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Reframing Inclusion: Cross-cultural interventions for families with Deaf children in Swaziland

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REFRAMING INCLUSION: CROSS-CULTURAL INTERVENTIONS FOR FAMILIES OF
DEAF CHILDREN IN SWAZILAND

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PIM 72

Independent Practitioner Inquiry Capstone
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Date: August 13, 2015

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ABSTRACT

Deaf children and their families continue to remain at the margins due to lack of services available. While previous studies acknowledge the necessity of having an Early Identification and Family Intervention program, measures have not been taken to implement such a program in Swaziland. This study emphasized the importance of adopting cross-cultural approaches to bridge the communication and cultural gap between Deaf children and their families. This paper asked the question: *What interventions can be implemented in Swaziland in order to encourage the integration and inclusion of Deaf children into their families?*

The three data collection methods used were: a questionnaire for parents and caregivers at one school for the Deaf, and semi-structured interviews by six parents and eight Deaf students. Findings revealed that there is a gap visible between the existing policies and the practices that are put into place when it comes to inclusivity. This is largely due to insufficient resources and services available to assist Deaf children and their families, which in turn perpetuates the language and communication gap experienced. The study also revealed the attitudes and beliefs shared by parents and caregivers, and the lack of awareness of the steps to take to ensure inclusivity. Thus, there is great room for improvement in terms of building the capacity of, and establishing additional services for Deaf children and their families.

INTRODUCTION AND STATEMENT OF RESEARCH QUESTION

The purpose of this study was to gain insight into the existing attitudes and beliefs held by parents and caregivers towards their Deaf¹ children. The findings will influence the additional goal of this research, which is to design and implement an Early Identification and Family

¹ To clarify, “Deaf” will be used to reference all individuals who are either medically or socially Deaf. The big “D” tends to indicate a person who identifies as socially Deaf, whereas the little “d” tends to represent a medical diagnosis. For simplification purposes, the researcher has chosen to refer to all Deaf people and cases of deafness using the big “D”, particularly as the study refers to a specific cultural group.

Intervention program in Swaziland. The main objective of this study was to understand what resources and assistance should be given to families with Deaf children as a means to encourage greater access to education and psychosocial support. This corresponds with sub-questions focused on the existing knowledge and experiences shared by parents and caregivers, as well as Deaf youths in Swaziland surrounding deafness.

The methodology for this study involved a series of interviews with relevant stakeholders². The research also indicates the significance of incorporating cross-cultural mediation and intercultural communication into a program of this form, especially given that the majority of parents and students identify as members of differing cultural groups (Leonard et. al, 2003; Sass-Lehrer, 2002; Störbeck, 2012). Finally, it is the hope that this research will result in sensitizing families and health care professionals in Swaziland on Deaf culture, seeking to dismantle the stigmatization that Deaf individuals face.

PROBLEM STATEMENT

The majority of Deaf children are born to hearing parents who have rarely experienced deafness prior (Feher-Prout, 1996). Parents tend to move through a spectrum of emotional responses to this news, often beginning in a state of grief, shock and denial, as well as feeling guilty and ashamed. In fact, the phrase “ngeva buhlungu” is commonly used by parents to describe feelings of pain and heartache upon learning of their child’s deafness in Swaziland. Initial responses might include hiding their child, or even visiting traditional healers as a means to correct the child’s deafness. Bearing these issues in mind and as a result of this study, it is vital that measures be taken to provide the much needed support and guidance to Deaf children and their families. Moreover, there is an apparent lack of research relating to deafness in

² Including parents and caregivers of current students, as well as students enrolled at a school for the Deaf

Swaziland. There is a lack of recorded information regarding the number of Deaf children living in Swaziland. This includes statistics on the number enrolled in mainstream schools. A study assessing the attitudes and knowledge in regards to deafness has also never been conducted. Thus, the data gathered from this study will benefit various stakeholders in the future, as resources and services develop.

My experience as a Peace Corps Volunteer in the Youth in Development sector in Swaziland at a school for the Deaf led me to this project. I have been working on a variety of programs centered on confronting the communication gap existing between hearing and Deaf individuals. In working closely with the students, teachers and house parents at the school it became clear that a program designed to provide guidance and support to parents and caregivers is necessary in order to help current and future students not only access education, but also pave the way for greater inclusion of Deaf individuals in all facets of society.

RESEARCH QUESTIONS

The overarching question driving this research is: **What interventions can be implemented in Swaziland in order to encourage the integration and inclusion of Deaf children into their families?** The following sub-questions were considered in order to further develop the main question:

Barriers affecting acceptance:

1. What attitudes and beliefs do parents and caregivers hold or express towards their Deaf children?

Family Interactions and levels of Integration:

2. What cross-cultural practices can be implemented to best mediate positive family-child interactions?

CONCEPTUAL FRAMEWORK & CONTEXT RELATED TO THE PROBLEM

The study sought to better understand the existing barriers to the inclusion of Deaf children into their families, working to identify the attitudes and beliefs held towards deafness by caregivers and parents. The information compiled will assist in the creation of interventions aimed at providing support and guidance to parents and caregivers of children who are Deaf or hard of hearing (D/HH). As there are currently no available services in this area, research will play a significant role in creating the foundation for this program. Research was conducted through the distribution of a questionnaire to parents and caregivers at one school for the Deaf, and use of semi-structured interviews with both parents/caregivers and Deaf children. Resting at the heart of this issue, is the need to reframe the way in which a hearing person and the professional, understands and relates to the idea of hearing loss or deafness. Bauman and Murray (2009) describe this reframing as “Deaf gain”. They argue,

Deafness has long been viewed as a hearing loss –an absence, a void, a lack. It is virtually impossible to think of deafness without thinking of loss. And yet, Deaf people do not consider their lives to be defined by loss” (pp. 3).

It is of particular importance to understand the continuum within which the frame of deafness is bound. On one extreme, is the medical model, the ideology that understands “deafness as a pathology, focusing on the cures or mitigation of the perceived handicap”, while on the other end, the social frame of deafness falls more in line with this concept of “Deaf Gain” (Senghas & Monaghan, 2002, pp. 69).

Within the social model, emerges a need to appreciate sign language and Deaf culture as valid in its own right. Although, this perspective has often been overshadowed by the medical model. Dotter (1999) illustrates that the systematic devaluation of sign languages as legitimate forms of communication has no scientific support. He notes that negative perceptions of sign

language, such as “Because all of us are competent in gestures (‘body language’), we are either already competent in sign language...” lend to a “negative evaluation of the capacity and/or efficiency of signed compared to spoken languages” (p. 4). These negative perceptions tend to seep into the way in which hearing people view D/HH individuals.

Under the medical framework, D/HH people deviate from societies’ perceptions of “normal”. Thus, the language and culture celebrated by this group of people is devalued as equally abnormal. In fact, the expressive ability of people is a crucial aspect of how intelligence is perceived and interpreted. Therefore, the presence of a language and cultural barrier critically shapes the beliefs and attitudes shared not only by parents and caregivers of D/HH learners, but the learners themselves.

In a study conducted by Obasi (2008), “it contends that the continued use of the word deafness is unworkable and should be more widely recognized as a social construct, which has current usage beyond the paradigm in which it was originally intended” (pp. 455). In order to dismantle such perceptions, the way in which they are constructed and reinforced needs to be understood and criticized. Obasi (2008) continues, “Some important dimensions to identity discourse are those of power, powerlessness, identity as a source of power, and the intersection between the three” (pp. 456). Understanding the power dimensions that exist between hearing parents and the Deaf youth as a linguistic and cultural minority is key to addressing barriers to change and creating interventions that will serve to mitigate this imbalance. A fundamental component of this study was the need to consider the unique identities of all participants, thus validating their experiences, cultures and languages.

Meadow’s (1969) notes, internalizing beliefs and associations becomes a subconscious process, reinforced by an individual’s experiences with the people he or she interacts with

throughout life. A D/HH child's identity construction needs to be understood in order to ensure that interventions are carefully designed to foster positive interactions between parents and caregivers and the child. Meadow (1969) furthers

Language in the usual sense does not develop naturally among deaf children as it does in normal hearing children. Neither receptive nor expressive communication with others through speech is available to a Deaf child without a prolonged and arduous course of special training in lip-reading and voice production (pp. 429).

This "arduous course" is the first step that D/HH individuals take in the game of inclusion, the goal being to achieve the best methods in imitating what is perceived to be "normal". It is clear that the medical model of deafness is embedded in much of the past research on subjects relating to deafness and Deaf identity. This is perhaps in large part because the majority of early studies written about D/HH individuals have been written by hearing professionals in specific fields (i.e. health, education, etc.). This poses an interesting caveat: the D/HH experience is at the risk of being defined by people who can never fully understand Deaf culture and identity. Regardless of the tone through which research is narrated, it acts as an artifact, revealing common or generic attitudes and beliefs held about deafness and Deaf culture, and even sign language.

Paradoxically, I too am at fault for maintaining this conundrum. I myself am not Deaf, nor have much experience in Deaf culture. For this reason exactly, it was necessary to consider the frame through which one gazes upon a situation, and also the voices present in validating what is witnessed. Therefore, throughout the process of this study, consideration will be made to recognize and legitimize the various voices and narratives shared by the participants. This precaution should be heeded in the creation of the interventions that emerge as a result of this study.

LITERATURE REVIEW

Introduction & Background

Early identification and family intervention is not a new concept. Störbeck (2012) recognizes “the primary objective of early intervention is access to communication, whether auditory or visual” in addition to meeting the “developmental needs of the child and the needs of their family relating to their child’s development” (pp. 62). However, early intervention often appears to encourage the “normalization” of the D/HH child into the family. As Western nations have had the lead on developing such programs, practices and interventions are not easily accessible or relevant to Southern Africa and Swaziland. Moreover, the drive for “normalization” suggests that the real goal of intervening is for Deaf individuals to communicate as another hearing member of society. While it is essential that parents and caregivers be able to make informed decisions, to what extent will these decisions affect the identity development of D/HH children, especially if emphasis is placed on their ability to “fit in” to the hearing world?

