

## PERSPECTIVES OF HEARING PARENTS AND THEIR DEAF CHILDREN: EXPLORING NEEDS AND SUPPORT SYSTEMS IN IPOH, MALAYSIA

Lee Wan Ying

Faculty of Arts and Social Science

Universiti Tunku Abdul Rahman, 31900 Kampar, Malaysia

Email: lwyiing@utar.edu.my

Joanna Tan Tjin Ai

Faculty of Arts and Social Science

Universiti Tunku Abdul Rahman, 31900 Kampar, Malaysia

Email: tanta@utar.edu.my

### ABSTRACT

*As deafness is an invisible disability, taking steps for early intervention is crucial for the development of deaf children. In Malaysia, policies and various forms of support are provided for families and their deaf children. However, the usefulness and effectiveness of these initiatives for hearing parents and their deaf children have remain largely unexplored, with limited feedback from both parents and deaf individuals regarding these implementations. This study explores the perceived needs and government support received by hearing parents and their deaf adult children. Six pairs of hearing parents and their deaf adult children from Ipoh were interviewed to understand their life experiences, including raising a deaf child or growing up deaf, as well as the resources and support they accessed. Thematic analysis revealed an overarching theme emphasizing the need for continuous support in four areas: awareness of needs, deaf-friendly communication, support for financial independence, and holistic education. These themes highlighted participants' perceptions of the gaps in existing resources and the additional support required. The findings also led to a discussion on the perception of needs and support systems from two different perspectives. The implementation of policies through welfare and social models also help shed light on the complexity of the deaf community's situation. While participants' narratives are retrospective, valuable insights on the challenges currently faced by the deaf community in Ipoh are identified. It is recommended that future research expand on the exploration of the deaf community's needs in other contexts, such as urban areas, different states in Malaysia, or among deaf individuals of different ethnicities or socioeconomic status.*

Keywords: Deafness, Lived experience, Malaysia, Perceived needs, Thematic analysis

### INTRODUCTION

#### PREVALENCE OF DEAFNESS IN MALAYSIA

In 2023, Malaysian statistics recorded 42,652 persons with hearing impairment nationally. This is 6.69% of the overall persons with disabilities (PWD) of 637,537 persons (Jabatan Kebajikan Masyarakat [JKM], 2023) and 0.13% of the Malaysian population of 33.4 million citizens (Department of Statistics Malaysia, 2024). In simple words, 13 individuals per 10,000 in Malaysia live with hearing impairment. Among them, 11.85% are children (aged 18 years and below), 23.23% are young adults (aged 19 – 35), 36.60% are middle adults (aged 36 – 59), and 28.32% are older adults (aged 60 and above) (Jabatan Kebajikan Masyarakat [JKM], 2023). These individuals are distributed unevenly across the country, with Selangor (6,713), Johor (4,646), and Perak (3,591) recording the highest numbers of registered individuals with hearing impairment. However, these figures may not fully represent the population, as many deaf individuals relocate for education, employment, or marriage, often clustering in cities and towns that provide better access to jobs and social connections (*Deaf in Malaysia*, 2021).

Developing countries like Malaysia face significant challenges in addressing hearing loss and its implications. According to World Health Organisation [WHO] (2023), 75% of preventable hearing loss cases occur in low- and middle-income countries, compared to 49% in high-income countries. In developing contexts, such challenges are compounded by limited services for those with hearing impairment, a shortage of trained professionals, and low public awareness of the needs of the deaf community (Mackenzie & Smith, 2009). Malaysia is no exception as it navigates the dual challenges of preventing hearing loss and ensuring holistic development opportunities for those affected.

Addressing the dual challenges calls for a deeper exploration of the realities faced by deaf people in Malaysia. It is crucial to understand the lived experiences of deaf individuals and their families, particularly in assessing the effectiveness of existing support systems and identifying persistent gaps. This study aims to explore these issues through the perspectives of hearing parents and their deaf adult children, offering insights into the unique needs and challenges of the deaf people in Malaysia.

