6 did not want to work, so his father provided him with another opportunity to study for a bachelor's degree. Parent 6 had little expectation for his son to obtain a job through this diploma or degree qualification, but he emphasised learning and said, "To me, studying is to expose him to know something". All in all, Parent 6 expressed the importance of education in developing deaf persons' learning abilities to understand the world around them.

Parent 5, on the other hand, was very concerned about the quality of education his deaf son was receiving in the government special schools for the Deaf. He was very upset at the poor quality of teachers. He shared an incident he witnessed at school:

> When my son was in standard 6, instead of attending the Deaf school in Penang, he joined a few deaf classes in a school in Ipoh. It was a class for the deaf. One day, I went to check the class. The teacher was seated with two legs on the table while the kids were playing. I asked if I was in the wrong place and what they were doing. I was sarcastic because I was angry. My son goes there from 8 am to 3 pm, but the teacher didn't do anything. He had his two legs on the table while the kids ran around and

> played. The teacher knows sign language, but they are not teaching the deaf children. How can the deaf improve themself? They don't have… *(The parent was emotional at this point)* … good teachers. Let's not focus on my son. What about the other students? They are deaf; they may be very bright but are not given the opportunity to go further. How can they get a good job as electricians? They are looked down on by society. *(The parent was emotional as he said this)*. (Parent 5)

Parent 5 was emotional and held back tears when he conveyed this story. He was angry that his deaf son was deprived of a good education because the teacher was too lazy to teach. Parents of deaf children depend a lot on the government's special schools to teach their children because parents do not know how to teach their deaf children sign language. Deaf children also generally struggle with literacy. Research showed that deaf children are delayed in literacy development (e.g. development of grammar) even with early identification and appropriate interventions (Lederberg et al., 2013b). Hence, teachers need to give more attention to teaching deaf children. One proposed strategy is to use BIM as the main medium of instruction in school so that deaf students can learn better (Chong & Hussain, 2021).

Parent 5 was very upset and frustrated at the situation that he had little control over. He did not know how to teach his deaf son, and yet the teachers who were supposed to do their jobs took it so lightly. Poor education took away the skills the child needed to survive in society. Other parents and deaf participants did not complain about the quality of teachers. Perhaps, there was improvement over the years. Afterall, Deaf Participant 5 was the eldest among the other deaf participants.

Another suggestion to increase the quality of academic education is to have an interactive learning environment for deaf students. Deaf Participant 4 shared ideas on what would help the deaf student learn. She recommended tuition classes as they provided interactive learning and forced focused attention. This is her explanation:

> There is only so much you can pick up in class alone. But for tuition classes, it is a two-way interaction. You can learn more with two-way communication. It is good to go for tuition - some additional courses to help us focus, rather than staying at the hostel. You can ask questions; they test you. It is easier to learn with this two-way interaction. Teaching is just one way. We nod our heads and easily forget. (Deaf Participant 4)

It seems that deaf individuals have a hard time focusing. They lose attention to the one-way communication teaching method. Perhaps this is more so for deaf students. Once the deaf student looks away, information is missed out. Sight is the only channel for information input, but the long duration of one-way input can be tiring for them. They get bored and they lose focus. Perhaps there is a threshold of how long a deaf person can focus with their eyes. An interactive learning environment with questions asked while they respond would help them focus their attention.

4.6.4.2 Holistic Education. Participants did not explicitly suggest having holistic education as this need had been provided for through the YMCA Deaf Club. All the deaf participants, except Deaf Participant 3, had the opportunity to benefit from Deaf clubs like the YMCA during their childhood and youth.

YMCA Deaf Club provided holistic education that provided exposure for deaf children to develop in other areas outside the academic classroom. Exposure trips and activities helped the deaf children to develop socially, emotionally, spiritually, mentally, and physically. Although participants did not highlight this need nor gave suggestions to improve in this area, there were themes of how these events were beneficial, which is worth noting and documenting. The codes that made up this subtheme were *independent living skills, social skills, and a platform for holistic education.*

Parent 5 talked a lot about the Deaf club and how he believed that the Deaf club contributed to his deaf son's holistic development as a person. He said it would be good if the YMCA reopened for other young deaf people. He emphasised the importance of exposure trips for the child's practice of independent living. He shared:

> We took them to Cameron Highlands to stay overnight. We did not allow their parents to follow. If their parents were there, they would be distracted. We wanted them to be independent. We organised another trip to Pangkor island - just one night, for the same purpose. (Parent 5)

These trips were initiated and organized by Parent 5 through the Deaf club, to expose the deaf children to different situations and environments so that the children will be able to learn the necessary living skills and develop independence.

The YMCA Deaf club also organised social programs for the Deaf children to learn to interact with the society. Parent 5 shared a fond memory of seeing deaf children learn how to interact with the old folks.

> One time, they went to the old folk's home. They want to let the children see there are deaf old people in old folk homes. We made sure the children fed them. It was very nice. Four or five of them were dancers, so they danced for the old folks. It was beautiful. (Parent 5)

These activities taught the deaf children how to relate to other people outside their normal environment. These experiences can be a powerful tool to teach deaf children lessons and skills that cannot be learnt in the academic classroom.

The YMCA Deaf Club has been a platform for deaf individuals to come together for socialising, exposure, and learning. It was set up and then closed down three times, according to Parent 5, who was involved from the beginning. It would be the fourth time starting up should there be any group of people who might initiate to do so.

From Parent 5's feedback about the benefits of deaf clubs, it would be a great loss for the current deaf children and youth if they did not have such a club for further holistic development. The deaf club could not sustain itself. Parent 5 shared his opinion on the matter and concluded there was no one who wanted to initiate and sustain the deaf club. This is his comment on the matter:

> It would be good if clubs like the YMCA would be revived. The attitude of the people over here is different from that of big cities like KL. At least some will join, but maybe after a few months, they will lose interest in it. If not mistaken, the previous founder left the club to the committee members, but the committee members were not responsive. I thought it was still on. However, when I went to the YMCA, I learned that it had closed many years ago. (Parent 5)

The YMCA Deaf Club closed a few years ago because there was no sustainability. In 2017, Parent 2 was given a task to get deaf people to sign for a project. She searched for other organisations that might have deaf people, but she found none. The society she founded was an organisation for all PWDs, which did not cater specifically for the needs of Deaf people. This is what she said:

> I tried to look for the Persatuan Pekak in Ipoh. I couldn't find it. They have put all the PWDs together. For example, there was an organisation for the handicapped in Sg. Siput. I was searching for a deaf society in Ipoh, but there was none. But I could find such societies in KL. (Parent 2)

Both Parents 2 and 5 verified that they did not know or could not find an existing deaf club in Ipoh in 2019. The current participants seemed not to need the deaf club for exposure learning anymore as they are now adults and have found other ways to meet their needs. Having said that, the current and future young deaf children and youth will benefit from the deaf club and its activities.

The purpose and function of the Deaf club and Deaf community in Ipoh differed from what Western literature advocated for. The deaf participants of this study did not express a great need for a Deaf community. When the YMCA Deaf club in Ipoh closed, no deaf person fought to keep it going. This finding is interesting as it is contrary to the strong emphasis on the need for a Deaf community for Deaf people in the Western context. The Western literature points to the importance of the Deaf community as a platform to develop sign language and pass down Deaf history, Deaf norms, Deaf education, and cultural values (Ladd, 2005b). It is also a means to protect deaf people from 'the damage done by oralism' (p.44). The Ipoh deaf participants may not have embraced the cultural Deaf identity as conceptualised by the West. Hence, coming together to develop the Deaf community in Ipoh was a low priority.

In regardtoof Deaf clubs, traditionally in the West, clubs were open a few times a week for social activities or special interest meetings, workshops, or training. However, over the past 15 years, there has been a decline in club attendance in America (Ladd, 2005a). Reasons for this decline include technological development and greater mobility. The Deaf participants of this study might have their own deaf cliques and hence did not depend on the Deaf club.

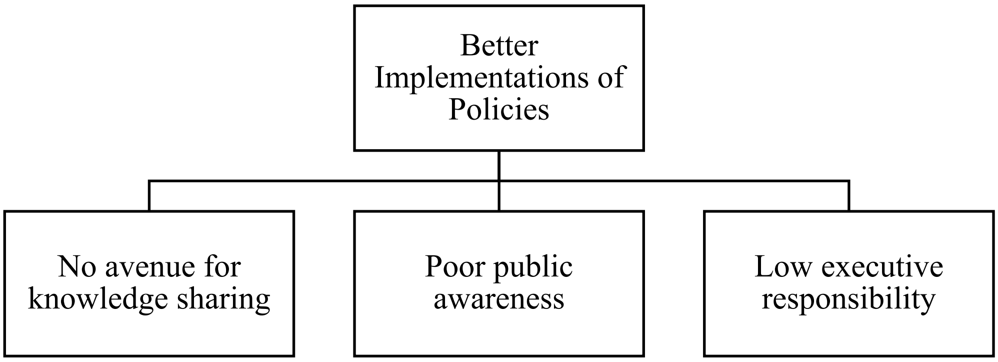
4.6.5 Better Policy Implementation

The government has policies to support PWDs, which include deaf people. However, Parent 5 voiced a concern about the failure of its implementation. There was a consistent theme theme that emerged from the interview with Parent 5 about the faulty implementations of the policies. Other participants (both deaf participants and hearing parents) were rather silent about these. Perhaps the majority of the participants lack the knowledge of how things are done in other countries to have a blueprint of what “better” might look like. Hence, they did not advocate for their own needs. Another possible reason for the silence is participants felt powerless to make a difference in the situation. They did not think that they could influence the policies that had already been set, or they were not willing to go through the trouble fighting a battle they didn’t believe they could win. However, the latter is less likely to be the reason for participants’ silence in policy implementation as throughout the interviews, participants genuinely showed they did not know what to do and depended on what the government would provide for them.

Parent 5 was different from the other participants. He saw the potential of deaf people and knew what resources were lacking. He personally played an active role in seeking out resources for the sake of his deaf son’s development. He said he has ‘turned over every rock’ to look for resources so that his deaf son would have the best possible opportunity in life as a deaf person. His enthusiastic initiatives and research provided him with a wider perspective and deeper insights into the needs of the deaf. He probably also saw the “holes”, “gaps”, and “lack” in Malaysia. Hence, he actively fought for the rights of the deaf people. He not only sought out resources that were necessary for his deaf son, but he also questioned government personnel when they did not follow government policies or challenged the existing application of policies. From his experience, the main point and theme that emerged was the *poor implementation of policies*. There was *no avenue for knowledge sharing*, *poor public awareness*, and *low executive responsibility*. View Figure 4.16 below.