Interestingly, most programs in place do not adopt a cross-cultural model as a means to build relationships and encourage integration of Deaf children into their hearing families. This absence suggests a need to reevaluate how cross-cultural mediation may be integrated into the design and implementation, as a means to address the beliefs and attitudes shared by parents, caregivers, students and healthcare professionals.

Policies in place in Swaziland

The 2008 National Children’s Policy of the Kingdom of Swaziland, revealed several gaps in the ability to provide services to vulnerable children (including those that are orphaned, HIV+, or have disabilities and special needs). These included a lack of resources for the advancement of support programs, as well as limited geographical outreach and absence of family support. It further emphasized that early childhood care and development was not widely accessible or affordable to most families.

Children with special educational needs face more barriers to learning due to a number of factors. National data reveal that only a fraction of children with special needs are enrolled in special schools... these [factors] include the lack of early identification and intervention services (National Children's Policy, 2008, pp. 25- 26).

An additional point under this policy was the need to educate the public on how best to care for children with "special educational needs", including the importance of being able to "communicate with children in ways that build confidence and self-esteem" as a means to address the fact that "children with disabilities are frequently misunderstood and mistreated, leading to a lack of acceptance" (National Children's Policy, 2008, pp. 35).

Further concerns for the educational and overall well being of a Deaf child are echoed in the Swaziland Education and Training Sector Policy of 2011.

No child should be denied access to education at any level on the basis of disability. All attitudinal and physical barriers to inclusive education shall be removed; all education and training facilities shall be improved (pp. 16).

Barriers to Acceptance

Globally, information supporting the need for early identification and intervention programs is readily available, but rarely identified as part of the solution to addressing the challenges facing the Deaf community in Swaziland. In responding to the question "Do you agree with the view that an early intervention approach would help to improve outcomes for Deaf children and young people in Glasgow?" The National Deaf Children's Society (NDCS) of Scotland concurs,

Yes. Early detection of deafness combined with co-ordinated multi-agency interventions is vital in order to enable a deaf child to have the best possible opportunity to develop crucial language and communication skills (2009, pp. 2).

Having access to education and other means of support in the early stages of a child's maturation enables the development of "critical, social, emotional, cognitive and linguistic skills" (Situation Analysis of Children and Women, UNICEF, 2008, pp. 34). This is especially crucial to Deaf

children with hearing parents. This is further supported by Sass-Lehrer (2011), where it is understood that

Researchers have found that when a baby's hearing abilities are identified early and children and families receive excellent intervention services by one year of age, these children can attain language skills near the level of their hearing peers by the time they are five years old (pp. 1).

On average, children are enrolled at the schools for the Deaf in Swaziland at 9 years.³ However, the range is far broader, with children as young as 3 years, and as old as 16 entering the school system. The challenge remains the importance of the program in initiating it within the varied social and cultural contexts, of both Deaf children and their families.

An additional purpose of early identification and family intervention is to remove barriers to education that are experienced by Deaf and hard of hearing learners. The opportunity to join in a school community, especially one where shared culture and language takes place, is invaluable to children as they develop their own identities. Moreover, Collins and Coleman (2008) support this claim; "Schools generally have common roles to play in the organization of *social life*, and the shaping of *social identities*" (pp. 282). Historically, Deaf education is riddled with narratives depicting the control of language and cultural expression of Deaf individuals. Efforts to enforce oralism⁴ as the main medium of instruction in the 1970s meant forbidding students from communicating in Swazi Sign Language (SSL). Thus, students converted the dormitories to places in which their natural language could develop, and thrive.

This is further reinforced by Gulliver and Kitzel (2014), who state "It was the idea that realities emerge from embodied experience of the environment and ongoing social interaction that established the validity of a Deaf reality, and opened the door to Deaf Geographies" (pp. 2).

³ Information was roughly computed from the school's admission book. This year alone, 2 students aged 15 and above were enrolled at the school. They had only received at most a pre-school level education.

⁴ A method of teaching Deaf learners whereby the instructor places their hands behind their back and teach only through verbal means of communication.

While a space may be controlled by a group of people, those who inhabit the space can find means to undermine the system, which is why Deaf Culture, sign languages and Deaf identities remain visible. Therefore, the practices adopted in intervention programs need to allow space for the acceptance of Deaf identities, if the tension between these two communities is to be relieved.

Understanding Deafness

Deaf Identity Construction

Glickman's Deaf/Hearing cultural identity paradigm is used to understand identity construction within these groups. While the spectrum includes four distinct identities, three are particularly relevant to this study. He notes,

The first cultural orientation refers to those who are cultural Hearing, meaning that hearing norms are the reference point for normality, health, and spoken communication. The role of deafness in one's identity is not emphasized... The third identity reflects immersion in Deaf culture to the extent that there is a positive and uncritical identification with Deaf persons. Hearing values are denigrated. Lastly, those with a bicultural identity possess the skill to comfortably negotiate Hearing and Deaf settings. They embrace Deaf culture and also value hearing contacts (Leigh, 1998, pp. 331).

It is pertinent to consider the possible identities that may be expressed by the Deaf students and their families, and to not value one over the other.

Leigh (1998) further emphasizes that "the experience of being deaf/hard of hearing with hearing parents influences one's identity development in a way that is significantly different from the identity development for a hearing or deaf/hard-of-hearing person of deaf parents." (Pp. 336). As the majority of Deaf individuals are born to hearing parents, this was a relevant notion that needed to be kept in mind. However, it was essential to consider the stages that each individual may be at, and how that shapes their values and attitudes.

Attitudes and Beliefs shared by parents of Deaf children

Understanding the impact and function of stigmatization should be applied in the development of appropriate interventions for families of Deaf children. Jones (2002) suggests,

Individuals who are stigmatized by society... have been known to transform their stigmas into the basis for group identification... Since the concept of stigma can be negative, because it separates the individual from the norm, an individual must re-define the stigma in order to maintain positive self-esteem (p. 481).

The school serves as a social hub for the Deaf community, and provides there is a very strong, positive group identity amongst the students, as deafness is the norm. However, the inverse of this is true when the students return to their families. Only a few students have siblings who are also Deaf, and often siblings stay with different relatives over the school breaks, eliminating one of their positive social outlets. While at home, the Deaf individuals are faced with justifying their identity on a daily basis. This was evident in the student interviews, where students explained that they have to communicate through a variety of different methods—village sign, gestures, even speaking some siSwati, despite the fact that they learn only English and SSL in school.

Cross-cultural practices

Cross-cultural mediation and elements of biculturalism

Barkai (2008) acknowledges that “cross-cultural differences often result in labeling behavior that is interpreted by a person from another culture as, at a minimum, strange, if not insulting or offending” (pp. 44). Thus, culture is the way in which others render a person’s particular behavior either appropriate or inappropriate in relation to their own behavior, and what is commonly expected in specific settings. This can vary depending on a person’s social identity. Barkai (2008) further stipulates, “the result is that cross-cultural differences can cause a range of responses, from minor annoyances to a high degree of friction and frustration” (pp. 46). As later stated, the findings revealed that the language barrier creates a deterrence for working through cross-cultural misunderstandings as they arise.

Family-child interactions

Typically, socialization occurs naturally, through a child mimicking the behavior of their parents, including how they react to certain situations, be that physically or verbally. However, this is different for D/HH children. Hulsebosch and Myers recognize that being aware of the cultural differences embedded in both the hearing and Deaf communities are essential to the growth and development of Deaf children. They note, “Deaf parents with Deaf children bring to child-rearing their own years of implicit as well as explicit experience, knowledge, and attitudes about what it means to be Deaf” (pp. 77). These parents are members of the same cultural group, utilizing the same language and communication patterns to express themselves and convey meaning. This lends itself to building self-esteem and confidence in their Deaf children where

Despite the fact that deaf parents are raised in a society that sees them as disabled and can seldom avoid the attitudes of deficiency, they also know the capabilities of themselves and their peers, and are more attuned to the potential of deaf children (pp. 77).

Hearing parents, on the other hand, tend to initially view their children as being medically Deaf, and thus disabled. Moreover, it is difficult for parents communicating and living in a way that they themselves can barely comprehend. Hearing-Deaf interactions will furthermore be observed in connection with cross-cultural mediation practices, addressing the differences between each group, and the ways in which these differences can be navigated and appreciated by all parties involved. Understanding the expectations that each group holds in terms of communication and language is central to the success of future interventions.

The Medical Perspective: Viewpoints of Healthcare Professionals on Deafness

The medical framework of deafness

In her article “Childhood hearing loss in the developing world”, Störbeck (2012) distinguishes the key setbacks that South Africa faced in administering tests to help identify early

childhood deafness or hearing loss. She clarifies, “Hearing loss is the most frequently occurring birth defect and the World Health Organisation (WHO) estimates that it is among the 20 leading causes of the global burden of disease” (pp. 59). Here, deafness is seen as an ailment or disease, a disability. This echoes the sentiments often shared by healthcare professionals who view deafness from the medical framework, rather than the cultural perspective, which sees deafness as an integral aspect of someone’s identity.

Yet, what fails to be seen here, is that hearing loss or deafness in itself is not the disability. It is in the inability of healthcare professionals, teachers and other social workers to help bridge the communication and language gap that forces deafness to become a hindrance. Although the concerns that Störbeck address are legitimate, research indicates that early detection and adequate support can provide the opportunities needed for Deaf children to be on par with their hearing peers. Universal hearing screenings do not currently take place in hospitals or clinics in Swaziland. This means that children are not tested for deafness or hearing loss immediately after birth, nor routinely at later stages in their childhood. The findings highlight this, and display how parents or relatives self-diagnose their children, and later receive confirmation from the hospital or clinic.

If the critical timeframe of action exists within the first few years of a child’s life, then programs will have to respond accordingly. This means identifying the child, and counseling the parents or caregivers to ensure that the Deaf child does not have language, cognitive or other developmental delays associated with early childhood hearing loss and deafness. The most critical component of this supports the importance of sign language, playing a key role in addressing these concerns.

