

## The Inclusion of Deaf Children in Malaysian Primary Schools: Parents' Experiences and Advocacy

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**Abstract:** Malaysian law has developed to improve the support received by pupils with disability. A national review of policy and provision for pupils with disability and their families is gathering momentum. This article draws on the findings of a study conducted in three primary schools, involving interviews with seven parents, five school leaders, five mainstream teachers, five specialist teachers and three teaching assistants in the most developed state, Selangor, Malaysia. The study was guided by the following research question: 'What are stakeholders' experiences of the inclusion of deaf children in mainstream schools?' Findings revealed that networking can help parents to build confidence and social capital in order to better support their children. This emerging trend among parents to advocate and take a leading role in supporting their children's educational needs demonstrates a concerted effort to encourage the acceptance of children with diverse needs. Professionals working with deaf children need to be trained to deal with the different opinions about which mode of communication to use, where to educate a deaf child, and what are the best methods to use to teach deaf children, because these have been ongoing sources of controversy and seem likely to continue to be debated. One way to understand the inclusion of deaf children is from the perspective of 'dimensions of inclusion'. These dimensions include location, curriculum, language and communication, acoustics, amplification, friendship and socialisation and are all inter-related.

**Keywords:** Deaf children; inclusion; inclusive education; malaysia

### INTRODUCTION

In response to the global trend to promote equitable and inclusive education for all children, the government of Malaysia is committed to eliminating discrimination against people with disabilities. Malaysian law has developed to improve the support received by pupils with disability. A national review of policy and provision for pupils with disability and their families is gathering momentum. The government has a target of ensuring that 75% of children with disabilities, including deaf children, are educated in mainstream classrooms by 2025 (Ministry of Education, 2013). In contrast, the government is also committed to retaining special schools as part of a broad spectrum of provision and to enable parents to choose a special school placement for their child if that is their preference. There are only approximately 1% of deaf children being educated in the official government Inclusive Education Programme. This statistic only includes those in special school and Special Education Integration Programme settings. Deaf children in mainstream schools are not formally registered so it is currently unknown if there are more or less unidentified deaf children enrolled in mainstream schools.

Primary prevention of hearing loss through immunisation, health education, and improved maternal and child health services has been the government's priority. Services to support children's audiological and speech needs have improved greatly since the introduction of audiological support in the 1960s. The Ministry of Health has provided cochlear implants to more than 600 severely and profoundly deaf children since 1995 (Mukari, Ling, & Ghani, 2007). The introduction of the Newborn Hearing Screening in 2001 has enabled deaf children to be identified before their first birthday. In Malaysia, support from teachers of the deaf is only available when children attend schools and there are no specialist teachers available to support deaf children outside of special education services (Khairuddin & Miles, 2020). Therefore, parents are more likely to have contact with medical professionals than with educationalists before their children start school. Doctors and audiologists have the most influence on deaf children's mode of communication as they are involved in the

initial diagnosis and the fitting of hearing aids. Subsidies are available from the Government, however, approval of these subsidies can take up to two years so parents often have to cover the cost of the technology and its maintenance (Yusoff, Umat, & Mukari, 2017). While families are coming to terms with their child's deafness diagnosis, they must also understand the management of hearing technology and its benefits.

The majority of deaf children are born to hearing parents with no experiences to draw upon, no expectations to refer to, and no close family or friends to consult. There are many issues for parents to consider in deciding their child's communication needs. Increasingly, initiatives are supporting the learning of sign language but there are limited resources available. Support for learning BIM (Bahasa Isyarat Malaysia – Malaysian sign language) is only provided by NGOs, such as the Malaysian Federation of the Deaf, and training for interpreters is also limited. Therefore, parents often experience difficulties to make appropriate decision to develop their deaf children's language and communication skills before they turned three; when the ability to learn a language becomes more difficult (Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013).

The presence of deafness in a family has the potential to affect all areas of family life. When they receive news about their child deafness, parents often have negative feelings and thoughts (Jackson & Turnbull, 2004). Given the complexity of deafness, the often confusing process of identification and intervention for deaf children, especially when parents lack sufficient information and resources, they are left to make decisions about the intervention, communication and educational needs of their deaf child (Young et al., 2006). Parents tend also not to be prepared for the implications of their decisions. Following the identification of deafness, there are many decisions that parents have to take on behalf of their children that have long-lasting implications on the life of the children as well as their other family members. The perspective of families and children about their experiences of deaf children's inclusion is poorly represented in the literature, especially in low and middle income countries.

## METHOD

This paper explores the initial stages of the development of an inclusive and equitable education system for deaf children in Malaysia from the perspective of parents. The data reported here are taken from a larger study which explored a wider group of stakeholders' experiences of inclusion. Individual semi-structured interviews (Kvale & Brinkmann, 2009) were conducted in 2016 with thirty-seven (37) participants, including two deaf adults, three head teachers, two SEIP coordinators, three SEIP teachers, five mainstream teachers, two teachers of the deaf, three teaching assistants, seven parents of deaf children, seven deaf children and three of their hearing classmates. The seven deaf children and three classmates in the study were aged between 9-13 years and were attending three mainstream primary schools. The larger study shed light on the experiences of deaf children from their identification at the age of three, to the experience of some deaf adults in higher education (Khairuddin, Miles, & Mccracken, 2018). All recorded data were transcribed and analysed with computer assisted qualitative data analysis software (CAQDAS) Nvivo 10 (Gibbs, 2005). A thematic analysis approach was applied to identify patterns through a rigorous process of data familiarisation, data coding, and the development and revision of key themes (Braun & Clarke, 2006).