Figure 4.16

Subthemes of Better Implementations of Policies



4.6.5.1 No Avenue for Knowledge Sharing. Parent 5 expressed in the interview that there was no avenue for knowledge sharing. Traditionally, Deaf clubs and parental support groups play an important role in connecting other deaf individuals and parents of deaf children. In Ipoh, the YMCA Deaf club used to be a place where the Ipoh deaf people gather before it ceased functioning around year 2013-2014. None of the participants were sure when it closed and why. Although there were two other deaf associations in Ipoh with majority of its members being Malay ethnic (Perak Society for the Deaf and Perak Deaf Sports Association), none of the participants mentioned of the association's existence to the researcher during the interviews. it is either Parents and Deaf Participants did not know about it, chose not to get involved, or the associations did not meet the needs of the parents and deaf child at that time.

Parents 1, 2, and 5 often mention in the interviews about the help offered by YMCA Deaf Club in the early years while their deaf child was below 18 years old. The YMCA Deaf Club organized many social activities (e.g. Chinese New Year celebrations, family games) and learning activities (e.g. field trips, visitations to old folks home, Health talks) for the deaf community. It also offered sign language classes.

YMCA Deaf Club provided opportunities for parents of deaf children to meet other parents with deaf children. The deaf child, on the other hand, could meet other deaf people – be it their peers or older deaf mentors. It was through the YMCA Deaf Club that Parent Participants 1, 2, 5, and 6 met each other. Deaf Participants 1, 2, 5, and 6 were school-going age at that time. Parent participants supported each other in their parenting journey and attended Sign Language classes together. Parent Participants 1, 2, 5, and 6 expressed their gratitude to the help from YMCA Deaf Club during the interviews. The Deaf Club truly provided for the needs of the deaf and their parents.

However, all these events were of the past. YMCA Deaf Club is no longer functioning almost a decade ago. In the interviews, none of the participants seem to be upset or concerned that the YMCA Deaf Club is no longer an available social networking and learning platform for them. Perhaps, they have all out-grown the need for a Deaf Club for social or learning purposes. Afterall, the Deaf Participants are now in their early to middle adulthood and have obtained all the survival skills in the earlier years.

Another possible reasons for the lack of interest in Deaf clubs could be the advent and trending use of the internet in the past decades. The internet has opened up ample opportunities for social networking and learning, which are the two functions that the Deaf Club caters for. Perhaps, similar to the situation in United Kingdom (UK), Deaf space in Ipoh is evolving, rather than declining (Valentine & Skelton, 2008). In UK, Deaf ICT (Information and Communication Technology) users meet others like themselves online and take the friendship offline in other spaces (e.g. homes, pubs, etc.). The Deaf ICT literate users abandon the Deaf clubs and go online, while the Deaf clubs are becoming homogenous with the older generation who remain non-users of the internet because they lack resources, skills, or interest to access the technology. For the Deaf club situation in Ipoh, it is likely that the Deaf ICT literate users do take their social networking and learning online. But the Deaf club cannot continue as it has been run by the younger deaf who are ICT literate. In other words, the running of the Deaf club depends on the young capable deaf who are ICT literate who might no longer put priority on the physical Deaf club.

While YMCA Deaf club provided opportunities for parents to meet, there was still a need for proper parental support groups with experts and other parent mentors to provide guidance and share knowledge about deaf related matters. Parent 2 shared how she learnt and benefited from a parent support group in KL, which served as a place for knowledge and information sharing. Sadly, there was no such group in Ipoh.

> I think it's important to mix around with deaf children. At least once a month. And it's good to mix around with the parents too. For example, I have a group in KL – Cochlear Implant group. Every month, mothers will gather and share their experience. It's very good. You can learn how to take care of children… everything! I can learn everything from the group. But it's in KL, it's so far away. (Parent 2)

Parents who stayed further away from Ipoh, also showed how ignorant they were in upbringing their deaf child. Other well-meaning parents (such as Parent 5) gave advice and counsel to these parents. This kind of knowledge sharing, guidance and mentoring could be available more often if there was an avenue to do so. Parent 5 shared his counsel to a fellow parent of the deaf, who had no contact with other parents of deaf children:

> There was a mother from Sitiawan. She said to me, "you know sign language? You talk to the deaf children?" I told her, even if you do not know sign, you can use body language. They do understand. Do you take your son out at night? Why not? What is wrong with that? You don't expect them to sit down there and do nothing. They are deaf. You see, she did not let her son go out. But after telling this, she started to take her son out soon after. (Parent 5)

In conclusion, even though the deaf adults may not need the Deaf club to meet their own needs, it is still important to have a physical platform for deaf children and their parents who needs it for connection and knowledge sharing.

4.6.5.2 Poor Public Awareness. Parents of deaf children were not aware about the government social policies and benefits to support them. They found out through the word of mouth of other parents and teachers. These are some of the accounts:

> I didn't know (that I needed to apply for the OKU care before I could get these benefits) the teachers found out and they told us. We did it ourselves, and applied through Bank National, and into own account. (Parent 1)

> This lady has a deaf daughter. this lady didn't know can receive RM400 of financial assistance, until they met me. They just came back from Singapore. I told her, are you sure? They talk to supervisor, took company van, and send her to social department, true enough, she got it. Nobody knew. She didn't know for 2 years. They should know these things. There is no awareness. It's only during chit chat over dinner one night that she found out about the financial assistance by social department. (Parent 5)

Parent 5 not only shared about the social policies and benefits for the deaf but also provided procedural information to the family to apply for the PWD card to get the allowance. He shared:

> The government can afford it. They don't know how to register (for the OKU card), so I helped them; I don't mind. I help them. (Parent 5)

The service providers were also not aware of the social policies. Parent 5 had to voice and point out to the bus company about such policies, and only they provided the fee waiver for PWD. This is what happened:

> I sent my son to Penang. He would come back every Friday evening, and I would send him to take a bus on Sunday night. By right, they should have a special price for OKU to go up and down. The bus company said there is no instruction about this discount. It so happens that I met the director, she is my sis' best friend; I told her that there should be a discount for the OKU. The next week, Ritchie got a special price. I said it is not about the money, it is because they are entitled to. They didn't know they can give all these to them. The buses only Plusliner did it. And Sri Maju. The rest didn't do it. The government should do it. For now, the bus – Sri Maju yes, the rest I don't know. (Parent 5)

The results showed that that there was poor awareness of government policies and benefits for the deaf community.

4.6.5.3 Low Executive Responsibility. Parent 5 observed flawed execution of policies and plans even though resources has been made available to the deaf community. He pointed out this observation of the different settings, but it all pointed to the same issue – poor execution of plans and policies. Resources were provided for but there was poor follow-up on its execution. For example, government provided the hearing aids, but there was no proper follow up of caring and maintaining the hearing abilities. Parent 5 expressed this issue:

> There were a lot of things that the school should have done. I told the headmaster, I see a lot of children without hearing aids. Does the government provide them? They said, "They only gave us four sets." Where are the four sets? It was there, but the children were not wearing

> them. This is because the children complained that it was noisy, or it had no battery, or maybe it was because it was not comfortable to wear as the mould needed to be custom-made. The typical mold that the government gave might not be suitable. Sometimes, I think the government should get the specialist to come and help the school with proper hearing aid fitting and speech therapist. (Parent 5)

It was not that the government did not provide for resources for the deaf community. There were hearing aids provided but there was no one responsible to ensure it was used. As a concerned parent, he followed up on the matter and found:

> I have checked the hearing aid equipment. It is there in the room, but no one is using it. We could at least invite the experts from KL to come test it. I can arrange it since I go to hearing aid center every month. If want, I could arrange it. The government gave what the school wanted. But it is not being used. What's the point? There is planning, but no execution. No one to executive it properly. The Social Welfare Department gave the hearing aids, not no one is making use of it. (Parent 5)

Parent 5 gave another case in point of the government having good plans but poor execution of it. Computers were donated to the school for the deaf student to use. In writing but in fact, the deaf student never got to use the computers due to flawed execution by the school. He expressed his frustration:

> The government did do a lot of things. The planning is very good. But there is no execution - no one to carry out the work and execute. When my son was a primary school student, in one of the YMCA programs, the Menteri Besar and teachers were invited. The Menteri Besar's wife knew the headmaster and had a conversation. Menteri Besar's wife said, she has one computer and another six that are donated to her; and she would like to donate all the computers to the school for the deaf children to use. A few months later, I asked the headmaster about the computers donated by the Menteri Besar's wife. It was in the headmaster's office. It was

> meant for the students. Let the deaf kids use it. It is true that there is a concern that the children might spoil it. But you could appoint a teacher to watch over while they learn how to use the computer. But it is now just in the office not being used. (Parent 5)

Parent 5 felt that policies were in place and resources given but there was no one responsible to follow through accordingly. He seemed upset that there was a good plan and policy to support the deaf community but no follow-up on proper executive action to make it a reality.

4.6.6 Summary

Overall, all parents were aware of the government's provision for education for their deaf children. Policies were constructed based on the social model (e.g., One per cent employment for PWDs, inclusive education). Although the education aspect was not investigated in this study, the results shed light on the current awareness and situation – the majority of the community in Ipoh is still functioning under the medical-welfare model and is slow to adapt to the social model, which emphasizes inclusivity. Lee and Low (2014) were right in pointing out the concern about Malaysia being a 'late starter', slow in moving from the medical-welfare model to the social model. All the needs for on-going support for *awareness of needs, deaf-friendly communications, support for financial independence, essential education, and better implementation of policies* are helpful feedback to understand the situation in Ipoh. It is also insightful to hear the feedback and suggestions from deaf and parent participants in their journey about improvements in the support system for future parents and children with hearing impairment.

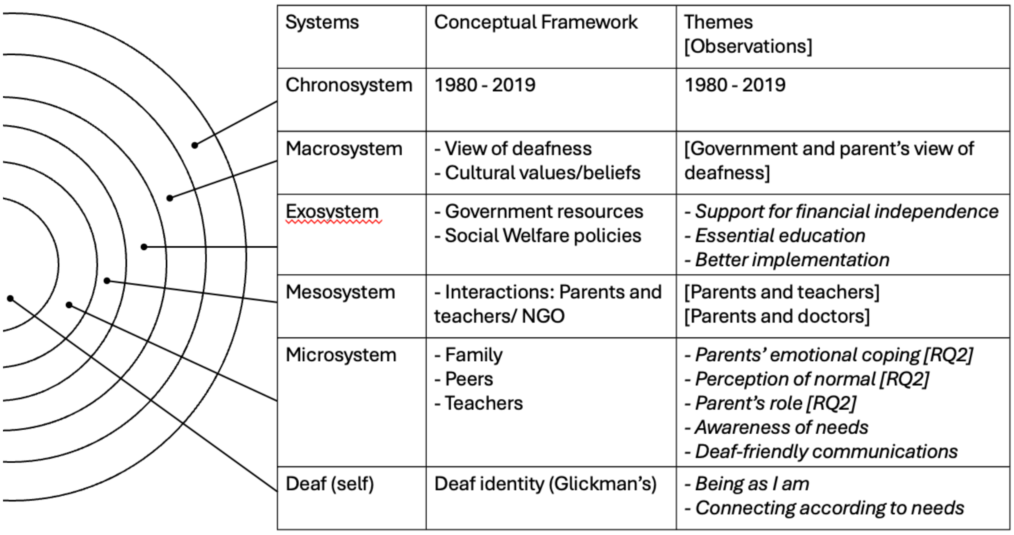
4.6.7 Discussion

While results revealed the various needs in the support system for the deaf individual (e.g., awareness of needs, deaf friendly communication, financial independence, essential education, and better policy implementation), Bronfenbrenner's' ecological system theory provides a structure to view how each party in society influence the deaf person. Figure 4.17 below captures the themes that emerged from the participants, as discussed in the above section. It also includes the researcher's observational points for the other systems that had no themes mapped to them.