Störbeck (2012) further scrutinizes the disparity that exists between those countries identified as “developed” in comparison to countries such as South Africa or Swaziland, which fall in the “developing” faction of this spectrum. It appears the biggest challenge these countries face in establishing a program of this magnitude is a lack of human capital that is competent and qualified to carry out the necessary screenings, or even institute the programs. It is obvious that the approaches used in Western nations need to be seriously examined and transformed in order to address the localized concerns of Deaf individuals and their families in Swaziland, while also creating appropriate interventions that are feasible based on available infrastructure and resources.

A challenging component linked to creating interventions is navigating how to handle the perception or stigmatization of deafness in general. In this area, developing interventions through a cross-cultural lens can be particularly beneficial to all parties. Such a program may focus beyond the medical view that sees deafness or hearing loss as a disability that needs to be cured. Instead, the program will strive to address the areas of dissonance within a family or community, seeking to balance the valuable aspects of both cultures more harmoniously.

Tackling the issue in Swaziland

The literature review highlights the significance of implementing an Early Identification and Family Intervention program, as well as various components that should be considered at such a program's inception. This was guided by the main research question, and sub-questions, which aimed to better understand what interventions should be implemented to encourage greater inclusion of Deaf children into their families. This followed two pathways geared at pinpointing the barriers that hinder acceptance and evaluate the interactions of Deaf children and family

members, as a means to determine the overall inclusivity of Deaf individuals within the home or community.

The purpose of such programs is to assist in alleviating these barriers, while the literature also supported the need to understand and appreciate Deaf identity formation, Deaf Culture and Sign Language. Programs that ignore these components may be inadequately assist families in bridging the cultural and communicative gap. Early Identification and Family Intervention practices cannot be successful without first acknowledging the many factors that prohibit the formation of strong parent-child and parent-family relationships.

Programs located in other countries emerged in response to a similar process that Swaziland is currently undergoing. That process relates to a shift from awareness to actual behavior change; from symbolic ideology to tangible practice. However, Swaziland is not where other countries are, infrastructurally and attitudinally. Therefore, to fully understand where Swaziland is at, in order to create interventions that are applicable and feasible in order to assist Deaf children and their families.

RESEARCH METHODOLOGY

The study aimed to expose the cross-cultural awareness of parents and caregivers of Deaf learners, as well as the practices already in place for interacting with their Deaf child. At the time of this study, I had been living and working within the school nearly two years, and while there is still much to gain from this community, I had a reasonable foundation from which to conduct a thoughtful and rich study. Thus, the study explored the attitudes and beliefs of parents, scrutinizing the medical perspective on deafness and comparing it with the cultural model. In addition to that, several Deaf children in grades 5-7, aged 14-18 were interviewed to gain their perspectives on how they navigate a hearing-centered world. Moreover, their experiences will

help shape the interventions developed, in order to meet their very specific needs. In this sense, the research serves as a conduit through which Deaf children and their caregivers were able to share their experiences through a narrative inquiry approach. This was achieved through both qualitative and quantitative methods.

For the purposes of this research, quantitative analysis took form a questionnaire, designed to capture the positive or negative attitudes parents or caregivers hold towards their D/HH child. The questionnaire provided insight into the larger trends and surrounding knowledge on deafness, and the beliefs parents share in relation to a D/HH child's capabilities. Finally, the questionnaire aimed to collect information on the general areas that D/HH are involved in at home.

In contrast, qualitative research methods were utilized to gain a broader understanding on the factors affecting the inclusion of D/HH children into their families. This took shape in less formal, and semi-structured interviews (see Appendices IV and V). In this way, probing questions were used along with more open-ended questions, so as to allow for participants to inform the study in a less restricted and confined manner.

Sample Selection

Questionnaire

Sampling for the questionnaire was drawn from the pool of 200+ parents or caregivers of students at one school for the Deaf in Swaziland. The desired sample selection for the questionnaire was to have a 75 percent participation rate from parents and caregivers out of the 50 questionnaires that were distributed. A Systematic Sampling method was used to select the 50 participants. Creswell (2012) defines Systematic Sampling as choosing "every *n*th individual or site in the population until you reach your desired sample size" (pp. 143). Thus, every other

parent or caregiver was requested to complete a questionnaire. The parents and caregivers ranged in age and gender, with the majority being female and aged twenty-five to sixty, as mothers and grandmothers typically bring children to and from school. Otherwise, female participants were not specifically targeted.

Parent and Caregiver Interviews

The participants were selected through purposive sampling. Creswell (2012) indicates that such a method enables a researcher to decisively select participants who are ‘information rich’ with the goal of gaining deeper insight into the particular phenomenon (pp. 206). More specifically, snowball sampling was used to guide the selection process. I received assistance from the head teacher, and teachers at one school for the Deaf to select the parents and caregivers for the interviews (Creswell, 2012). In addition, purposive sampling was utilized in order to “handpick the cases to be included in the sample on the basis of [the researcher’s] judgment of their typicality or possession of the particular characteristics being sought” (Cohen, 2007, pp. 114-155).

The intent was to select parents and caregivers based on the grade range that their child was enrolled in. However, due to limitations, the 6 parents that did show up for the interviews represented a less broad range, with one parent from the pre-school, one from grade 2, three from grade 5 and 1 from the high school, who was interested in taking part in the study upon hearing about it from a friend. Consideration was also made to select parents who were geographically close to the school, as it is a boarding facility, housing students from across Swaziland. The parents interviewed were three mothers and three fathers, and three hearing and three Deaf parents. All parents received travel reimbursement to remove any financial strain that they may have accrued due to participating in the study.

Student Interviews

A total of 8 students were selected from the student body at the school (a pool of 142 students, ages 3-20) to participate in unstructured interviews. Cohen (2007) defines unstructured interviews as “an open situation, having greater flexibility and freedom” (pp. 355). While I had a set of questions were prepared for the interviews, the participants drove the conversation, so they were free to share stories that related to the topic and guide the discussion as they felt inspired to do so. The students selected for the interviews were in grades 5-7, (ages 14-18), strategically chosen due to their stronger language and communication skills, as well as the fact that they have been enrolled at the school for at least 5 years, and entered the school at a wide range of ages (some as early as 6 or 7, others as late as 11). Creswell (2012) justifies the need to take careful consideration when selecting a particular research methodology depending on the population you may be working with. This is especially true for vulnerable populations. Here, Creswell argues

Vulnerable populations (children, incarcerated individuals, people of color, those from lower socioeconomic classes, and those with limited education) represent high-risk populations... The researchers' quest for information should be tempered by proper ethical constraints aimed at protecting the participants (2012, pp. 231).

With this in mind, certain ethical considerations were made to ensure the protection of all vulnerable individuals that participated in this study. Creswell further recommends

In qualitative research, these issues relate to conveying the purpose of the study, avoiding deceptive practices, respecting vulnerable populations, being aware of potential power issues in data collection... not disclosing sensitive information, and masking the identities of participants (2000, pp. 553).

Transparency was a necessary tenant of this study. As an outsider in both the Swazi cultural community and the Deaf community, precautions were made to ensure participants understood their right to decline involvement in the study. Support from leaders within the school community proved beneficial to avoid consent that is driven by the fear to disrespect a foreigner

by turning down the opportunity to participate in the research. The Deputy Head Teacher in particular was instrumental in securing the interviews with the parents, and assisted in conducting the interviews in SiSwati, requesting additional help with note-taking.

Healthcare Perspectives: Doctors & Nurses

The goal was to have two unstructured, informal interviews with doctors or nurses from the Pediatric wing of two main hospitals in Swaziland. However, interviews with healthcare professionals unfortunately did not transpire as anticipated. Despite previous arrangements with the matrons at the hospitals, later inquiries revealed that the hospital policies around interviewing and research had changed. Interviewing health care professionals would have been crucial as the parent interviews revealed many gaps in available information provided to parents, regarding the wellbeing of their Deaf child. In moving forward, it will be essential for the Ministry of Education and Training to work alongside the Ministry of Health in implementing strategies to assist hospitals, clinics and Rural Health Motivators (RHMs) to identify D/HH children at an earlier age.

Pilot Study

A pilot study was conducted with two students to evaluate the interview questions used for the unstructured interviews. This provided the opportunity to ensure that the Deaf adult assisting with the research be familiar with the questions, as well as aware of appropriate behavior to conduct while assisting in the interview process. The pilot interviews allowed insight into how students respond to particular questions, serving as a means to clarify the questions. As acknowledged by Cohen (2007), the use of a pilot study allowed me to amend the observation methods used or procedures to ensure that I come closer to meeting the objectives of the study.

Data Collection Methods

According to Shenton (2004), credibility is a key component of trustworthiness in research, to ensure the study meets the expectations intended. A questionnaire was essential in gathering a broad base of knowledge on the attitudes, beliefs and understanding of parents and caregivers of Deaf children. The information gathered from the questionnaire and pilot study informed the interviews providing opportunity to delve deeper into the data generated. The research gained insight on the personal experiences of parents, caregivers and Deaf children. This produced data that will guide the intervention-making process.

The methods selected enabled triangulation. The use of a survey allowed for data to be gathered from a larger sample pool. Triangulation fosters confirmability in research (Shenton, 2004). Selecting a variety of methods was necessary in order to reduce the possibility of research bias. However, since complete objectivity is a challenge, it was pertinent to lay out the theoretical framework that marked the foundation of this study. Credibility can also be achieved through “the development of an early familiarity with the culture of participating organizations” (Shenton, 2004, pp. 65).

Data Analysis Methods

Creswell (2012) notes that quantitative research is characterized through “systematically identify[ing] our participants and sites through random sampling”, whereas qualitative research is driven by the use of purposeful sampling, based on places and people that can best help us understand our central phenomenon” (pp. 205). Given that the location of the study, and selection of the participants follows the above statement on qualitative research, this method is the most applicable to the study. In all cases, the participants and their experiences are at the center, as the research seeks to contemplate the complex experiences of all participants. Statistics and coding were used to compute the data collected from the questionnaires, and provide a

general overview of the knowledge and attitudes parents and caregivers have towards Deaf children.