## RESULT AND DISCUSSION

The parents in this study come from a wide range of backgrounds. Some were able to afford hearing aids and were willing to spend a considerable amount of money on the more advanced audiological technologies, while others believed that their deaf child's difficulty in speaking is the result of a supernatural force, and that one day they would be able to speak. The mothers' level of education ranges from high school certificate to a doctoral degree.

The deaf children were born in 2003 to 2007. This means that after the establishment of the Institute-HEARS cochlear implant centre in 1995 and the introduction of the High Risk New-Born Hearing Screening (HRNHS) program in 2001 but before the actual implementation of Universal Newborn Hearing Screening (UNHS) in public hospitals in 2009. Hearing assessment that was initiated by the medical team as a result of family history and illness has enabled the child to be assessed as soon as possible. In the lack of Universal Newborn Hearing Screening procedure implementation, parents' observation plays a significant role to initiate the diagnosis. Unilateral and mild bilateral hearing loss might be undetected until at the later stage when the language and communication gap is obvious compared to other children. The lack of parental knowledge and awareness of a child's language development milestone and superstitions further complicate the process of early identification.

'Losing time' emerged as one of the themes identified from the analysis of parents' experiences of their child's deafness. Substantial delays occurred between the identification, confirmation and intervention for all the parents. Another theme which emerged from the parents' experiences is the limited information

within their environment about how to support their deaf child. The considerable amount of efforts made by the parents to help their child to develop speech had strong influences on children's experience of inclusion in school.

While advanced medical services are available, guidance for parents on how to make decisions about educational provision for their deaf children is not provided. The child or family have to fit an existing service delivery model, rather than being offered an individualised plan that meets the specific developmental, communicative, educational, and social needs of the child and the family. There is a contradictory approach between the intervention by medical professionals with deaf children, and the mode of communication promoted by teachers of the deaf in schools. The general assumption that all deaf children communicate using sign language conflicts with and undermines the parents' aspirations for their children to continue learning to speak, as encouraged by the speech therapists.

Some parents regard the teachers as the experts in their children's education. Four of the seven parents think that there is only one way of educating deaf children – and that is in a specialist facility. These parents want their child to receive individual support so the organisation of deaf children into small special 'units' is considered to be appropriate, but three parents think otherwise. Those parents with a higher level of education played a stronger advocacy role in their deaf children's inclusion in education. These parents sought information on the internet, can afford the cost of private resources and intervention for their deaf child. One parent participated in the organisation of parents of deaf children. They perceive the placement of deaf children in mainstream classrooms as important in helping the development of spoken language and social skills.

## CONCLUSION

Findings from the parents reflected the complexity of deafness and its implication to the inclusion debate. The starting point of the parents varies, and this has an influence on the identification, amplification and intervention process. The parents lost time and had limited information in supporting their deaf child. Parents who are more aware, knowledgeable and willing to provide optimal support for their children will be in a better position to formulate their child's needs and ensure these are met. In order for deaf children to be included, being identified and early intervention is important to develop a child's language. Without effective language and good communication skills, children cannot be expected to fully participate in school. The fact that 'special education' is the dominant approach to educate deaf children represents a considerable barrier to the children participating in education.

Parents who were frustrated ended up neglecting the child or were unable to stay committed. This had a direct impact on children's wellbeing, as is the case in other developing countries such as Cameroon and Zimbabwe (Wilson, Miles, & Kaplan, 2008). The Government's initiatives on inclusion are in line with the agenda to increase the profile of those with disabilities so that the societies are more aware of their needs rather than denying their existence. Parents who are able and willing to spend time and money on supporting the deaf children's language and communication skills following their identification, were more likely to be committed to taking ownership of the decision they made for their child's communication and education.

This emerging trend among parents to advocate for and take a leading role in supporting their children's educational needs demonstrates a concerted effort to encourage the acceptance of children with diverse needs. The movement has been successful in including deaf children into mainstream schools, within their community, rather than in residential settings, in line with the government campaign to move towards an inclusive education system. Attending local schools raises awareness of diversity, increasing children's social inclusion as well as providing more opportunities for them to use hearing more effectively and develop greater spoken language abilities.

Professionals working with deaf children need training to understand that there are many ways of developing children's communication skills, and different approaches may need to be considered for each child. But most importantly professionals must be prepared to take parents' opinions seriously because a supportive parent will have been developing their child's communication for several years before they start school. More research in middle-income countries is needed to understand how deaf children learn in inclusive settings, particularly on the outcome of children fitted with advanced amplification.

Finally, the questioning and challenging of education practices must never slip out of the overall aim and purpose of education – despite these too are contested. In reality, deaf children of today are the citizens of tomorrow with all the rights and responsibilities to contribute to the 'people and planet' (UNESCO, 2016). The basic principle of education provided to all children including deaf children that reflect this wider agenda is argued to be necessary to promote sustainable futures.

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