Figure 4.17

Bronfenbrenner's Ecological System Theory in Malaysian Deaf Participants'

Context



Systems	Conceptual Framework	Themes [Observations]
Chronosystem	1980 - 2019	1980 - 2019
Macrosystem	- View of deafness - Cultural values/beliefs	[Government and parent's view of deafness]
Exosystem	- Government resources - Social Welfare policies	*- Support for financial independence* *- Essential education* *- Better implementation*
Mesosystem	- Interactions: Parents and teachers/ NGO	[Parents and teachers] [Parents and doctors]
Microsystem	- Family - Peers - Teachers	*- Parents' emotional coping [RQ2]* *- Perception of normal [RQ2]* *- Parent's role [RQ2]* *- Awareness of needs* *- Deaf-friendly communications*
Deaf (self)	Deaf identity (Glickman's)	*- Being as I am* *- Connecting according to needs*

Note. This figure displays the elements according to the conceptual framework (second column) and the results (third column) according to the systems of Bronfenbrenner's ecological system theory. The themes that emerged from the results are italicized, and the researcher's observations are bracketed.

One point to highlight is that the themes emerged from the data for this research question concentrated on the microsystem and exosystem with little said in regard to the macrosystem and mesosystem. Majority of the participant did not contribute much feedback to this section as they truly were satisfied with whatever that was offered to them during that time, or they were genuinely unsure what was needed. This shows a reliance on the government's system and plans (exosystem).

Although it may be argued that data saturation was not achieved for this question, the researcher considered participant's "satisfaction" or "unaware of needs" as part of the data rather than considering their brief response as insufficient to answer the question. Hence, when the same answer was given the for the fourth time among parents and deaf participants respectively, the researcher decided that data was saturated for this context.

This discussion will examine each system, beginning with the outermost layer of the ecological system (Chronosystem) and progressing inward through each subsequent layer until reaching the microsystem and self.

4.6.7.1 Chronosystem. This study was conducted between 2017 to 2023. However, the interviews were retrospective, as parents and their deaf adult children were asked about their experiences in their developmental years and up to the present. The eldest parent and deaf child pair started their journey in 1980. The interviews and observations were completed in 2019. Hence, this study's chronological context is between the years 1980 and 2019.

Two important events occurred during this period of 1980 to 2019 that impacted deaf people directly or indirectly. First, there was a change of models (view of disability) in this period. Starting from 1990, the government adopted a change from the socio-welfare model to a social model (Lee & Low, 2014). Second, the PWD Act enacted in 2008 (Government of Malaysia, 2008) caused a paradigm shift from the welfare model to a human rights model, which promoted full participation in society (Lee & Low, 2014). These events happened during the lifetime of the research participants. Their response and experiences recorded were within this context.

4.6.7.2 Macrosystem. The macrosystem would include the Malaysian cultural beliefs about deafness, the perception and attitude towards deaf people, and society's acceptance or inclusion of PWDs. However, no obvious themes emerged from the interviews with participants, especially when asked for feedback. Although this study did not explicitly collect data on the attitudes and perceptions of the different stakeholders towards deaf people, there were indications of parents and the government's perspectives towards deaf people through policies, thoughts, and behaviour.

The view of deafness in the Malaysian context can be derived from the government's perspective through the decisions in welfare and education policies and the enactment of the PWD Act 2008. The view of deafness can also be derived from parents' response when they received the child's diagnosis of hearing loss – parents' emotional coping, their perception of what is "normal", and their assumed parental roles (Refer to *Section 4.5 Research Question 2*). Generally, deaf people were still viewed from the medical and welfare model and slow to progress to the social model and rights model (as observed in *Section 1.4.2 Models of Disability*), and it has not changed much over the years.

Chong and Hussain (2022) reported similar findings in their study about mainstream society's view of deaf people. They found that mainstream society viewed deaf people as PWDs. This is not surprising as the government policies may reinforce the view of deafness in society. For example, the government's social policy in providing financial aid and employment schemes was designed from a welfare approach, whereby assistance is given for the welfare of PWDs. It is a governmental obligation to support those in need, and this providence is not a matter of rights or entitlement. In this aspect, deaf people are viewed as a group that needs help and welfare support. Deaf people were treated that way, and they typically accepted society's evaluation of them and played the expected roles (Chong and Hussain, 2022).

As for the educational policy for PWD with hearing impairment, the focus moved from the medical welfare model to the social model of disability (Lee & Low, 2014). The education policy views PWD with hearing impairment as individuals who are disabled because of social barriers. When social barriers are removed, PWDs can function like regular individuals. Hence, the educational plan of Malaysia is directed toward inclusivity, aligning with SDG 4 of equity of quality education (United Nations Department of Economic and Social Affairs, 2023). However, how deaf people are treated in society does not reflect the social model where deaf people are given accessibility and inclusivity. The themes in research question 1 revealed that deaf participants were not able to keep up and were *excluded from communications* when in the hearing community. There was also a lack of *deaf-friendly communication in the microsystem between the deaf person and their social contacts (e.g. parents, teachers, classmates, and* society).

As this research did not collect data on the attitude and behaviour towards deaf people from members of society, there is no substantial evidence to confirm a prevalent societal perspective on deafness. Although the subscription to the policies and the enactment of the PWD Act 2008 provides a guiding direction to the view of deafness, its implementation may have been less successful. Members of society, parents, and teachers may still need to undergo a paradigm shift from the medical/welfare model to the social model. At the same time, the welfare provision still implies that deaf people are perceived as PWDs in need of assistance. The various perspectives about deaf people from different people will pass through each layer – exosystem, mesosystem, microsystem, and eventually impact the deaf individuals.

4.6.7.3. Exosystem. The exosystem consists of the broader social and environmental contexts that indirectly impact deaf participants' development (Bronfenbrenner, 1979). In this research context, the exosystem includes government policies and resources. The deaf participants may not have direct contact with these elements; nonetheless, they may still influence the deaf individual's development. For example, the deaf participants (all except Deaf participant 2) had limited resources for cochlear implants and speech therapy. Hence, the majority of the parent participants opted for hearing aids and sending their child to a deaf school instead of mainstream or integrated schools. During the period of the deaf participant's developmental years (till secondary school), there was a Deaf club in the YMCA that provided a platform for the deaf children and their parents to meet, socialise, learn, and support each other. This created a healthy environment for the development of the deaf child.

The themes that emerged from the data for research question 3 include *support for financial independence, essential education,* and *implementation. Government policies rooted in the welfare and social model of disability assisted deaf participants in certain areas such as education, financial support,* and employment. However, the concern is the implementation of the policies and social services. Parent Participant 5 voiced out the government's lack of support and implementation of employment for PWD. Parents 1, 2, 3, and 6 expressed concern about their deaf child's employment whilst finding different solutions to help their deaf child gain financial stability (e.g., request jobs on behalf of a deaf child, employ their child under their own family business).

The exosystem plays an important role in creating a supportive environment for the deaf participant. Even though its impact is indirect, it will affect the deaf child's development and well-being, especially in the social, educational, and employment aspects. As previously highlighted in the macrosystem, the lack of awareness of deaf people's needs (e.g., deaf-friendly communications and language accessibility) needs to be emphasised and implemented as they are in the PWD Act 2008, government policies in welfare and education. The education system and policies can incorporate or emphasise the awareness of deaf people's communication and social needs and make the social environment more inclusive for them. The policies, especially for employment, need better implementation to help the deaf be financially independent from their parents. When these are implemented from the exosystem, the impact will ripple through the other layers (e.g., mesosystem and microsystem) for the betterment of deaf people.

4.6.7.4 Mesosystem. The mesosystem refers to the interactions of the microsystems (e.g., parents, other family members, teachers, doctors, and social services officers) that would influence the deaf individuals' development. For example, the good interaction between deaf participants' parents and the doctors influences the type of medical interventions (e.g., cochlear implants, hearing aids) for the child's well-being. Data from the interview for research question 3 did not directly reveal any themes. However, there were indications of parents' interactions with doctors in the early developmental years of their deaf child. Parent 2 received a lot of support from the medical doctor who oversaw her deaf daughter's hearing impairment. The doctor's recommendation led Parent 2 to get a cochlear implant and speech therapy for her daughter.

This study's results revealed that decision-making largely depended on the recommendations of healthcare professionals. This leaves parents at the mercy of the government's provision. While this burden falls on healthcare professionals, the dilemma stems from the lack of facilities (Wong et al., 2021) and human resources, such as the limited number of speech therapists in Malaysia (Chu et al., 2019). This is contrary to the practice in Western countries where shared and parent-focused decision-making was encouraged (Charles et al., 1999; Elwyn et al., 2012). Parents were empowered and given knowledge and skills to manage the child's deafness (Elwyn et al., 2012). Healthcare professionals first need to be educated well about deaf issues so that they can educate parents about managing their child's deafness. Although this study did not collect data about healthcare professionals' knowledge, recent studies have shown this lack of knowledge among healthcare professionals who provide hearing loss diagnoses (Mazlan & Wong, 2018). This communication between parents and healthcare professionals is essential.

Parents' communication with teachers and social service officers also impacted parents' choice of education for the deaf participant. All six parent participants of this study made educational decisions based on the advice of the teachers and social service officers. The interactions between parents in other social support groups, such as YMCA for Deaf Participants 1, 2, 5, and 6, impacted the deaf child's social development. The relationship between Parent 2 and the parental support group for children with cochlear implants was beneficial for Parent 2 in teaching her daughter to speak. The support provided by parents to other parents proved to be a helpful resource (Moeller et al., 2024). Unfortunately, this parental support group was too far for Parent 2 to commit to, so eventually, the support to continue speech therapy with the cochlear implants was insufficient for the successful use of cochlear implants and speech in Deaf Participant 2. This shows the kind of impact the mesosystem had on the deaf participant.

The mesosystem is where social support for the parents can be established to assist the parenting journey in developing the deaf child's potential. Ideally, good communication between parents with teachers, other parents, doctors, and social service officers will provide support to raise the deaf child together. Parties in the mesosystem, such as the teachers and parents, can discuss suitable education for the deaf child and assist in teaching and building a deaf-friendly communicative environment for the deaf child. Parents can communicate with social service officers about the strategies and policies to help deaf individuals gain employment or financial independence.