The data collected from the questionnaires and interviews were coded based on the relevant themes that emerged from the discussions, derived from the questions posed. However, basic quantitative analysis will occur for the questionnaires. Interviews were also characterized thematically to understand the broader implications in the observations and experiences of those interviewed. Data will remain accessible and applicable to the construction of future interventions between Deaf children and their parents, who are generally hearing. Furthermore, all data collected will carry the intent of being used to develop a universal, and sustainable Early Identification and Family Intervention plan set to be implemented in Swaziland in 2016.

The approach used in this study was interpretive, whereby “theory is emergent and must arise from particular situations” which means that analysis emerged through the process of data collection in order to compare across a larger whole (Cohen, 2001, pp. 22). Additionally, the study was influenced by the ethno-methodological theory, “concerned with how people make sense of their everyday world... it is directed as the mechanism by which participants achieve and sustain interaction in a social encounter—the assumptions they make, the conventions they utilize and the practices they adopt” (Cohen, year, pp. 23). Given the nature of the study, assessing the parent-child interactions broadened the knowledge around what factors are at play, where complications arise and what cross-cultural mediation tools will become useful to navigate social interactions.

The ethno-methodological theory gives way to indexicality and reflexivity, the former of which will play a significant role in how data may be analyzed and evaluated. It is understood that,

Indexicality refers to the ways in which actions and statements are related to the social contexts producing them; and to the way their meanings are shared by the participants but not necessarily stated explicitly (Cohen, 2001, pp. 23).

There are two types of ethno-methodology, situational and linguistic translating the deeper meanings of the interactions witnessed. For instance, analyzing and critically observing the use of language is a crucial aspect of this study, especially given the cultural identity of both groups involved. This is perhaps especially complicated in Swaziland. Valdés (1995) describes that

‘Mother tongue teaching’ takes the position that children who are at-risk educationally because of their socioeconomic and political status within the larger society need to develop first-language academic abilities first in order to succeed in school. (pp. 302).

The majority of learners involved in this study⁵ were born to hearing parents, whose mother-tongue is SiSwati, with English being a second language. Yet, for D/HH learners who attend a school for the Deaf, their mother-tongue becomes Swazi Sign Language, accompanied by English as a second language. This naturally created an interesting dynamic, adding another layer to the complexity of mitigating any language barriers. In this case, all three languages (SSL, SiSwati and English) needed to be valued and appreciated equally. This meant that the research design and methodology considered the use of procedures and data collection and analysis methods adaptable to the fluidity of languages present in the sample populations.

However, situational ethno-methodology cannot be ignored either, as this approach provides a broader, general analysis of all social activity, seeking “to understand the ways in which people negotiate the social contexts in which they find themselves” (Cohen, 2001, pp. 23-24). Quantitative methods of data collection, the questionnaire, helped ascertain information regarding the beliefs and attitudes held around the specific use of language. This revealed that

⁵ Only two students at the school for the Deaf used in this study were born to Deaf parents.

attitudes and beliefs of parents and caregivers played less of a role in parent-child relationships than initially anticipated. Rather, the most prevalent and acknowledged barrier remains to be language and communication-based.

Ethical Considerations

Several ethical components were considered for this study. Creswell (2012) acknowledges that, respect was shown by gaining permission before entering a site, by disturbing the site as little as possible during a study, and by viewing oneself as a ‘guest’ at the place of study” (pp. 23). Although I have been working within the school environment for nearly two years, it was important to remember that I was still an outsider to this community. This required me to work with gatekeepers who assisted me in following the correct protocol for this study.

All participants were requested to read and sign an informed consent letter upon agreeing to participate in the study. Care was taken in processing confidential and sensitive information. Two interpreters assisted in the study, transcribing the questionnaire data, and another was present for the interviews. In both cases, interpreters helped in the translation from SiSwati to English. The interpreters were briefed on the importance of maintaining confidentiality so as to protect the participants and keep the data collected within the study. In seeking to keep all identities anonymous, no names were utilized, instead, each participant was either “Parent A” or “Student 1”, etc.

As the study involved several youth participants, minors had an informed consent letter signed by a parent or a guardian. The study was also explained to all participants, including the purpose and objectives in their native languages. Additionally, a Deaf adult working as a

guidance counselor at the school was present at the interviews to provide psychological support as needed.

Response Rate

A total of 50 questionnaires (see Appendix III) were handed out to parents of D/HH children during the opening of the term. This was the most effective way to ensure that data could be collected from parents, as it is one out of 6 times in the year most parents are present at the school. Out of the 50 questionnaires, 28 were successfully completed and returned. While this was below the initial goal of 75% return rate, the information gathered was still helpful. Some limitations to the questionnaire were that some parents were not literate in either English or SiSwati, so that was a deterrent for filling out the survey. Additionally, around 20-30 of the student population arrive on their own or with another parent, thus limiting the number of parents who were available at the start of the term to complete the questionnaire. Finally, parents also had a tendency to arrive after school hours, outside of the window that I was passing out the survey, or were coming from far distances and lacked the time or energy to fill out the survey. Others said they would bring it back, but were unable to do so.

Additionally, parents or caregivers either opted not to answer or misunderstood the demographic questions at the start of the survey. While I kept a list of who returned the survey, I did not make a note of who was attached to each survey until after I started to compile and analyze the findings. Thus, I am aware of the gender and relationship to the child of the parent, but am however unable to tie them to a specific survey beyond mere speculation. This is an obvious limitation to the study.

FINDINGS

Several interesting themes emerged from the results of the questionnaires and interviews. The patterns will help pinpoint areas of intervention and strategies that may assist in better

supporting parents and families with Deaf children. The most obvious theme was communication: this was evident across all data collection materials. Another theme was availability and access to information. The questionnaires revealed that there is limited standard information available to parents with Deaf children that serve to guide parents on what to do, or what resources should be available to assist with communication. Other themes included spreading awareness and learning to navigate between both hearing and Deaf cultures, or overcoming exclusion.

QUESTIONNAIRE RESULTS

Of the 28 received, 23 were filled out by women, while only 5 were completed by men. All were either the mother or the father. Family hierarchy is very important in Swaziland, and several relatives did not feel comfortable completing the survey without first asking the parent. As anticipated, not many fathers were present at school when the term opened. When asked “at what age did you learn that your child is Deaf or Hard of Hearing?” the ages varied greatly. 27 out of the 28 parents supplied an answer, and the age range is from as early as 6 months to as late as 6 years. On average, parents learned of their child’s deafness or hearing loss when they were just under 3 years old (see figure 1 in Appendix VII. Further charts and tables are also located in Appendix VII).

Table 1 illustrates how parents learned of their child’s deafness or hearing loss. Significantly, 20 parents acknowledged a lack of responsiveness from their child, and from that suspected that their child was Deaf or hard of hearing. Interestingly, two parents attempted to test their child’s hearing abilities through making noises. Additionally, parents used their own knowledge of child development stages to analyze their child’s situation, particularly in

monitoring change (or lack –there-of) in their child’s behavior. Parents observed how their child interacted with other children during play, taking inventory on their communication habits.

Despite having an awareness that their child was D/HH, when asked “at what age was your child enrolled at the Primary School for the Deaf?”, some parents indicated that their child started school as late as 11 years, despite knowing for some years that their child was D/HH. The age range for enrollment in this study was between 3 and 11 years (see figure 2).

The findings indicate that while the average age of identification is 2.77, the average of enrollment is 4 years later. The main question that emerged from this, was why did it take so long? The answer to this became evident in observing the actions parents took after learning of their child’s deafness or hearing loss (Table 3). Moreover, the parent and student interviews provided insight into what delayed the process; lack of awareness that there was a school for the Deaf coupled with a lack of knowledge around where to go and what to do once they were aware of their child’s deafness or hearing loss.

Placing Figures 1 and 2 (see Appendix VII) on top of each other creates an intriguing image. Gaps represent absent responses from parents. Through simultaneously comparing the charts, the lag between initial identification and enrolling their child at school becomes starker. The majority of children had not been previously enrolled at another school. 24 of the 28 parents responded “no”, while only four had marked “yes” (see Figure 3). Furthermore, figure 4 illustrates that the majority of parents learned of the Primary School for the Deaf through a hospital or clinic.

Other ways that parents learned about the school was through community members, including pastors, neighbors, employers and other people with whom they worked with. Finally, four parents identified the radio and other media sources as the means through which they

learned about the school. Although it was not a possible field to choose from, not a single parent commented that they had already known about the school. This depicts what actions parents took after learning about their child's deafness or hearing loss, which is depicted in Table 3.

Parents brought their child to a hospital or clinic seeking advice and support. Most parents appeared hopeful that the doctors could diagnose and provide a prescription to change the condition. Upon learning that there was not any medical solution, it seemed that some parents remained disappointed or expressed feelings of hopelessness (see Table 2⁶). However, other parents received positive advice from the doctors and encouraged them to accept their child's deafness, provided one parent with a solution: to send their child to the School for the Deaf. Other parents seemed a little misdirected or at a loss for guidance, seeking help from multiple places. Some parents went to traditional healers as well as hospitals. Some parents went to pastors, prophets and prayer warriors looking for a cure and comfort. As indicated by one parent, they did not feel satisfied with the outcome from the hospital visits, and continued to look for a means to counteract their child's deafness.

Addressing beliefs and attitudes that parents or family members may have towards their Deaf children, providing intriguing data. While 16 out of 28 parents stated that learning of their child's deafness did not change how they interacted with them (see figure 6), 21 parents expressed feeling pain or heartache upon learning that their child was D/HH (see Table 2). Parent H expressed concern at being able to help their child, indicating that part of the pain—or grief—was due to feeling overwhelmed with a surprising situation, and perhaps feeling ill-equipped to deal with the challenges that lay ahead. On the other hand, several parents expressed feelings of acceptance of their child's deafness or hearing loss, if not immediately, but as time went on.