#### SUPPORT SYSTEM AND RESOURCES IN MALAYSIA

A strong support system is essential for parents to effectively care for their deaf child and promote the child's development. Such a system can help parents manage the unique challenges associated with raising a deaf child, including parenting stress and emotional well-being (Yap et al., 2018; Zaidman-Zait et al., 2016) as well as decision-making about early interventions and communication interventions (Rees et al., 2015, Porter, Sheeran, Hood, & Creed, 2021; Fitzpatrick, Jacques, & Neuss (2011). Without adequate support, parents may struggle to meet both their own needs and the special needs of their child, potentially hindering the child's crucial developmental progress. A comprehensive support system should include the professional resources

offering family-centred services and coping services (Poon & Zaidman-zait, 2014), parental resources (Hintermair, 2006), and information resources on the role of sign language in language acquisition, cognitive development, and literacy (Humphries et al., 2019). Social support, including parent-to-parent networks (Henderson et al., 2016) is also vital. Notably, social support has been shown to improve parental coping and overall well-being (Åsberg et al., 2008; Hintermair, 2006; Poon & Zaidman-zait, 2014). These resources are critical in enabling parents to provide a nurturing environment that supports the deaf child’s early childhood development.

As for the resources available in Malaysia, the government and various organisations in the country provide support services such as early intervention, family support, education, and parent support groups. These organisations 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, however, the services offered and quality of social support systems may vary according to its locality. Organisations such as YMCA Kuala Lumpur have more established services and support for deaf people (YMCA of Kuala Lumpur, 2021). For example, sign language classes, activities for the deaf community, pre-school for deaf children. While much of the focus has been on developing the deaf community in major cities like Kuala Lumpur, smaller cities such as Ipoh have seen comparatively less development. Although Ipoh is a city, there are only three known organisations 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. Parents of deaf children are usually referred by healthcare personnel in hospitals to rehabilitation programs such as speech therapy or early intervention programs in Ipoh. Although there is support given in the form of rehabilitation programs, the development of sign language in communication is still lacking, leading to underdeveloped communication skills, especially in deaf children.

On the other hand, the strategization and implementation of action plans for PWDs in Malaysia by the government through KPWK (Kementerian Pembangunan Wanita Keluarga dan Masyarakat [KPWK], 2017) is commendable. However, the action plans are for all disabilities and may not address the specific needs of people with hearing impairment. There has been little documented feedback from deaf people about the implementation of these 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 play a vital role in influencing the development of the deaf person’s identity. Therefore, there is a need to explore the perceived need in the support system of deaf children and their parents.

**METHODOLOGY**

This study adopted the ethnography approach to explore the often-marginalised deaf community. It provided an insider’s perspective for a deeper understanding and authenticity into the diversity of deaf people’s lives. Upon ethical approval, recruitment was done through purposive and snowball sampling. Six pairs of hearing parents and their deaf adult children were interviewed. The parent-child pair were selected based on the criteria – (1) the deaf participant was the only deaf child in the family; (2) the deaf participant was aged between 18 and 40 years old; (3) Chinese ethnicity; and (4) an Ipoh resident. Table 1 below is a brief description of the participants.

**Table 1: Description of Participants**

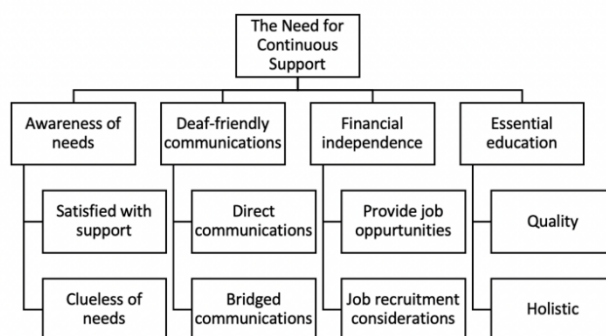
Parent-Child Pair	1	2	3	4	5	6
<b>Deaf Participant</b>						
Gender	Female	Female	Female	Female	Male	Male
Age	20	24	34	37	36	25
Hearing Status	Severe	Profound	Profound	Severe	Profound	Profound
Cochlear Implant	No	Yes	No	No	No	No
Hearing Aids	No	Yes	No	Yes	No	No
Education Level	Diploma	Diploma	Diploma	Diploma	Secondary	Diploma
<b>Hearing Parent</b>						
Gender	Female	Female	Female	Male	Male	Male
Age	48	55	60	70	69	65
SES	Middle	Middle	Low	Low	Middle	Middle
Education Level	Secondary	Secondary	Primary	Primary	Secondary	Tertiary

Semi-structured interviews were carried out individually with each participant. The interviews were conducted in English or Chinese with the hearing parents and Malaysian Sign Language with the deaf participants. Each interview lasted between 20 to 30 minutes. Interview questions include exploring the experiences and opinions about the support system available for parents while raising a deaf child. Deaf adult children were also asked about their experiences and opinions about the support system in meeting their needs. The interviews were transcribed and further explored using thematic analysis. The verbatims were coded by two independent coders to increase inter-rater reliability. The codes were grouped according to their similarities and eventually formed a theme. Triangulation using observations and document analysis were used to cross-check and reduce bias. Reflexibility was also done to reflect critically on the researcher’s perspective and remain objective during data analysis.