However, in reality, this support system seemed to be lacking. Parents 3 and 4 depended on the school system for their child's education and had little involvement with the child's education. Parent 5 complained about the poor teaching attitude of his deaf son's teacher. Social welfare officers did not help provide information, according to Parent 5. Parent social support groups for this group of participants only existed because of the YMCA, which has now been inactive for a decade. This is evidence that points to a lack of support for the parents in raising the deaf child. Members of the mesosystem, such as doctors, teachers and other parents, also lacked the knowledge and skills to assist the parents.

4.6.7.5 Microsystem. The results of this study revealed themes that related to their microsystem - Parents, teachers, and peers. This study limited its focus on the direct influence of parents as the deaf child's microsystem. Although the results might reveal the influence of teachers and peers, these were inferences from the researcher's observation based on the deaf participants' experience, as the researcher did not collect data from the primary source.

The themes that emerged under the microsystem include parents' response to their deaf child's diagnosis, as discussed in research question 2. Parent's emotional coping, whether they have come to an acceptance of the child's hearing condition, and the perception they have of 'deafness' or 'normal' impacted how they choose to play their role as parents, which affects the deaf child's growing up experience and development. Western literature has also emphasised the importance of parents' role and involvement in the early intervention of their deaf child (Moeller et al., 2024).

One interesting result of this study was the quality of communication between parents and deaf children. Although parents 1, 2, 5, and 6 took sign language classes and signed with their deaf children, they admitted that they felt limited in their communication. This was comparable to recent studies that also reported parents' limited sign language skills (Marippan & Yasin, 2020). However, this study's parents' limited sign language skills seem to have not hindered the quality of their relationship. But as for Parents 3 and 4, who had no sign language skills with their deaf daughter, their communication breakdown inevitably affected the quality of their relationship. Deaf participant 3 was very lonely and developed social interaction difficulties with deaf and hearing people as an adult. Deaf Participant 4 expressed a lot of hurt from being left out of family communications. This finding indicates the importance of good communication skills for parents and deaf children. Western literature has emphasised the need for quality communication and proposes sign language as part of the intervention as early as infancy (Humphries et al., 2022). As important as sign language skills are, there was a lack of awareness and accessibility for learning sign language in Ipoh.

Teachers and classmates also had a direct influence on deaf participants' development. A supportive school environment can shape the deaf child's esteem and confidence (Kef & Deković, 2004). Being able to communicate with the deaf child directly provides a healthy emotional attachment, which helps build self-esteem in adolescents (Gorrese & Ruggieri, 2013) and adults (Doinita, 2015). Teachers may also facilitate deaf friendly communications in classrooms so that deaf students can be included in school activities with other peers. The presence of peers (deaf and hearing) gives the deaf child the opportunity to socialize and learn from one another – a crucial influence on a sense of belonging.

The situation in Malaysia, as revealed through the study's result for research question 3, showed that there was a need for *deaf-friendly communications* and *awareness of needs. The r*esults of this study showed that deaf participants could not adapt to the hearing learning environment. They enjoyed socializing with deaf classmates in the Deaf school but were limited in learning (Deaf Participants 1, 2 and 4). This learning barrier may be explained by Chong and Hussain (2021), who argued that BIM should be the main instruction of teaching in Deaf classrooms. The lack of proper BIM skills has become a learning barrier for deaf students. Were teachers aware of the learning and communication needs of deaf students? Or did teachers have a different perspective on how deaf students learn? This calls for more research to find out the answers.

Other than parents, teachers, and classmates, the other elements in a deaf person's life are other family members, such as siblings and extended family. They were least talked about but mentioned by Deaf Participants 1, 3, 4, and 5. Only Deaf Participant 4 mentioned the involvement of the doctors in her immediate environment as an adult. These elements were part of the deaf participants' microsystem. However, this research did not obtain primary data from these people, as they were not the targeted focus. Hence, there is a limitation in making conclusions about their involvement and role in the deaf person's microsystem. More research is required to provide a comprehensive understanding of the role of other family members, doctors, and teachers in the deaf person's life.

4.6.7.6 The Influence on Identity Development. From a helicopter perspective, the results of this study provided some insights into the complications of the 'deaf identity' situation in Malaysia. The deaf person's identity is formed by the impact of each ecological system of Bronfenbrenner's ecological system theory.

In the context of this Malaysian study from 1980 to 2019, the view of deafness varied across the different stakeholders (e.g. government, healthcare professionals, educators, social workers, parents, members of society). Although policies are grounded in the social model (e.g., the PWD Act and Education blueprint), the intended philosophy behind the policies has not been internalised by the stakeholders, resulting in a diverse view of deafness. There seemed to be an imbalanced view of disability among the different stakeholders. Some parents view their deaf child's disability from only the medical model (Parents 3 and 4), while the other parents had a more balanced view incorporating the medical and social model. The teachers may also not be aware of the different views. It is important to note that the view of deafness (macrosystem) and policies (exosystem) mutually influence each other. It is a slow transition from the medical/welfare model to the social/rights model (Lee & Low, 2014)

In the exosystem, the government has attempted to provide a balance among all the three models (medical, social, and welfare), following the example of the International Classification of Functioning, Disability and Health (ICF) of the World Health Organisation that proposed that:

> A better model of disability is one that synthesises what is true in the medical and social models without making the mistake each makes in reducing the whole, complex notion of disability to one of its aspects (World Health Organization [WHO], 1980).

For example, the education blueprint provided three educational choices for deaf students – inclusive, integrated program, and special education (Ministry of Education Malaysia, 2013). The special education and integration programs are part of the social-welfare model, where the emphasis is to provide equal education opportunities and accessibility to all (L. W. Lee & Low, 2014). Inclusive education is the effort to move away from the welfare model and towards the social model of disability. Similarly, the PWD Act 2008 integrated the welfare, medical and social model to provide registration, protection, rehabilitation, development, and well-being of PWD, as well as for matters connected therewith (Persons with Disabilities Act, 2008).

Although the policies and laws in the exosystem attempted to keep a balance among the three models of disability for the well-being of deaf people, it has yet to consider including the linguistic model of disability that would help hasten the development of the deaf community. Though BIM has been recognised as the official language for deaf people in the PWD Act 2008, there is a lack of Malaysian sign linguistic research, which led to a debate on the appropriate language of instruction (KTBM or BIM) for deaf students.

Hence, when the Deaf movement influenced Malaysia, a group of Deaf people from the city strongly advocated for their identity as a linguistic minority (e.g., MyBIM – The Malaysian Sign Language and Deaf Studies Association). However, the influence of the Deaf Movement did not penetrate the Ipoh deaf people in this study (except Deaf Participant 4). The deaf participants of this study did not identify as linguistically minority deaf persons. The lack of awareness of the role of the linguistic model also explained the study results of (Chong & Hussain, 2022) that revealed the divided view of society towards deaf people and the deaf person's affirmation of their own identity as a linguistic minority.

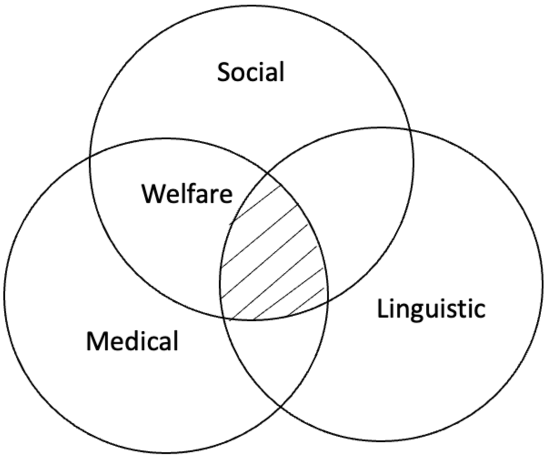
In the mesosystem, the interactions between parents, educators, and healthcare professionals are important as a support system for the parents. Parents depended on the knowledge and recommendations of healthcare professionals and teachers to make decisions for their deaf children. However, teachers and healthcare professionals have limited knowledge and experience in assisting parents with their child's hearing management (Mazlan & Wong, 2018). The lack of this support system impacts parents, who are the microsystem of the deaf child. The parent's grief and acceptance of the child's hearing loss, followed by the type of decisions made with the limited choices offered in Malaysia, impacted the experiences and development of the deaf child, influencing their identity formation.

These influences from the microsystem impacted the deaf individual's experience living in both the hearing and deaf community, resulting in their unique identities as deaf people. The identity of deaf participants in this study was not based on the culturally deaf identity in Glickman's theory but based on a more general social identity. The deaf participants of this study seemed to be 'fluid' - going in and out of groups according to how they were accepted and accommodated as deaf persons in the particular social context.

Figure 4.18 below shows the proposed hybrid model of disability consisting of the medical, social, welfare, and linguistic models of disability. The coloured section shows the ideal balance and hybrid of the four models.

Figure 4.18

Proposed Hybrid Model of Disability



The conclusion to this short discussion of the models of disability and the identity development of this study's deaf people is that while different parties emphasise on certain models to provide services (e.g. the doctors operate under the medical model, the social welfare department operates under the welfare model, the policies and acts are designed from the social model perspective), it is proposed that the individuals in the microsystem need to understand and strike a balance among these models of disability for the best possible development of the deaf people's social identity.

4.6.8 Conclusion

The third research question explored the feedback from participants about the resources available or needed for the deaf individual's development. Results revealed the themes where there is a need for – awareness of needs, deaf-friendly communication, financial independence, essential education, and better implementation of policies. Bronfenbrenner's ecological system theory explained how each party in the systems and their subscription of disability model types in the Malaysian context impacted deaf individuals during the period between the years 1980 and 2019.

CHAPTER 5

DISCUSSION

This chapter will start with a summary of the results for each of the three research questions. It is then followed by the theoretical implication of Bronfenbrenner's ecological system theory, Tajfel's social identity theory, and Glickman's deaf identity theory. The practical implications of the study's results will be reported next. The practical implication is written according to the ecological system, starting from the macrosystem, exosystem, mesosystem, and microsystem. Lastly, this section concludes with the limitations and recommendations of this study.

5.1 Summary of Results

This study explored parent's role in the identity development of six deaf participants in Malaysia. Bronfenbrenner's ecological system theory provided a context for understanding the development of a deaf person's identity. The direct and indirect influence of each system - microsystem (e.g., the parents), mesosystem (e.g., the interaction of parents with the teachers and doctors), exosystem (e.g., government resources and policies), and macrosystem (e.g., beliefs and attitudes towards deaf people) influenced the identity development of the deaf child.

Research question 1 explored the life experience of deaf participants growing up in a hearing family and community. Tajfel's social identity theory (1979) indicated that deaf people would find their sense of belonging in groups. Glickman (1996) proposed that deaf people form their identity based on two groups – Deaf cultured and Hearing cultured. Results of this study revealed that the Malaysian deaf participants struggled with keeping up and felt excluded when in the hearing world while they appreciated the communication without barriers and the ease of learning in the deaf world. The deaf participants did not identify themselves according to the two groups (Deaf vs Hearing) but rather according to the inclusiveness of the group they were with. They expressed their identity based on feelings of acceptance (being as I am – different or normal) and being accommodated (connecting according to needs - quality of social connections, learning opportunities, and having personal space).