⁶ Responses provided in the Tables represent translated text that was originally written in SiSwati. As SiSwati does not distinguish between genders, "he" will be used indiscriminately for both male and female persons.

Parents also indicated that they turned to faith to guide them through the process, whether as a blessing from God, or placing trust in a higher power that their child's deafness was part of a bigger plan. It is important to acknowledge the spectrum of reactions and emotions that parents may have felt, and also recognize that there are various ways in which parents or caregivers can learn to cope with each situation.

Figure 6 represents the attitudes of parents and caregivers that resulted in learning that their child was D/HH. 16 parents stated that learning of their child's deafness did **not** change how they interacted with the child. Conversely, 11 parents acknowledged that it had changed their interactions. Parents were in agreement that there is a stigma Deaf individuals, with 18 out of 28 stating that there was (see figure 8). However, 9 parents felt like that was not the case.

When it came to inclusion and integration into the family, it became evident that despite the language barrier, most children were able to socialize and take part in similar activities to those of their hearing counterparts. When asked "what activities is your deaf child involved with at home?" most parents indicated that their child participates in very typical activities found on a Swazi homestead (figure 9). The majority of children are sited as playing with other children, followed by washing clothes, and cleaning. The "other" category incorporated activities such as selling items for their parents, herding cattle and studying, to name a few.

Finally, when asked about communication strategies, parents indicated that although attempting to use several means of communication (figure 11), communicating with their children remained difficult (figure 12). 13 parents explained that they had either learned or were learning Sign Language. Only a few indicated that these were formal lessons, and one parent or caregiver mentioned that other family members were also enrolled in a sign language course. 15 parents cited the use of miming, gestures or body language as the method in which they use the

most to communicate with their child. Finally, 8 work at communicating through speaking or talking, while 4 use written communication. Some parents denoted that they use more than one method to communicate. 16 parents disclosed that they do indeed find communicating with their child difficult, while 12 parents felt differently; that they could indeed communicate easily with their child.

When questioned what support they wished that the school could provide, 11 out the 28 parents stated they wished that there was a way for them to learn SSL (see Table 5). 6 out of the 11 parents further commented that SSL lessons would assist in strengthening their ability to communicate with their child. Two parents cited this as a means to overcome the barriers that “bars me from interacting freely with him” and would enable “[me] to communicate directly with my child”.

Parent Q voiced the idea that Deaf students be taught how to speak so that their child could communicate on a more dynamic level, “That the teachers talk to children who are partially impaired so that they master both spoken and sign languages”. In this case, parent Q is asserting that teachers capitalize on the student’s abilities to build their skills. Parent Y even stated that they wished the school would assist in informing the parents on their child’s social skills development, and advise them on what strategies to use to help him with anger management.

The purpose of including the question, “What behavior does your child exhibit at home”, was to try to determine if parents viewed their Deaf children in a specific light, or if they held a stigma against. However, upon reviewing the responses, this assumption was dispelled. Most parents noted behavior that is common to children in general.

Most of the parental observations on the behaviors of their children were positive, with only 4 parents stating more negative comments. The positive responses depicted the Deaf children as well-behaved, obedient and respectful.

PARENT INTERVIEWS

The parent interviews explored the attitudes and beliefs held by parents of Deaf children, and provided further explanation regarding the barriers that exist in communicating with Deaf or hard of hearing children, as well as the challenges that hinder full inclusion and integration into the hearing world (See Appendix IV for a full list of questions). 6 were interviews, three hearing and three Deaf. It worked out that three were also mothers, and the other three were fathers of Deaf children.

Experiences of Hearing Parents

The interviews with the hearing parents opened up the complexities of the family dynamics upon realization that the child is Deaf. Two of the three mothers indicated that upon learning that the child was Deaf, the father withdrew support and other family members claimed that it was a waste of money to support the child. Two of the mothers also had rather difficult pregnancies, but had never contemplated that that would affect their child, or that their child might be D/HH. The third mother gave birth to a hearing baby, who later, due to an unexplainable circumstance lost his hearing at age 7. It was actually the child's teacher who revealed that he had difficulty hearing and following along with lessons. See Appendix VII, Table 6 for further findings.

Expectations

Initially, the hearing parents were troubled, and unsure of what the future for their children would hold. However, this attitude was later adjusted after the children were enrolled in

school, where they realized that the children were capable of achieving beyond their initial expectations. The hearing parents highlighted the importance of education, stating “Deaf children can do anything once they have an education... other talents will be revealed as he is awarded more opportunities” and “If you allow the child to go to school, he will be able to do everything. It is important to train him as normal kids”. The third parent concluded “[My child] has the same capabilities as hearing children, they just need access to the information.”⁷

The hearing parents revealed that, while they had seen Deaf people, they did not have any close relations with a Deaf person. One even stated that she had “felt pain for that Deaf person” while another suggested that it had never occurred to her that her child may become Deaf, “I couldn’t believe it, but later I learned to accept it”.

The hearing parents even expressed small levels of awe in their children’s’ capabilities, especially in the lengths they go to communicate. “My child has many types of languages –home language and school language.” However, the parents also explained that there are frequent instances of miscommunication, which causes the child to become stressed or angry, and that the child signs too quickly for the parents or family members to understand. Despite this, overall, the hearing parents find that they have a positive relationship with their Deaf child, while perhaps unconventional. The parents seek to treat them equally to the hearing children, and make the effort to understand them and impart knowledge. However, while the mothers especially are accepting of their child’s Deafness, the same cannot be said for other members of the family. One mother lamented “it is painful because each time I go home, the father’s mother complains that the father does not have the money to support the child” and other family members have expressed that the child is useless, and should not be taken to school. In this case, it is clear that

⁷ Interviews were conducted in SiSwati or Swazi Sign Language, so all quotations are translations or interpretations of the original conversation.

parents of Deaf children, particularly single mothers need significant support in the early years of the child's life to not only sensitize the parents, but also other family members as well.

Communication and Relationship-building

All three hearing parents voiced that the biggest barrier affecting the relationship with the child is communication, with a lack of family support and the inability to provide advice to the child as secondary concerns. This last element came forward several times, particularly when parents were asked about the importance of schooling their Deaf child. The hearing parents expressed their concern that their Deaf child was not receiving important information/advice or life skills at home, and were grateful that the school provided an outlet for that area of learning. It appeared painful that the parents could not impart the wisdom or knowledge to their children themselves, but they were happy knowing that the school acted as a means to fill this gap.

Positive relationships can be created across language barriers, lending to more effective communication as parents display patience and a willingness to understand their child. Despite this, a limited knowledge of sign language still leads to frequent episodes of miscommunication, and parents indicated a need to prevent such situations from being stressful or overwhelming. One mother stated, "I work to find ways to communicate clearly, and take the time to explain or understand when issues arise. It is important to offer a chance for apologies and forgiveness."

Beliefs and Attitudes

Two of the hearing parents also revealed that there are still many superstitions and stigmas held towards Deaf people, especially represented in feelings of shame at having a Deaf child. One mother was told she was dumb and had done something wrong to anger the ancestors. Seeking to ignore these hateful words, the mother chose to see the child as a special gift from God. Regardless, parents of Deaf children often receive pity from other family members,

neighbors or community members, as deafness is perceived to be a negatively thing. All three hearing parents stated that they wished that the school would provide support in learning sign language and offer advice to parents on how to care for and communicate with their children.

Experiences of Deaf Parents

Patterns also emerged during the interviews with Deaf parents. Given the semi-structured nature of the interviews, the questions varied slightly, focusing more on the Deaf adults personal experiences growing up in hearing families, but also in their present family dynamics having Deaf children of their own. Once it was discovered that the child was Deaf, there was no delay in bringing them to school. However, it had never dawned on them that their child(ren) might be Deaf; rather their parents were the ones who realized that their grandchildren were Deaf, after seeing similar behavior from when their children were young. See Appendix VII, Tables 7 and 8 for further findings.

Personal Experiences

Growing up in hearing families was challenging for them, but they each felt they had either a parent or sibling who was willing to support them. It appears as if the younger siblings are more likely to learn sign language and take the initiative to build relationships with their Deaf sibling. Moreover, all three adults expressed feeling like their older siblings were jealous of them because they received extra care and support from the parents. The current family dynamics differ because they are now more balanced Deaf household.

All three Deaf parents (all men) had married or dated D/HH women who know sign language and went to school together. Because sign language would be one of the first languages of both hearing and Deaf children, as that is the language of the parents, both hearing and Deaf children have a fluency in sign language. The hearing children are able to act as interpreters. One

parent noted “I am happy to have both Deaf and hearing children, and it was easy to accept them into my life. We can easily and freely communicate in my family... It is really easy to counsel and advise my children because we all speak sign language”.

Language and Communications

Deaf parents use similar strategies that hearing parents do when it comes to introducing their children to language. Another parent noted,

I didn't actively teach [my son] sign language as he was growing up. I would communicate to him using gestures, and adjust as he grew older. He really learned sign language once he entered school, and I could see his sign language skills developing as the years went on. I didn't want him to feel ashamed of sign language. I wanted him to know it was the way he was meant to be communicating. My other two children are hearing, and they have been learning some sign language. It's really easy to communicate with my son.

In this way, sign language is naturally acquired through similar means that hearing children learn spoken language.

Equality and Inclusion

All three parents expressed similar concerns regarding barriers to inclusion of Deaf people in a hearing world. The biggest challenge initially, is for people to feel comfortable communicating in a different way. Once hearing people are able to get past this awkward stage, communicating became more easily acknowledged. Although, one parent acknowledges that not everyone will take the time to learn to communicate through the use of sign language. He stated,

It's difficult when I go to places where people do not know me, because they have a lack of awareness and treat me differently, especially when I am the only Deaf person. I don't scold them or get angry, it's just best to leave it be. It's important to have patience and just keep going.