**RESULTS**

Data obtained from the interviews led to the emergence of one main theme – The need for continuous support. This was further divided to four areas, namely (1) parents’ awareness, (2) deaf-friendly communication, (3) financial independence, and (4) essential education. Figure 1 shows the themes derived from the need for continuous support.

Figure 1: Themes of the Need for Continuous Support



**THE AWARENESS OF NEEDS**

The parents and deaf adult children did not provide much feedback on the support systems that were available. They were either aware of the needs that need to be addressed and satisfied with the support or clueless about the needs.

**Satisfied with support.** Parent 1 stated that “I received help needed from the day my child was suspected to have hearing loss until today”. The hospital helped her with the medical issue of hearing loss. She was provided with contacts to a special needs’ preschool, where the teachers and fellow parents provided the much-needed support and help. Sign language classes and social activities in the YMCA contributed to her daughter’s childhood development, in particular the socialization aspect. Her daughter completed primary and secondary education, and went on to obtain a diploma awarded by a polytechnic that catered for deaf students.

This was similar for Parent 2, who received good support from her doctor, financial help from the government. She also had knowledge about the education choices for her child with some help from her neighbours. Although there were some inconveniences in obtaining affordable services in Kuala Lumpur, she was thankful for the help received. She stated, “The hospital arranged suitable appointments for me. I’m thankful for the help.” In terms of the support system, no suggestions were given on the improvements. 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.

**Clueless about needs.** Other participants, however, seemed to indicate that they did not know the type of support or services that would be helpful for the deaf community. Deaf Participant 5 responded, “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 and did not provide further suggestions for improvement.

Deaf Participant 3 also stated “Nothing. I don’t know.” when asked for her opinion about her needs. She was not involved in the deaf community and hence did not know or have anything to suggest for improvement. She had been isolated from the deaf community since her completion of school education. 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.

Participants’ responses “no”, “not sure”, “don’t know”, “nothing” 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 2 below, all parents were aware of the medical interventions that the government provided, for example cochlear implants or hearing aids. These actions of support by the government highlighted an emphasis on restoring hearing abilities, which is only seen as a medical condition that can be treated.

Table 2: 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 participants' awareness of the support given by the government.

### DEAF-FRIENDLY COMMUNICATIONS

The second subtheme that emerged from the interviews is the need for *deaf-friendly communications - direct communications and bridged communications*.

**Direct communications.** Deaf participants understood their limitations in communicating through speech and hearing. Although they know that they would not be able to keep up with spoken conversations without hearing, there is a persistence to be included in the communication. To reduce this “dinner table syndrome” (Meek, 2020), deaf participants suggested direct communication by using basic non-verbal communication and visual aids. 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. Or, if they don’t know how to sign, they can fingerspell.’ (Deaf Participant 2)*

*‘Hearing people in America can sign. Why not Malaysians? They can just learn the basics like ABC? Not expecting the difficult ones. Just one simple sign. Everyone can learn ABC. It is helpful for everyone to be able to communicate a tiny little bit, even if it is just using ABC.’ (Deaf Participant 4)*

**Bridged Communications.** When direct communication with the deaf person is not available, the next best way to bridge communication is 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 was 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 due to her experience of being in situations that led to a communication breakdown, she emphasized the need for bridged communications as 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. I would like to have access to information like hearing people.’ (Deaf Participant 4)*

### FINANCIAL INDEPENDENCE

The results revealed that there was also the need for *financial independence*, where deaf people would have more job opportunities, job recruitment considerations, and better remunerations at work. Parent 5 expressed the lack of job opportunities for the PWDs in general. He stated:

*‘1% of government staff must be PWDs. I went to the labor department a few years back to ask if there were any vacancies. There was none. My (deaf) son registered but no one called. Why didn’t they call back to tell us that there are no vacancies? At least, give them a chance to be interviewed. And if they failed to get the job, it’s okay. Since my son was 18 years old until now (39 years old), he did not receive a single call from the labor office in labor... until today, no governmental department have that 1% of PWD workforce. Let them be office boy. At least, they got a job. They may not be very educated, but at least a job for them – photocopy, sweeper, etc... just create a job for them.’ (Parent 5)*

He shared that although 1% of government staff must consist of PWD staff, he found that there were no job opportunities for his deaf son (Deaf Participant 5). He concluded that there was a flaw in the execution of the One Percent Employment in Civil Service for Persons with Disabilities Policy (PP16/2010).