Next, research question 2 focused on the microsystem and mesosystem and explored parents' role and experience in bringing up their deaf child. The results of this study revealed that Malaysian parents, though limited in their resources, played an important role in the deaf child's life as the provider (e.g., to provide exposure for learning, opportunity for career, and connection for social needs) and advocator (e.g., advocate for quality education, well-being, and the needs of the child). Parents also experienced grief, but it was finite. Once the deaf child and their deafness were accepted, parents were more positive in parenting.

Research question 3 explored parents' and deaf participants' feedback on the current support system and resources available for the development of the deaf community. This question reviewed the exosystem (e.g., government resources and policies) and macrosystem (e.g., beliefs and perceptions of deaf people, law, and policies) to provide context on how the wider system influences the deaf child's identity development. Overall, there is a provision from the Malaysian government, but the implementation of policies was not efficient. The results of this study revealed that parents need to be more aware of the deaf child's needs; there is a need for more deaf-friendly communications, more support for assisting deaf people to be financially independent, more improvement in providing essential education, and better implementation of existing policies.

5.2 Theoretical Contribution

Three theories were used in this study to frame the research. The implications of these three theories are discussed below.

5.2.1 Bronfenbrenner's Ecological System Theory

Bronfenbrenner's ecological system theory (1986) explained how each layer of society influences the individual directly or indirectly. For this study, this theory was applied specifically to the context of the deaf person in Ipoh rather than a general context. The benefit of this theory is that it is adaptable in its application. When applied to the specific context of the target population group, it provides a good framework to obtain a better understanding of how the whole society in each system affects the individual. Through this framework, it is easier to pinpoint areas that need to be changed so that solutions within context can be generated. Below are some examples of how the theory has been extended within the context of the deaf person, starting with the outer layer to the inner layer of the ecological system – chronosystem, macrosystem, exosystem, mesosystem, and microsystem.

The chronosystem placed the results of this study in a timeframe of 1980 to 2019. It provides the context to what the situation was like in Ipoh in those years. For example, the enactment of the PWD Act 2008, the educational system, the welfare provision from the government, and changing perspectives of deafness across the ecological systems in Malaysia at that period.

The macrosystem included the underlying perspectives of deafness in society that influence policymakers, healthcare professionals, educators, social workers, parents, and members of society. These perspectives of deafness in Malaysia are bonded by the Malaysian culture and differ from those in the Western context. Deaf people in Malaysia, as this research showed, are still perceived as PWDs that need assistance through the government's welfare provision. In the lens of the more developed countries in the West, deaf people are viewed from the social or linguistic model, where they are a cultural-linguistic minority or PWDs that are empowered and provided equal accessibility to be equal members of society.

The exosystem refers to the indirect influences such as resources, social services, and mass media (Bronfenbrenner, 1986). Bronfenbrenner's ecological system theory is extended into the specific Malaysian context of the deaf person. The exosystem for the deaf person includes the type of education system choices they have based on the government's education blueprint and PWD Act 2008. In the Malaysian context, they could attend inclusive programs in mainstream schools, integrated programs, or special schools to meet the child's educational needs (Ministry of Education Malaysia, 2013). Other social services such as employment placement, medical benefits, and financial assistance are made available for deaf people to access. However, the failure of implementation of the system or policy also impacts the deaf person. For example, the failure of the execution of the 1% quota policy that aimed to integrate PWDs into the workforce through employment in civil services (Dewi et al., 2020).

The mesosystem consists of the interaction between the elements of the microsystem, such as interactions between parents and teachers or healthcare professionals. For the mesosystem of a typical child, parents may not need to interact closely with the teacher or doctors. However, when this theory is applied in the Ipoh context, healthcare professionals and teachers are the parent's support system. Parents depend on the recommendations of healthcare professionals and teachers for the well-being of their children (Greene-Woods, 2020; Hamilton & Clark, 2020). Western countries have different practices, where there is more shared decision-making between parents and healthcare professionals (Charles et al., 1999; Elwyn et al., 2012).

Similarly, Bronfenbrenner's ecological system theory is extended to the deaf person's microsystem. In this study, it is the parents of the deaf child. How parents responded to the diagnosis of their deaf child, the view they had of their child's deafness, and the support that they received from the government influenced the decisions they made regarding the deaf child's hearing rehabilitation, mode of communication and education choices. All these layers of environment shaped the deaf person's experience in Ipoh, which formed his or her perceived identity.

In summary, Bronfenbrenner's ecological system theory extended its implication by providing a unique framework to contextualise the experiences of the deaf people in Malaysia.

5.2.2 Tajfel's Social Identity Theory

The social identity theory proposed by Tajfel and Turner (1979) suggests that individuals experience collective identity based on their membership in a group. The eight common social identities include age, gender, race, ethnicity, social class, nationality, dis(ability), sexual orientation and religion. For this research, it focused on the hearing disability category to determine the in-group and out-group.

The results of this Malaysian study on the deaf people in Ipoh revealed that participants did not have a strong social identity according to this category of disability by Glickman. In fact, their social identity was not based on status but rather on the inclusivity of the group they interacted with. To be more specific, the in-group would have characteristics of inclusivity – acceptance of deaf persons and accommodation of needs. Hence, the categorisation of the in- or out-group can be classified as a new non-status categorisation. It is based on the 'characteristics' of the group to obtain a sense of belonging or social identity for the deaf individual. This new insight is a contribution to this theory – extends its implication of group membership to the characteristics of the groups rather than merely the status of the group.

The results of this study propose to consider the post-modernist concept of identity fluidity (McIlroy & Storbeck, 2011; Sherrell, 2023) for the disability category. Identity fluidity refers to the interactions, engagement, and dialogue across the conventional dividing line between the two groups – Deaf and hearing cultural communities. The result of this research agrees with McIlroy and Storbeck (2011) that there may be a possible paradigm shift away from the binary conceptions of deafness (Deaf vs hearing) towards understanding Deaf identities as a fluid phenomenon. Hence, while reviewing Tajfel's social identity theory,I noticed that this fluidity concept may add a dimension to the application ofg this theory.

5.2.3 Glickman's Deaf Identity Theory

Glickman's deaf identity theory could not be applied exactly to explain the results of this study. Results of this study showed that deaf participants did not have a clear, distinct identity categorised according to the exact definition of the culturally Deaf identity. Glickman's deaf identity theory emerged from the Western context, where history records the ban on sign language usage and the oppression of deaf people (International Congress on the Deaf, 1880). The Deaf social movement emerged to protect the rights of the linguistic minority Deaf people, which includes the rights to use sign language and the accessibility to Deaf education. Glickman's deaf identity theory was constructed based on the premise that Deaf people are a cultural and linguistic minority group, not a group with disabilities. Hence, this theory developed the four identity stages of deaf people – hearing, marginal, immersion, and bicultural deaf identity (Glickman, 2013).

When the results of this study were compared to Glickman's deaf identity theory, the researcher attempted to categorise participants according to the four classifications of Glickman's deaf identities but used a more general, universal understanding of Deaf culture (e.g., the deaf norms and behaviour). This is because the Malaysian deaf culture seems to differ from the Western definition of Deaf culture that is used in Glickman's deaf identity theory. The Malaysian deaf participants interviewed did not experience the effect of deaf oppression from a political level and , therefore, did not have a strong reaction tothe advocacy of sign language, Deaf culture, and identity as the Western countries do.

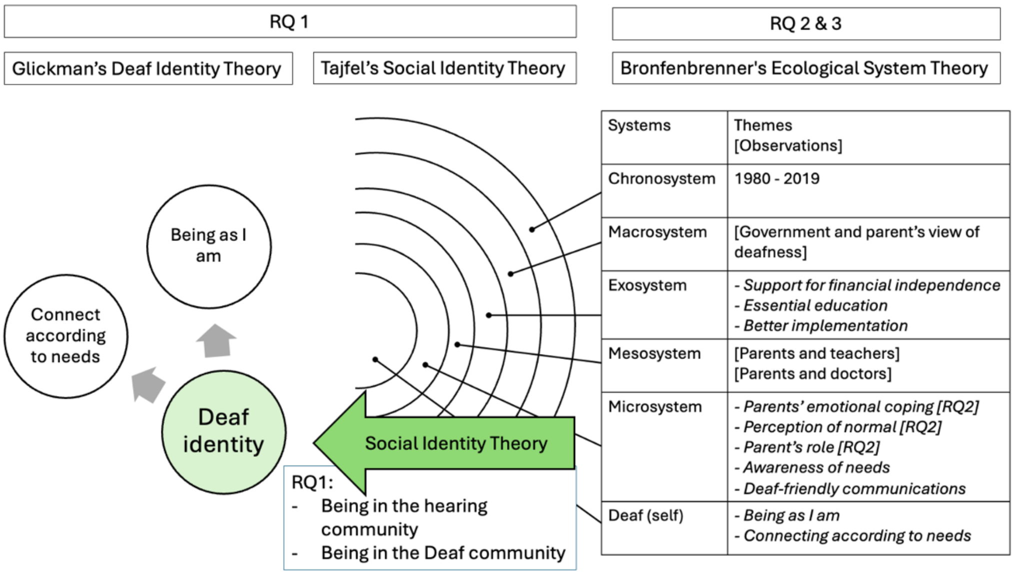
Hence, it seemed fair to conclude that Glickman's deaf identity theory was not entirely culturally suitable to be used in the Malaysian context as the Malaysian deaf people do not subscribe to the same Deaf culture according to the Western culture. The deaf people in Malaysia may be a linguistic minority who subscribe to Deaf norms and are users of sign language. However, because of the different social, cultural, and political backgrounds of Malaysia, the culture developed among the deaf in Malaysia would differ from the Western Deaf culture. The Malaysian deaf culture has not yet been documented. Therefore, future research may explore the deaf culture of Malaysia from the grassroots level and develop a Malaysian Deaf culture identity theory rather than adopt a pre-existing Western Deaf culture identity theory (Glickman, 1996; Holcomb, 1997).

5.3 Practical Implications

This study explored the experiences of deaf adults and their parents in Malaysia and how those experiences influenced the deaf person's identity. Bronfenbrenner's ecological system theory was used as a framework for understanding how the different systems of the environment impacted the deaf person's identity. This section discusses the practical implications of the study according to the ecological system of Bronfenbrenner. Figure 5.1 below is a summary of the conceptual framework with the study's results.

Figure 5.1

Conceptual Framework With This Study's Results



Systems	Themes [Observations]
Chronosystem	1980 - 2019
Macrosystem	[Government and parent's view of deafness]
Exosystem	- *Support for financial independence* - *Essential education* - *Better implementation*
Mesosystem	[Parents and teachers] [Parents and doctors]
Microsystem	- *Parents' emotional coping [RQ2]* - *Perception of normal [RQ2]* - *Parent's role [RQ2]* - *Awareness of needs* - *Deaf-friendly communications*
Deaf (self)	- *Being as I am* - *Connecting according to needs*

5.3.1 Macrosystem

The macrosystem involves the beliefs and perceptions about deaf people in Malaysia. The results of this study showed that people had different views of deafness. This change of perception needs to start from the macrosystem and slowly ripple through the other systems. There is evidence in this research that parents (microsystem) still have a poor view of deaf people (e.g., Parent 4 viewed that her deaf child would be a burden and hence wanted to abort the unborn child; Parent 3 didn't think their deaf child could be independent). A change of perception towards deaf people in every ecological system in society should ideally be translated into being inclusive in education, employment, and everyday living.