The other parents acknowledged that they feel most accepted in their communities because people are used to them and know they have to communicate differently. Another parent furthered,

In order for Deaf and hearing people to be equal, people need to understand that Deaf people are capable in the same ways and work as hearing people. Deaf people can be teachers, so it's important that they have this awareness... Many Swazis aren't aware that there are Deaf people all over the world, and that deafness is normal too. But spreading awareness takes time, so it must be little by little.

However, one parent mentioned that it can sometimes be challenging navigating the two worlds. "I'm lucky in some ways because I have a wife and daughter who are Deaf. But then I have 2 hearing children, so I feel sort of trapped between two worlds..."

The adults also showed a sense of pride towards sign language. When asked what advice they would provide new parents of Deaf children, one asserted, "I want hearing parents of Deaf children to know that Deaf people are able to communicate on the same level as hearing and blind people –we're all the same."

Finally, the Deaf parents expressed the importance for Deaf children to have the same opportunities as hearing children, especially in terms of schooling. One parent lamented that his son has taken twice as long to get to the same grade level as his younger sisters. This is very frustrating and painful to him, and he cannot understand why it is taking so long, especially to watch his two other children advance while the other is stagnated.

Summary of Parent Interviews

The interviews with the parents proved to be revealing, especially in regards to attitudes faced by other family members as they sought to raise their children and receive support. The interviews also provided rich insight into the methods and means of communication, and the areas in which could be strengthened through an early identification and intervention program.

Most strikingly, at least those parents or caregivers involved in the study did not display negative attitudes or beliefs towards their D/HH children. This is of particular interest as this revelation was not anticipated at the onset of the study. Instead, it is clear that those outside the

immediate family are the ones that need to be reached out to, in terms of changing attitudes and negative perceptions they may hold towards their Deaf child or relative. It is clear that all parties—parents and children alike—recognize that the major area of improvement is bridging the communication gap. This indicates that parents are well aware that a barrier exists, but lack the resources or access to services that could assist in changing their circumstances.

STUDENT INTERVIEWS

In total, 8 students aged 14 to 18 answered questions regarding their experiences as a D/HH person at home as compared with their experiences at the school (See Appendix V). The students were in grades 5 through 7 and had been enrolled at the school for at least 5 years. Three of the students had a Deaf sibling, while the other 5 were the only Deaf individuals in their family. Several students selected had initiated several conversations with the researcher prior to the inception of the study, expressing their concerns and frustrations towards the barriers that restricted communication between their parents or immediate caregivers. In addition to that, students themselves already had several ideas or strategies that might be suitable to address the gap, but with limited resources available to implement these methods on their own. This sparked the interviews conducted in this study. See Appendix VII (Tables 9-11), for additional findings from the student interviews.

Addressing the Language Gap

A common theme stated, was although students appreciated and cared for their family members, all pinpointed the language gap specifically. Besides the presence of Deaf siblings, Deaf children lack individuals at home who can serve as a means of socialization and companionship. While efforts seem to be made to include the Deaf children into their family's routines and family time, the lack of sufficient and effective communication strategies leave the

Deaf child feeling marginalized. The students indicated that meaningful conversation rarely occur while at home, instead, the school serves as the main location where socializing and sharing ideas can take place. One student recounted,

...At home, I'll start signing and people will freeze, they'll start talking and then realize they cannot communicate with me that way, then they wave awkwardly and give me a hug. I'll try to ask my mother a question – like when are we returning to Siteki? (return when visit Siteki) and she'll get confused, so I've learned to alter how I communicate so she understands me better (return car) and mother will say I must go with my two sisters, because that makes her happy.⁸

Unfortunately, through personal observations and student accounts, it takes a sizeable amount of time and patience to bridge the communication gap. This is particularly challenging as the students remain at the school for most of the year, returning home every few months for 2-4 weeks of break. This leaves little time for parents to build on previously developed language skills. Due to the socio-economic situation of many parents and caregivers in Swaziland, many parents do not have the luxury to work near home, thus further limiting the time they have available to spend with their Deaf child. In this sense, hearing children naturally acquire language and absorbing cultural practices and behaviors automatically. Deaf children, on the other hand, especially in the case of Swaziland, learn Sign Language through interacting with other Deaf people or through school. Thus, hearing parents lack the skills needed to bridge the cultural and communicative gap due to limited experiences with this.

As Swaziland is a rather homogenous state, Swazis rarely encounter individuals who are not like them, nor find themselves in circumstances where they cannot communicate in a language they understand. Although all children enrolled in school learn English alongside SiSwati, it taught by Swazi teachers and not as a foreign language. Thus, parents and caregivers may be unaware or unsympathetic to the need to adopt cross-cultural competence. On the

⁸ Interviews were conducted in Swazi Sign Language, so all quotations are translations or interpretations of the original conversation.

flipside, Deaf children grow up constantly adapting to their environment, and in this sense are bicultural. It's even common for students to return from break having forgotten common signs or signing incoherently. Another student emphasizes, "When I stay in Matsapha it is nicer because there are many Deaf people there, but... If I stay in Pigg's Peak for very long and return to school or meet other deaf people I've noticed that my sign is weaker." When prompted if this was due to spending weeks adjusting how he communicates he signed "yes". This is further supported by the 5th student I interviewed. She explains,

It's lucky to have the Deaf school because I am able to communicate freely and on a deeper level with people. At school, people understand me, and we can socialize. At home it's more difficult because I have to adapt my language to be understood, and to understand. People use village sign which isn't really sign language. It's the best effort most people make to communicate with me.

Other Deaf students expressed similar stories and circumstances where after the initial attempts to communicate through sign language or gestures, family members or neighbors will revert back to vocalizing to accommodate other hearing members who may be present, eventually either ignoring or forgetting the Deaf individual they were originally interacting with. At this point, the Deaf child will exit the conversation and find other means to occupy their time.

Situations such as this make it difficult to identify one specific strategy that could be adopted to better integrate and include Deaf individuals into their families. All individuals could take greater steps to bridge the communication gap and be sensitive to the cultural identities present at home. Perhaps a main challenge embedded is an overall lack of knowledge and awareness on a shared Deaf culture. Given that resources from the Deaf community are non-existent, there is limited means available to guide parents and caregivers on how best to include their child in their family, particularly, offering strategies to bridge the communication gap.

Instead, a lack of cross-cultural awareness and competence perpetuates situations where children feel alien in their own households.

Family Support

Besides the parent, interviewees acknowledged that their younger siblings have the best signing ability within the family, with similar comments were made by their parents. In fact, the younger sibling is often likely to be the one member of the family who acts as interpreter should the need arise. Thus, a follow-up study could examine these relationships and interventions could work to include younger siblings in cross-cultural initiatives as they might be the most conversant with Deaf culture and Sign Language amongst other family members. A wider study could reveal if this is a larger pattern, or merely coincidental to those involved in study.

ANALYSIS

Several noteworthy and pertinent findings were revealed in the data. These assisted in explaining the current phenomena surrounding early identification of D/HH children, and addressed the areas in which families could receive more support and guidance. Several variables affecting the phenomena were identified and will further inform the strategies and interventions that will be implemented at the start of the program. Finally, the findings pinpointed areas that require greater exploration and deeper understanding (e.g. reasons for why there is such a massive gap between initial identification of a Deaf child, and enrolling them in school, and so on). Appendices VII and VIII will serve as references for this section.

QUESTIONNAIRE RESULTS

Seeking Medical Support

Some areas that immediately stood out in response to the findings was the need to involve hospitals, clinics and specific healthcare professionals in the program. This is necessary

for several reasons, the first being to ensure that accurate and adequate information be distributed to parents and caregivers. Secondly, as the majority of parents and caregivers sought medical advice, hospitals and clinics serve as a critical entry point where interventions can begin. This is especially crucial as the majority of parents learned about their child's deafness or hearing loss on their own, independently from hospitals or clinics. Moreover, such a system would also assist disseminating information to targeted and vulnerable groups.

Responses also indicated that the advice of health care workers is inconsistent, and limited in terms of offering guidance and support to the parents and caregivers. Many parents appeared to be uncertain what steps to take to assist their child, and on top of that, were unsure of what services were actually available. All of these variables could be the cause for why D/HH children are detected at such a late stage, and as to why parents and caregivers tend to enroll their child in school years after identification. Finally, sensitizing doctors and other medical staff in trainings could help mitigate the emotional responses of parents of D/HH children.

As acknowledged in Table 2, while several parents have learned to accept their child's deafness or hearing loss, this cannot conceal that most initial reactions of parents and caregivers was heartache and disappointment. If the appropriate people were trained in the right areas to help parents, caregivers and additional family members cope, they might feel less helpless in the situation, and more importantly ready to support their child.

Pivotal Ages of Identification and Enrollment

Findings revealed that on average, D/HH children were identified almost three years after birth. The literature suggests that this is far too late, and that initial identification should first take place within the first year of the child's life. Moreover, early detection would serve as a means to record the number of children that are born Deaf, while also capturing significant data on the rate

of hearing loss in Swaziland, perhaps leading to better understanding the causes. In this way, interventions could also be created to address early childhood hearing loss, providing services that would help transition parents and children and address the serious issue of early language acquisition.

The literature supported this concern, demonstrating the need for D/HH children to be enrolled in school at an earlier age to ensure that they have social, cognitive and emotional outlets that are crucial to child development. Although there are pre-school facilities available at the school, many students continue to enter the school system above the age of 6, as recognized in figures 2 and 13. Earlier enrollment would serve as a positive catalyst, addressing one of the major barriers that D/HH children and adults encounter in the search for inclusion. Delayed entry into the school means that children first must acquire SSL, and the fundamentals of education, beginning with bilingualism (introduction of English as a second language) .

The students that are enrolled far beyond the pre-school stage are often placed in arbitrary classrooms based on their age or identified capabilities. However, age in numbers does not always match with a child's developmental age. The arbitrary placement of students in classrooms, opens up a plethora of entirely new concerns. These include filling classrooms with learners that are not academically at the same level, or even have had instruction in the same topics, subjects, etc., thus perpetuating problems that impact the individuals full inclusion into the larger society.