Other than job opportunities, there was a concern about the job recruitment process. Deaf Participant 4 tried to apply for 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. She stated:

*'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)*

Deaf Participant 4 also pointed out how deaf people were easily discriminated against for job opportunities because of their poor academic performance. 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 screening criteria. Even though a 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 her age (mid-30s). It was seen as 'death sentence' in her career journey due to the failure in her early academic years. She stated, *"At this age, I do not have the energy and time to 'correct that mistake'. I mean, do you want me to resit for my SPM again?"*. 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.

## ESSENTIAL EDUCATION

The other theme emerged from the data was education for the deaf child. Only three participants (Deaf Participant 4, Parent 5, and Parent 6) highlighted the importance and need of essential education for deaf children. They gave feedback about the education for deaf students and indicated a need for a more holistic education. This is their feedback:

*'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 classes - some additional courses to help us focus rather than staying at the hostel. You can ask questions, and they test you. It is easier to learn with this two-way interaction. If teaching is just one way, we nod our heads and easily forget what was taught.' (Deaf Participant 4)*

*'We took them (deaf children) 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)*

*'We want to expose the children to see that there are deaf people in old folks' homes. We made sure the children fed them. The children also danced for the old folks.' (Parent 5)*

Participants felt that education should not be limited to academic performances and the traditional classroom but extend to learning different skills that involves experiential learning – 'holistic education'. The feedback given by participants indicated that out-the-class activities can help the deaf learn 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.

## DISCUSSION

This study explored the experiences and opinions of hearing parents and their deaf adult children regarding the existing support system for deaf individuals. The results revealed that participants were either unaware of the needs of the deaf community or expressed satisfaction with the support provided. This reliance on government support may inadvertently hinder the development of deaf individuals, as government systems often face resources limitations and underdevelopment.

The support system and resources available in Malaysia are predominantly based on the medical and welfare model of disability. Although the official list of provisions for deaf individuals is extensive – covering areas such as financial aid for medical treatment, transportation, and education – the focus remains primarily on hearing rehabilitation and speech development. Even within this framework, there are notable limitations: while hearing aids are provided, cochlear implants and speech therapy are not included in the government's provisions.

Early intervention programs in Malaysia are predominantly rooted in the medical model of rehabilitation, focusing on measures to restore hearing. However, there is a lack of emphasis and resources aligned with the social model of disability, which prioritizes language learning and communication development of deaf children. Resources for learning sign language for communication are limited to certain contexts. This contrasts with early intervention programs in other countries, which emphasize parental support and equipping deaf children with language and communication skills, rather than relying solely on medical professionals and hearing rehabilitation as the primary option. Recent research has increasingly advocated for 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).

Overall, all parent participants were aware of the government's provision for their deaf children. Policies constructed based on the social model such as the one per cent employment for Persons with Disabilities (PWD) and inclusive education initiatives, indicate progress towards inclusivity. However, the findings highlight that the majority of the community in Ipoh continues to operate predominantly within the medical-welfare model and has been slow to transition to the social model. Lee and

Low (2014) aptly described Malaysia as being a 'late starter', highlighting concerns about the country's slow shift from the medical-welfare model to the social model.

The study's findings highlight the critical need to address key areas such as *deaf-friendly communications*, *financial independence*, and access to *essential education*, offering valuable insights into the situation in Ipoh. Participants' feedback and suggestions offer practical guidance for strengthening support systems to better serve future parents and their deaf children. These results underscore the importance of collaboration among the government agencies, educators, parents, and society to meet the communication and social needs of the deaf community across their lifespan while ensuring tailored, inclusive support.

## CONCLUSION

While this study provides valuable insights, its scope is limited to the experiences of Chinese families in Ipoh from 1982 to 2019. These findings may not have fully captured the diversity of experiences across different ethnicities, socioeconomic status, or different settings in Malaysia. Future research may explore the perspectives of families from various backgrounds and regions. Such studies could offer a more comprehensive understanding on ways to enhance the support system for the deaf community nationwide.

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