Another point to note from the research's findings is that the various views of deaf people among the different stakeholders may have caused confusion in providing the right assistance to deaf people. For example, a deaf person with a linguistic identity may not want welfare support but language accessibility through a BIM interpreter. On the other hand, treating the deaf person according to a welfare model may not empower the deaf person to be independent.

The different treatment of deaf people from different members of society who hold different perspectives of deafness may add to the confusion in deaf people's own perception of themselves. Chong and Hussian (2022) reported that deaf people in Malaysia "typically accepted society's evaluation by identifying with it and played the expected roles of a PWD" (p.1). The deaf participants of this study expressed a fluid identity where they conformed to the situation accordingly to meet their needs without establishing a specific identity.

Therefore, it is important for the government, educators, and social workers to address the perception and attitude towards deaf people. Creating awareness about deafness will provide a balanced view and understanding of deaf people and the challenges of deafness. Projects and campaigns that create awareness about deaf people and sign language will help break down communication barriers. Addressing the misconceptions about deaf people would also help make an inclusive society possible. An inclusive society may help reduce the bullying, isolation, and mental health issues of deaf people (Eichengreen et al., 2021; Leigh et al., 1990).

5.3.2 Exosystem

For the context of this study, the exosystem included government resources such as policies, programs, and services. Results of the study showed that the social policies and the Person with Disability Act 2008 are based on the social model of disability, which aims to remove social barriers to ensure equal accessibility to information, social services, education, etc., for PWDs. However, the implementation of these social policies has not been successful. For example, the 1% employment rate for PWD in civil services (Dewi et al., 2020; Jabatan Pembangunan Orang Kurang Upaya [JPOKU], 2023), which has also been voiced out by parent participant 5. Hence, it is proposed that researchers focus on the implementation of employment, especially among deaf people, and find out the challenges of employers and deaf citizens so that training and workshops can be designed to address these unique challenges of the deaf community.

In addition, as participants voiced out poor executions of policies and strategies, it would be a step forward if the government would review the execution and the effectiveness of the social welfare policies. One area of review is the rehabilitation programs at the PDKs. They are for all PWDs. It would be good to review how the proposed developmental interventions in PDKs are effective for deaf individuals. Perhaps more focus and resources can be placed on sign language development and interpreting services to bridge the gap in communication between the hearing and deaf communities.

Next, the results from research question three reported the types of resources that were available or lacking. All parents depended heavily on the government's provision of resources for their deaf child's development, while Parent 6, who was the eldest in the group, took the initiative to find or develop the needed support. Based on this finding, it is suggested that the social welfare department, healthcare professionals, and educators work closely together to develop a holistic support system and navigation plan for caregivers of deaf children. This navigation system could include an outline of professionals whom parents of the deaf child should approach for advice (e.g., medical doctors, audiologists, psychologists, early intervention educators, speech therapists, etc.) so that they can make informed decisions for their deaf child.

The navigation system can also include a directory of resources and support groups for parents to reach out to. This navigation system would help ensure that lower-educated parents and deaf persons will not be ignorant of where to go for help. Malaysian government may have these systems in place, but the promotion or publicity of such available resources are insufficient. Parent 6 verified that in 2019, he was unable to locate the resources that could benefit the deaf community (e.g., sign language classes, support groups, deaf clubs).

Other than a navigation system, the research's findings underscore the urgent need to improve early interventions. The UNHS should be made accessible in all hospitals in Malaysia to screen the hearing of newborns so that Early intervention can be provided to prevent risks of developmental delays when hearing loss detection and diagnosis are early. It is recommended that the discussions of the intervention for the deaf change from a reliance on the medical professional to a collaborative decision-making approach (Charles et al., 1999; Elwyn et al., 2012). Empowering parents with knowledge and skills to decide and manage their child’s well-being will lighten the burden and dependency of parents on healthcare professionals for the child’s well-being.

Another important component of early intervention is communication and language skills. Sign language interventions such as BIM should be provided as an alternative for those who may not be able to restore hearing. BIM intervention should be offered as early as possible as it prevents the risk of language deprivation that leads to other development issues (e.g. emotional, social and behavior, and academic problems). Introducing deaf adults in interventions can be a good support for families with deaf children as they can learn communication strategies.

The results of this study also indicated a need for better-quality education for deaf people. Therefore, in terms of the implementation of education policies, an evaluation of training programs to equip teachers to handle integration and inclusive education would provide good feedback for the MOHE. It is part of the MOE’s blueprint for the year 2013 to 2025 (Ministry of Education Malaysia, 2013). Also, it is recommended that topics on “social awareness” be included in the student’s curriculum. The social awareness program could include an introduction about deafness, how to relate to other deaf individuals and some basic communication in BIM. This will prepare society to be more aware of and inclusive of deaf people.

5.3.3 Mesosystem

In this study's context, the mesosystem refers to the interactions between parents, healthcare professionals, teachers, social workers, and other parents. They are the front liners who help educate and advise parents about their deaf children. It would be good to educate and equip frontline medical staff with basic knowledge and awareness about deafness, resources, interventions, support systems, so that they are better equipped to educate and provide navigation for families with deaf children.

As for social workers and those who provide early intervention fordeaf childrend, they should be equipped to run programs that include knowledge and awareness about managing deafness, counselling, and communication skills for both deaf children and family members. Such programs will help parents in the initial stages of accepting and managing their child's deafness by providing the support and empowerment they need to parent their deaf child. Setting up parental support groups that involve deaf adults may benefit parents in the long term as they see a model of an independent deaf adult (Gale, 2021).

5.3.4 Microsystem

The microsystem is the immediate environment and has a direct influence on the deaf person's life. Parents are the caregivers and main decision-makers for the child. Results of this study showed that parents went through an emotional period upon receiving the child's hearing loss diagnosis. Some counselling and guidance will be helpful for parents in grieving, accepting, and adapting to the child's deafness (Brand et al., 2018b). Parents' acceptance and perception of their deaf child influenced their parenting role and choice of communication with the child, impacting the quality of the parent-child relationship. Hence, interventions should emphasizs communication skills, as communication between hearing parents and deaf children is essential to better parent-child relationships and development (Vaccari & Marschark, 1997).

Teachers are the next important group of people in the deaf person's life. Teachers have a direct influence on the deaf child's development for long periods of time. Hence, it is important to equip teachers with more awareness and knowledge about teaching and managing deaf students. Teacher training programs should include skills for classroom management, specifically for the special needs of deaf students. It also may be beneficial to evaluate the effectiveness of the current medium of instruction for deaf students, as research highlighted the importance of BIM in reducing the learning barrier in class (Chong & Hussain, 2021).

5.3.5 The Individual Deaf Person

It is just as important to provide deaf individuals with guidance and emotional and social support in the community to navigate through life's challenges as a deaf person. There should be an emphasis on providing communication strategies in both the hearing and deaf community for the deaf person. Even if the hearing community may not know how to reach out to the deaf individual, the deaf person should be able to confidently communicate with the hearing community.

For healthy development, the deaf individual should develop learning strategies and a good attitude and outlook in life. Counselling and guidance might be helpful for the deaf individual in their journey of discovering their identity and adaptability to the hearing world, being confident with themselves, and strengthening their resilience to tackle life's challenges. With sufficient support and empowerment, a deaf person would be able to build their confidence and take the initiative to develop skills for personal growth.

5.3 Limitations and Recommendations for Future Research

This study focused on the Chinese ethnic, low to middle socio-economic status families located in Ipoh City. The results of this study shed light on understanding parent's role in bringing up deaf children and how this specific context influenced the identity of the deaf participant. As identity development is said to be influenced by these factors, it is recommended that future research explore populations of other races, higher socioeconomic status and populations located in the cities.

This study is limited to the ethnic Chinese also because it is the only deaf community that the research has established trust in and has gained entry into. The experiences of deaf people and their parents from other ethnic groups, such as the Malays, Indians, and native people (Orang Asli), were not explored. These other ethnic groups' cultural values and religious beliefs are different from those of the Chinese ethnic group, which may result in different perceptions, attitudes, and treatments towards deafness and deaf people. Hence, future research may focus more specifically on the cultural values of other ethnic groups and how those cultural values influence their perception, attitude, choice of parenting the deaf child, and its impact on the deaf person.

Another limitation of the study is that it is focused on deaf people in Perak, a preliminary qualitative study to explore what is on the ground and grassroots level. The results of the study shed light on the possible issues and are a preliminary study. However, it is unknown if these results would be the same among deaf people and their parents in different parts of the country. The results of this study have not provided sufficient evidence to be generalised to the Malaysian population. Hence, with the themes that emerged from the data, future research may do a quantitative study on perception or attitude towards deaf people for parents and the community. Data on the awareness of the available resources and needs in the Malaysian context of 2023 onwards may also be collected to get an updated national view of the current situation in Malaysia.

This study is retrospective, as the participants' parenting experience was from 1980 to 2009. It investigated the outcome of earlier decisions and circumstances and how it has affected the child's identity. Future researchers are encouraged to investigate families that are currently in the beginning stages of parenting. For example, families who discovered their child's hearing impairment in the 2020s. Perhaps new changes with better technology and resources available would change parental decisions for the deaf child and thereby influence the identity development of deaf children. Future research may consider conducting a longitudinal study of the well-being and development of the deaf child to adulthood in Malaysia.

Other than that, this study focused on the parents' role in shaping the child's identity, but little emphasis was given to the role of teachers in the deaf child's life. Both parents and teachers are direct influences on the deaf child (Calderon & Greenberg, 2012). The schooling experience of the deaf child would also have a significant influence on the child's identity development. The school environment, mode of communication, teachers, and classmates play a role in the children's learning and learning about themselves in a bigger community. Hence, it is suggested that the role of the Malaysian school education system be investigated in future research on deaf children's identity development.

Lastly, this study only obtained some evidence about the poor awareness of deafness and deaf people based on the statements made by deaf people in their shared experience. It is suggested that a nationwide survey could be conducted on the attitude towards deaf people to create deaf and sign language awareness. The results would provide more evidence to effectively plan awareness workshops to change the negative views of deafness to positive ones. This will help the country plan effective strategies to prepare an inclusive society for the deaf community and achieve SDG 4 and 8 (equity and inclusivity) (United Nations Department of Economic and Social Affairs, 2023).