Involvement of the School

Findings also acknowledge the need to involve the school in creating and implementing strategies. There is a need for the school to self-promote, and provide community outreach. The findings depict that parents and caregivers learned of the school through indirect means –word of

mouth—and not due to recruiting strategies implemented by the school itself. Assisting the school in creating a broader recruitment system would also work to address the late age of enrollment, as the public becomes aware that the school exists. Parents, caregivers and other relatives would also see the school as a valuable resource and place of support.

Observations of the current enrollment process at the school points out that often, parents and caregivers were referred to the school by one of the other “Special Schools” found in Swaziland. Sometimes, the other school sends parents and caregivers with children who are not necessarily appropriate candidates for enrollment. However, having been turned away at the other institutions, there is not much for the parents, or the school to do, except enroll that child, as is their right to education. This leads to an abundance of students who are not D/HH enrolled at the school, adding further strain on teachers and house parents whom are not trained in helping these children.

Communication

Findings from the questionnaire also highlighted the need to address the communication gap, and develop strategies that will assist parents and caregivers in learning Swazi Sign Language to better communicate with their children. A significant number of parents and caregivers expressed interest in developing linguistic skills. Thus, interventions should incorporate this as a main objective to derive strategies around. As the literature indicated, language is an important aspect of self-expression, culture and identity. Providing parents and caregivers with the opportunity to enhance their communicative skills would be an excellent first step in bridging both the language and cultural gap.

PARENT INTERVIEWS

Hearing Parent Experiences

Expectations

Interviews with the hearing parents revealed that despite initial feelings of pain and concern, parents adopted positive expectations for their children, even going so far as advocating for their right to an education and their ability to excel in areas the same as any other child. Moreover, the interviews clearly mark an evident change in attitude and beliefs held towards the child, as parents revel in awe in their child's ability to find several creative means to communicate. Encouraging the parents to have a greater involvement in the school could assist in building on these skills so that the D/HH child meets the surprisingly high expectations of the parents. The students themselves fall victim to fatalism, feeling both capable and incapable of having larger goals and dreams. Nurturing these positive expectations of D/HH children could be a crucial starting point for addressing the various barriers that prohibit the learners from excelling academically.

Communication and Relationship-building

As noted in the findings section, the hearing parents raised concerns regarding their ability to communicate with their child. They expressed how it was often difficult to understand their child due to the language barrier. The structure of the school may add to this challenge. As the school is a boarding facility, students only return home to their families for several weeks out of the year. Long-standing periods where parents and caregivers do not interact with the D/HH child would limit their retention of SSL. Moreover, as the majority of students enrolled at the school are the only D/HH child in the family, parents or caregivers also lack people with whom they can practice and continue developing their skills whilst their child is at school.

The parents also acknowledged that the school serves as a positive place for the child to adopt appropriate behavior, including independence, emotional management and friendship.

These are all areas that are limited at home due to the communication gap. Parents struggle to impart a deep sense of knowledge to their children. While they are able to offer cautionary advice, conversations may be constricted to only addressing “do this, not that”, and not encompassing the “why” or “why not”. Calling attention to the above traits is also significant because it is in line with the parental concerns that their child be able to stand on their own. Despite these high hopes, many steps need to be taken to help bridge the prevailing gap in order to address this particular barrier.

Socio-economic means may also serve to hinder parents and caregivers from developing stronger communication skills and strategies. The cost of transportation alone limits parents from visiting their children throughout the term. Transportation fees also prohibit the students from having the opportunity to go home on weekends. As the school serves students on a national level, and not just regionally, children come from all corners of the country. Moreover, while there are several Sign Language schools in a few pockets of Swaziland, the courses are costly and not accessible to the average parent or caregiver who is caring for multiple children. Thus, cost-effective strategies should be developed to ensure parents and caregivers have access to these services.

Beliefs and Attitudes

While the parents themselves did not outwardly express any negative attitudes or beliefs towards their D/HH child, two related that they wished they had more support from the extended family. Their cases were significant in that both had faced stigmatization from other family members whom laid claims to superstitions, blaming the mother for having a Deaf child. These individuals also served as barriers to inclusion, discouraging or even preventing the mother from enrolling the child in school, through withholding funds or withdrawing support altogether.

Experiences of Deaf Parents

Personal Experiences

In sharing their personal experiences, the Deaf parents provided valuable insight into how they have come to terms with their deafness, and also how they have worked to bridge the communication and cultural gap over the years. The most interesting aspect of these interviews was gaining insight into how they manage to balance both the Hearing and Deaf worlds occupied by their children. All three parents had both hearing and Deaf children. The children born to Deaf parents would acquire SSL in the same way that a hearing child born to hearing parents would learn SiSwati or other mother-tongue languages. The hearing child is at an advantage because they exist within the majority language and cultural group, and are not stagnated from accessing services that are not so easily accessible for their Deaf parents and siblings.

Furthermore, the Deaf adults sought companionship with other Deaf individuals when it came to starting a family. In this sense they selected to date or marry individuals who shared cultural values and conversed in the same language. It highlights the importance of existing within similar cultural groups as a means to feel satisfied and comfortable. Having another person with whom to talk to would enable self-expression and positive identity formation.

Language and Communication

The interviews with the Deaf parents discerned natural language acquisition as the best means through which D/HH children learn SSL and communication skills. This reinforces the need for D/HH children born to hearing parents to be identified early, and streamlined into programs that could assist in early language acquisition, as their hearing parents and caregivers would most likely be unable to provide adequate linguistic stimulation to develop the necessary language skills. This further supports the need for earlier enrollment in school, as that might

serve as the first time D/HH are exposed to SSL and Deaf Culture. Deaf adults could also serve as mentors to hearing parents in imparting cultural norms and language skills.

Equality and Inclusion

The Deaf parents distinguished the communication gap as the main barrier to inclusion. It became apparent that attitudes and behaviors of hearing individuals towards Swazi Sign Language and deafness changed the longer hearing individuals were acquainted with the Deaf person. However, a common phenomenon is the learned patience that Deaf people adopt towards language and communication. As members of a language and cultural minority, Deaf individuals are used to having to adjust their communication methods to be understood by those they are conversing with.

One negative aspect of being part of a minority group is the fact that it may be challenging to find people committed to learning your language, seeing it as a valuable skill and useful for communication. In this case, parents, caregivers or even other family members might not be as motivated to learn SSL for several reasons. For one, it is not their main means of communication, and secondly, the language would be used to communicate with maybe one or two individuals. It is understandable given the aforementioned variables that affect inclusion. In order to address this issue, the perception of deafness needs to shift substantially to a place where parents, caregivers and even community members value, appreciate and desire the need for Deaf voices to be heard, and included into all aspects of life. This can be achieved through spreading awareness as a means to combat negative attitudes and beliefs that other individuals hold towards Deaf people, working to move away from pitying Deaf individuals to embracing them as productive members of society.

STUDENT INTERVIEWS

Addressing the Language Gap

Deaf children when they seek to address certain individuals who are not as conversant with SSL, particularly within their own family and household. Despite these strategies, the Deaf children involved in this study expressed feelings of exclusion and loneliness when reflecting on their experiences at home. In fact, the three students who have another sibling who is Deaf responded quite differently when asked “what do you enjoy at home”, compared to those who are the only Deaf person in the family. Having a second person who is able to relate information, stories and so on provides an outlet that other Deaf children do not necessarily have.

Having constantly to adjust communication strategies and methods would be exhausting. One component of cross-cultural competency is being able to express an idea across a language, ensuring its cultural relevancy and incorporating contextual information that would guarantee comprehension. This is a skill exhibited by the Deaf children interviewed for this study, whom, in recounting experiences at home depict how they adjust their language to select cultural markers that would be better understood to someone who is less “Deaf Friendly”. Such strategies work to bridge the communication gap, but also restrict the students’ SSL development. In addition to that, it appears that inclusion is not always a two-way street. The Deaf children may have to go to great lengths to remind people to sign, or place continued effort on teaching family members SSL. Thus, a barrier is also present in a lack of interest of hearing people to not only learn sign language, but also have the empathy to understand, and thus work to overcome feelings of isolation and exclusion shared by Deaf individuals.

Family Support

The findings unveiled a particularly interesting pattern in relation to the family member that knew the most SSL or understood Deaf Culture the best. This person in most cases tended to

be a younger sibling. This is perhaps due to the fact that the realization or news of having a Deaf sibling would not be shocking or surprising. The younger sibling would have grown up alongside them, thus normalizing communication to a degree. The Deaf child, as the older sibling may have been responsible for assisting in caring for them or be the closest person with whom early-childhood play occurred. In other words, this would naturally build cross-cultural competence between the siblings, who grow up using other means of communication to express their needs, interests and wants. Engaging the younger sibling in interventions might be a good starting point to working towards engaging more family members.

The students also indicated that their parents and even siblings are often busy with work. Job obligations or even the pursuit of higher education can act as a barrier to addressing the language and cultural gap. If parents are gone for the better part of the day, Deaf children are prevented from spending quality time with them, time that could be spent in language learning, cultural exchange or other parent-child interactions, such as imparting life skills and so on.

REFLECTIONS AND FUTURE CONSIDERATIONS

Several things struck me throughout the data collection process that worked to shape my understanding and perceptions of why the communication gap persists, leaving Deaf children to be a foreign minority in their own homes. The first, is that parents of Deaf children (at least by the time they have enrolled their child into school), have accepted their child's deafness and genuinely want to see them become successful, independent adults just like their hearing children. The major issue is that parents are often left out of the decision-making process when it comes to educational decisions involving their children.

Moreover, given that the school is located in a distant corner of the country, many parents travel from far, making visiting the school more than twice a term can be challenging. Based on

my observations, while the general attitude amongst teachers, staff and students is that parents do not value the children, I think that distance plays a huge role in parental participation, further limiting the successful outreach of the school. That being said, the parents who did come in for the interviews are also those that tend to be more involved in their child's education. The school continues to face challenges in getting parents to attend workshops, meetings and Open Days.