5.5 Conclusion

Deafness presents a unique challenge, encompassing both a physical disability and a linguistic identity. While Malaysia is in the process of transitioning from a medical and welfare model of disability to a more inclusive social model at the policy level, the implementation of this transition has been met with various challenges. The diverse perspectives on deafness within society have resulted in unmet needs for deaf individuals. Through an exploration of the experiences of deaf individuals and their parents from early development to the present, this research has shed light on the complexities of deaf identity and the barriers faced by the deaf community in Malaysia.

The study's findings underscore the urgent need for interventions that address the linguistic needs of deaf individuals and provide better support systems for parents raising deaf children. The interactions between the deaf and hearing communities significantly shape the identity of deaf individuals, highlighting the importance of creating inclusive environments that empower and support their diverse needs.

While this study did not identify a clear category or social identity among deaf participants, it is evident that they embrace their identity while seeking connections with various social groups to fulfil their needs. To promote the well-being of deaf individuals in Malaysia, it is imperative to raise awareness and educate stakeholders and society about deafness, sign language, and the unique needs of the deaf community. Without a shift in societal mindset and attitude towards deaf people and without continuous effort to empower deaf individuals, their well-being will continue to be at risk.

In conclusion, this research emphasises the importance of creating a more inclusive and supportive society for deaf people in Malaysia. By addressing the needs of the deaf community and raising awareness about deaf people, we can work towards a more equitable and inclusive society for all.

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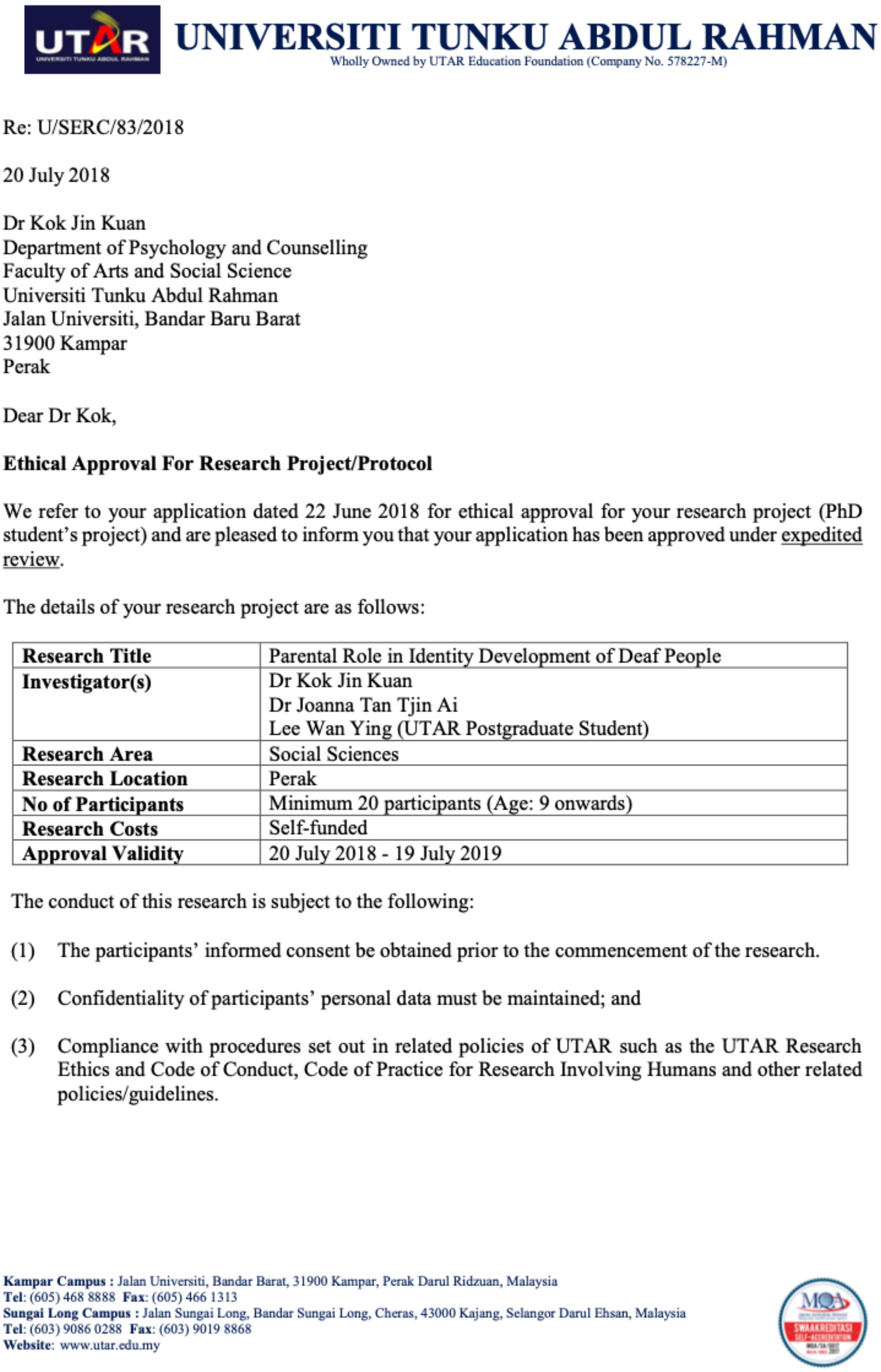
APPENDIX A



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Re: U/SERC/83/2018

20 July 2018

Dr Kok Jin Kuan
Department of Psychology and Counselling
Faculty of Arts and Social Science
Universiti Tunku Abdul Rahman
Jalan Universiti, Bandar Baru Barat
31900 Kampar
Perak

Dear Dr Kok,

Ethical Approval For Research Project/Protocol

We refer to your application dated 22 June 2018 for ethical approval for your research project (PhD student's project) and are pleased to inform you that your application has been approved under expedited review.

The details of your research project are as follows:

Research Title	Parental Role in Identity Development of Deaf People
Investigator(s)	Dr Kok Jin Kuan Dr Joanna Tan Tjin Ai Lee Wan Ying (UTAR Postgraduate Student)
Research Area	Social Sciences
Research Location	Perak
No of Participants	Minimum 20 participants (Age: 9 onwards)
Research Costs	Self-funded
Approval Validity	20 July 2018 - 19 July 2019

The conduct of this research is subject to the following:

(1) The participants' informed consent be obtained prior to the commencement of the research.

(2) Confidentiality of participants' personal data must be maintained; and

(3) Compliance with procedures set out in related policies of UTAR such as the UTAR Research Ethics and Code of Conduct, Code of Practice for Research Involving Humans and other related policies/guidelines.

Kampar Campus : Jalan Universiti, Bandar Barat, 31900 Kampar, Perak Darul Ridzuan, Malaysia
Tel: (605) 468 8888 **Fax:** (605) 466 1313
Sungai Long Campus : Jalan Sungai Long, Bandar Sungai Long, Cheras, 43000 Kajang, Selangor Darul Ehsan, Malaysia
Tel: (603) 9086 0288 **Fax:** (603) 9019 8868
Website: www.utar.edu.my

Should you collect personal data of participants in your study, please have the participants sign the attached Personal Data Protection Statement for your records.

The University wishes you all the best in your research.

Thank you.

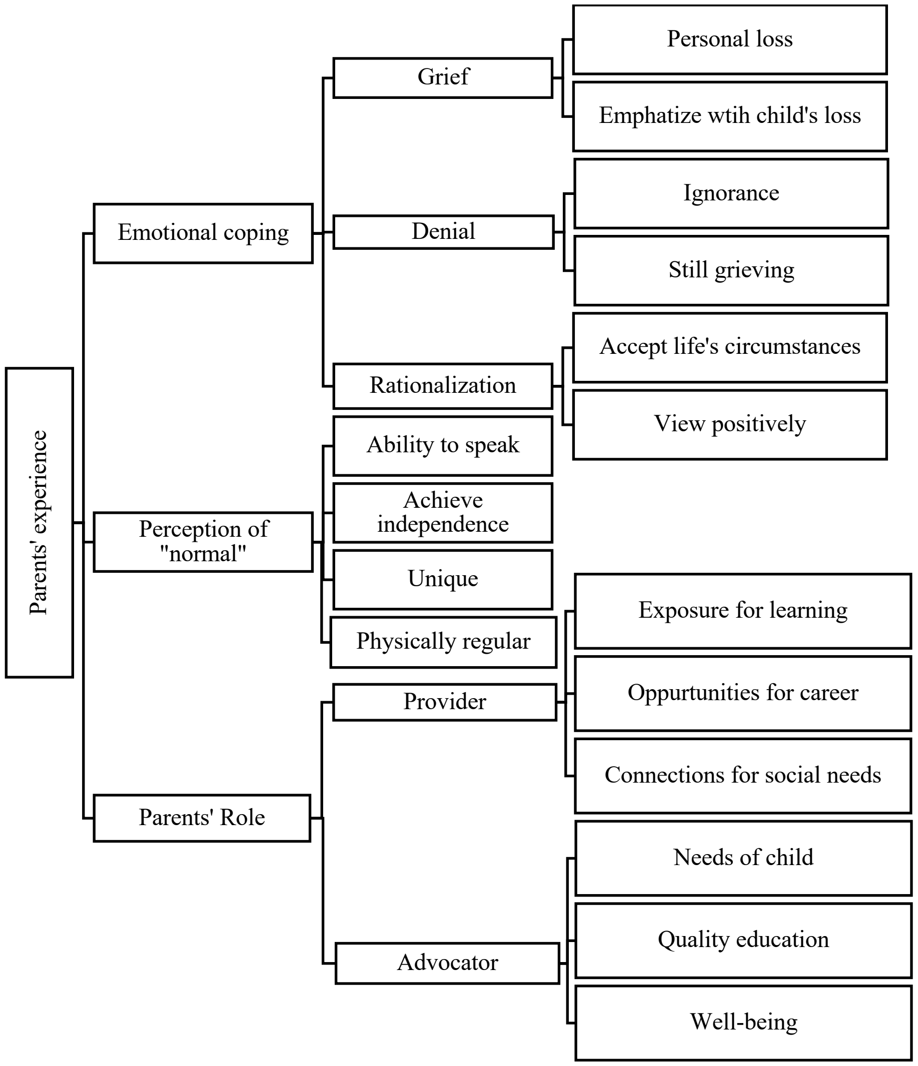
Yours sincerely,

Professor Ir Dr Lee Sze Wei
Chairman
UTAR Scientific and Ethical Review Committee

c.c Dean, Faculty of Arts and Social Science
Director, Institute of Postgraduate Studies and Research

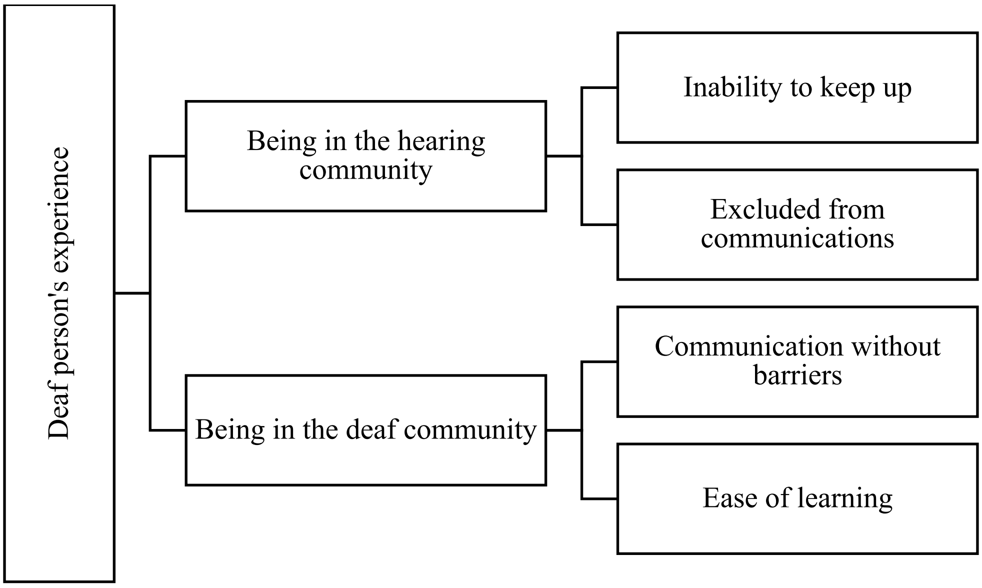
APPENDIX B

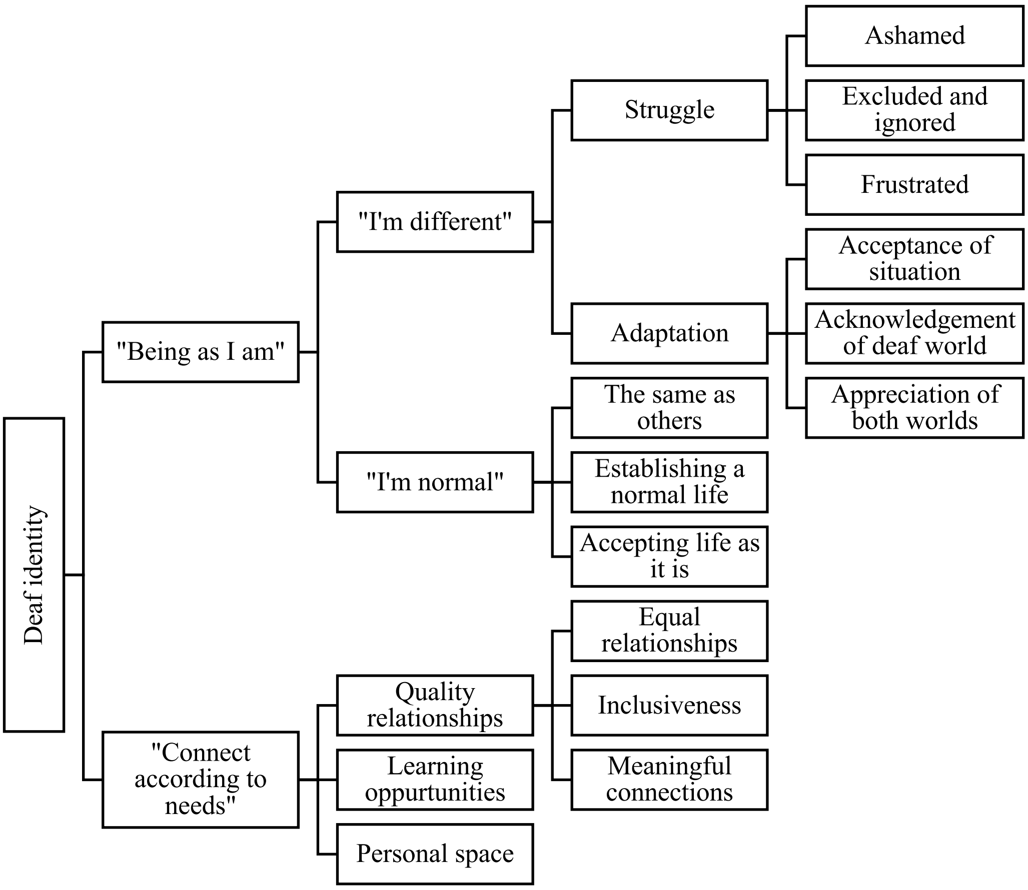
Themes and Codes of Research Question 1



APPENDIX C

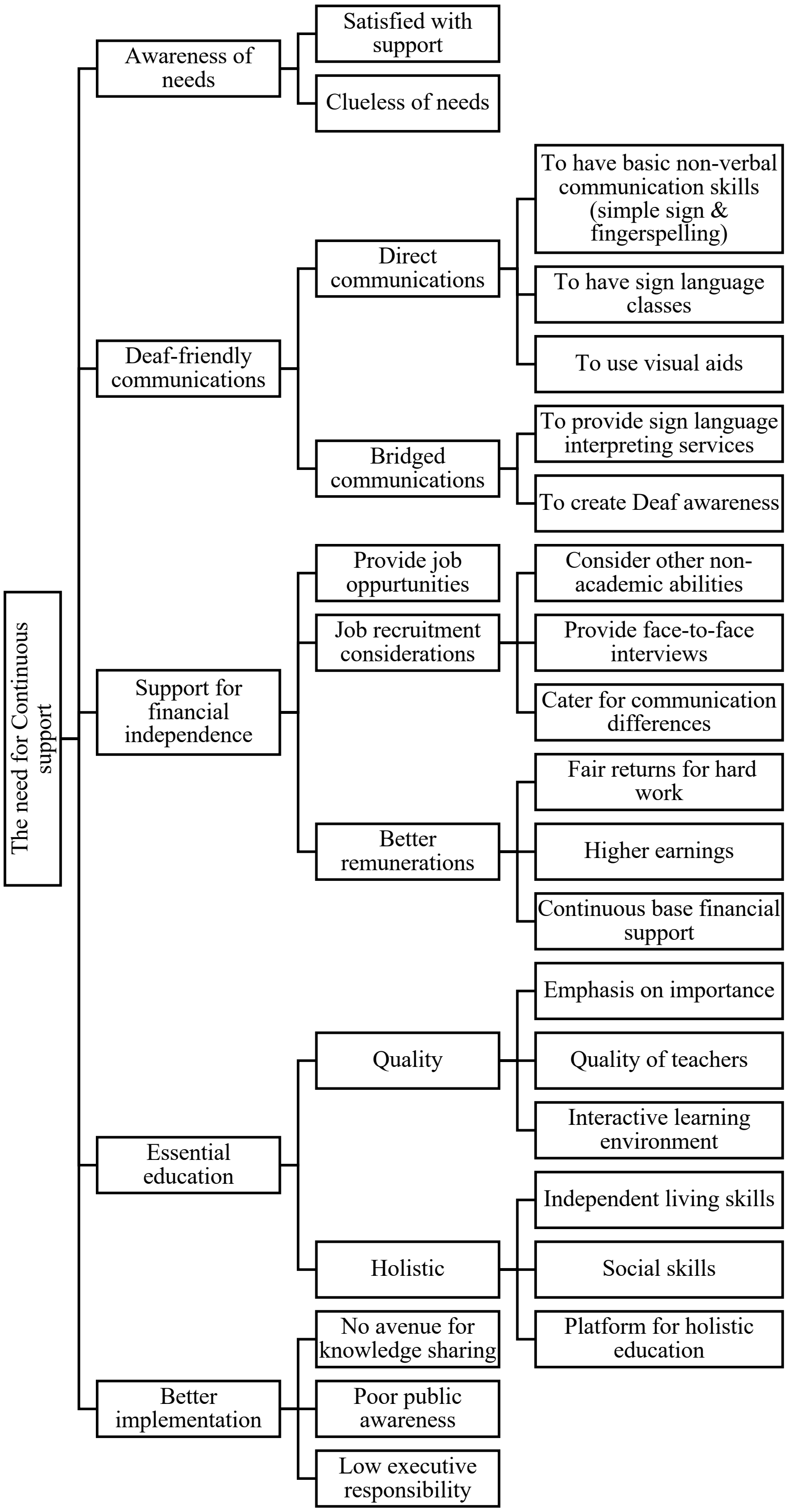
Themes and Codes of Research Question 2





APPENDIX D

Themes and Codes of Research Question 3



APPENDIX E

Example of Observational Checklist

Observational Checklist

Date: ____________; Time: ____________; Event: ____________________
No. of people: __ deaf; ___ hearing interpreters; ___ hearing signers; __ hearing non-signers

Interaction			
Who interact with		Type of interaction	
☐ deaf friend (peers)	☐ hearing friend	☐ one to one	☐ one to > three
☐ deaf older friend	☐ hearing stranger	☐ one to two	☐ big group
☐ deaf stranger	☐ others		
How many people interact with?		Type of interactor	How many people?
☐ 0	☐ 3	☐ Initiator	☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ > 5
☐ 1	☐ 4	☐ Waiting to be approached	☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ > 5
☐ 2	☐ >5		
Style of communication			
Comm with deaf	Comm with hearing interpreters	Comm with hearing signers	Comm with hearing strangers
☐ Sign language (eng) - pidgin	☐ Sign language (eng) -pidgin	☐ Sign language (eng) - pidgin	☐ Sign language (eng) pidgin
☐ Sign language (BIM)	☐ Sign language (BIM)	☐ Sign language (BIM)	☐ Sign language (BIM)
☐ SEE	☐ SEE	☐ SEE	☐ SEE
☐ KTBM	☐ KTBM	☐ KTBM	☐ KTBM
☐ Home sign	☐ Home sign	☐ Home sign	☐ Home sign
☐ Oral comm	☐ Oral comm	☐ Oral comm	☐ Oral comm
☐ Cued speech	☐ Cued speech	☐ Cued speech	☐ Cued speech
☐ Total comm	☐ Total comm	☐ Total comm	☐ Total comm
☐ Gesture	☐ Gesture	☐ Gesture	☐ Gesture
☐ ____________	☐ ____________	☐ ____________	☐ ____________
Conversational Topics			
☐ Family	☐ Friends	☐ Church	☐ Technology
☐ Deaf related activities	☐ Sports	☐ Food	☐ Entertainment
☐ Politics	☐ Weather	☐ Current news	☐ Others
Field Notes			

APPENDIX F

Participatory Observation Checklist Summary

	Deaf Participants’ Interaction							
Deaf Participants	1		2		3		4	
Meeting No.	1	2	1	2	1	2	1	2
Interaction								
Deaf friend	/	/	/	/		/	/	/
Deaf stranger		/		/	/			
Hearing friend	/		/	/	/	/	/	/
Hearing stranger		/		/	/			
Communication mode								
Malaysian sign language (BIM)	/	/	/	/			/	/
Pidgin sign language		/		/	/	/		
Sign Exact Malay/ English					/	/		
Writing					/	/		
Conversation topics								
Family	/	/	/					
Friends	/	/	/	/			/	/
Current happenings	/		/		/	/		/
Deaf-related activities		/					/	/
Food		/		/			/	

Note: Deaf Participants 5 and 6 did not attend the meetings.