Initial Thoughts

Tackling communication gap continues to be problematic. I have been working with the school on developing a Swazi Sign Language dictionary, with the idea that parents of Deaf children will be able to have a basic means to assist in helping them retain some of what their children teach them. One of the negative aspects of the boarding school setting, is that parents only see their children typically once after every couple of months, thus making it difficult for them to retain what little SSL they have learned. A remedy first step is really working to build relationships between the school and the parents. Developing a rapport between the school and the parents can establish a mutually beneficial relationship. This could be achieved through sending children home with letters or information booklets with tips or suggestions on how to better communicate with their children. This would also work to build a greater sense of community on a broader scale.

Designing an orientation for new parents who are enrolling their children at the school might be a good first step. As Deaf people move from the periphery into the fold, more awareness will be generated thus, slowly working to shape the perceptions and attitudes held towards Deaf people. However, the school should be a fore-runner in addressing these attitudes and barriers. It appeared that the hearing parents of Deaf children want the support, they just are not sure how that support will manifest itself, or perhaps, how to ask for it.

The creation of parent support groups in the four regions of the country might be another direction that the school could pursue. This would enable parents to reach out to each other, form support groups and engage their Deaf children in a community where they can express themselves freely. Particularly, as children often feel isolated while at home. This aspect is of particular importance, as parents recognized their inability to advise their children on certain issues such as puberty. The opportunity for students to meet up during the school holidays would enable the continuation of supportive peer groups, while also perhaps creating more awareness in the communities about Deaf culture and other Deaf issues.

Although Deaf children are not excluded as members of their families, the fact that the hearing parents expressed concern that it is difficult to understand and communicate with their children needs to be further evaluated. Informal conversations with the students suggest that they may love their parents, but their parents are also removed from the role of providing mentorship and guidance to their children. Developing better communication skills include: pace of signing, and other cultural differences that may go against the grain. Moreover, I think interventions could be created to help parents and children work through the communication gap, such as the introduction of a family camp, or teaching games or methods to help children and parents establish a common language if learning SSL remains problematic. The most fascinating aspect of this, is that children are taught English in school, while some parents and family members are only able to communicate through SiSwati, this therefore limits the ability for parents and children to correspond through written communication.

Although children are present and are able to participate in daily activities, the issue is how included do they really feel, when the world revolving around them is not one they can directly relate to, or fully participate in. The limited ability of family members to communicate

through the use of SSL is amplified when Deaf children are present amongst all hearing family members. If no one takes the initiative to interpret even basic conversations, the Deaf child is systematically excluded to basic socializing. Thus, strategies could be adopted at home to encourage family members and parents to consider looking at the world through their children's eyes.

Deaf culture has nuances that clash with how one shows respect in Swazi culture. For example, eye contact is an important part of Deaf culture, in particular direct eye contact. However, Swazi culture says that children should not look up when talking to adults. This obviously poses a challenge for Deaf children, who rely on facial expressions and body language to interpret tone and gather information, especially when there is no use of sign language. Moreover, by ignoring certain customs, Deaf children can be seen as rude or indignant, rather than their behavior being understood as necessary for clearer communication.

Unfortunately, as the Deaf population is a minority in Swaziland, the general belief is that they must adapt to living in a hearing world, and as frequently, Deaf individuals tend to be one of only a few in their communities, as they are viewed as a small minority. There is a need to engage parents and families and Deaf children on how to overcome these barriers. A story-telling initiative could help facilitate the development of non-verbal skills between parents and children. This is an area where parents and caregivers could adopt new means of communication.

DISCUSSION

Deaf individuals in Swaziland are a separate cultural group. Recognizing this is essential to encouraging families to adopt a more cross-culturally competent approach to communicating and interacting with their Deaf family members. A hindrance to this is the continued view that deafness is a disability or affects Deaf individuals in a similar way that other "disabilities" do.

Padden (2005) reiterates, “Truth be told, deaf people see themselves an odd fit in disability studies. We’ve been segregated for such a long time that we see our history as set apart from others, and it feels strange to have the company of other disabled people” (pp. 508). While written from the U.S. context, Padden’s words relate to what has been exhibited in Swaziland. Padden (2005) concludes, “As they moved into the twentieth century, deaf people agreed to modernize their language, first ceasing to refer to one another as ‘deaf-mutes’ and ‘deaf and dumb’ in an effort to end the perception of themselves as silenced” (pp. 509).

Deaf individuals view the world from a different perspective than other people, capitalizing on their visual receptivity, and spatial awareness. While their language is not audible, it is no less beautiful in the range of expression and ability to “convey ‘their thoughts and souls, their feelings, desires and needs’” (pp. 509). While Deaf children make great efforts to be understood, and understand, the fact that parents and caregivers expressed an interest in learning Swazi Sign Language is a crucial step in legitimizing Deaf culture in Swaziland. Finally, in citing Baker and Padden, Leonard, Duran and Reiman (2003) assert that ““at the heart of every community is its language. This language embodies the thoughts and experiences of its users, and they, in turn, learn about their own culture and share in it together through their language” (pp. 2).

Creating a sense of community is another component to designing and implementing an early identification and family intervention program. Leonard et. al. (2003) cautions, “...most of [hearing] parents do not seek out Deaf adults and do not know about the existence of the Deaf community” (pp. 4). Despite the small size of the country geographical, transportation and socio-economic standing can hinder a parent’s mobility. Deaf adults remain on the periphery and are

rarely called upon as experts of their own experiences, language and culture. Leonard et. al.

(2003) continues:

Because parents of deaf children get their information from the medical community and not Deaf adults or organizations, deafness has historically been viewed from a pathological perspective as something to be fixed. The state of having diminished hearing has been seen as a deficiency, as if a person with a hearing loss were broken... The stigma associated with being deaf combined with external attempts to discontinue the use of ASL and otherwise undermine Deaf people's linguistic and cultural integrity are strongly suggestive of oppression... ” (pp. 4).

Schools in Swaziland are not equipped with the materials or system needed to even make or mold hearing aids to distribute to the students. Beyond that, there is a lack of resources and services available that are relevant in the Swazi context, that can also be supported by the limited infrastructure.

While Swaziland has launched a series initiatives as acknowledged by the literature, it is still a work in progress, as the ministry seeks to adopt similar practices of their colleagues abroad. There have yet to be implemented fully. Currently, there are no population records of the number of D/HH individuals in Swaziland that should benefit from the services. Supplying hospitals and clinics with the appropriate equipment to adequately screen all newborns and children up to the age of three would be a massively expensive under-taking, and is also time consuming. Staff training, developing campaign awareness requires additional time before families with Deaf children receive support. Devising a way to utilize cross-cultural mediation to develop interventions cost effectively would increase positive feelings and beliefs for Deaf children and their families. These interventions are the crux of this movement.

As acknowledged in the parent interviews with the Deaf adults, providing opportunities for Deaf individuals to be more visible helps shift deafness from strange to normal. Through placing emphasis on bridging this cultural gap, parents and caregivers will naturally have more

support, as family members lose the attitudes and beliefs that remain devastating to new parents of Deaf children. Deaf children will be included into society naturally.

Cross-cultural mediation also places strong emphasis on the importance of uninhibited communication and self-expression. Thus, having more parents communicate effectively with their children, and thus bridge the cultural and communicative gap would mean having individuals who could serve as role models and mentors to new parents of Deaf children. Parents could then inform guidebooks, pamphlets, schools, hospitals and so on, addressing the issues presented in both the literature and the research at a grassroots level. Moreover, parents of Deaf children is one resource that Swaziland actually has readily available, albeit untapped. Hosting workshops to train parents and caregivers of Deaf children, along with Deaf adults on methods of cross-cultural communication would begin the long process of mainstreaming deafness in Swaziland. Such trainings should occur locally, enabling rapport to develop and cohesion to exist so parents do not have to pay the fees to go to distant schools to gain knowledge in these areas.

THE CRUCIAL NEXT STEP

Deaf adults must be involved in programs that seek to educate parents and caregivers on how to bridge the communication and cultural gap, and better support their children. Using the experiences and expertise of these individuals will provide both parents and Deaf children with a support system, which can assist also in addressing the way in which deafness is perceived and related to. Therefore, Deaf adults should be at the center for instituting interventions and strategies to help bridge the gap between hearing parents or caregivers and their Deaf children.

Leonard et. al. (2003) provide guidelines for individuals mediating in situations involving both Deaf and hearing people. The first emphasizes the importance of establishing and supporting linguistic needs of all participants and removing methods of communication that may

obstruct the mediation process. They clarify, “when working with participants who use a different language, it is also extremely important to define concepts and terms to ensure accurate comprehension. Any opportunity to clarify meaning, check with the participants’ perspectives, and restate essential ideas should be utilized” (Leonard et. al., 2003, pp. 5). Deaf children enrolled at the School for the Deaf learn two languages; Swazi Sign Language and English. Again, although English is taught in mainstream schools, many parents, caregivers or other family members may not be conversant enough in English to hold successful written correspondence as a means to communicate. Additionally, hard of hearing students are in unique circumstance when they can lip-read and voice words in SiSwati, often unaware that they are not speaking English. In situations where parents or caregivers do not know SSL, an interpreter will facilitate dialogue between the two parties to ensure that both feel represented.

The second guideline recognizes the importance of observing the “cultural values that will influence both the Deaf and hearing parties’ behavior, response and understanding of the mediation process” (Leonard et. al., 2003, pp. 5). Here it is labeled “the ‘normalization’ of mediation” (Leonard et. al., 2003, pp. 5). Disregarding the cultural values that may influence how Deaf and hearing people behave, could drive the gap wider, instead of working to bridge it. It is important to pay attention to the differences and similarities between Swazi culture and Deaf culture, as previously stated. These nuances should be explained to both groups.

The final area that needs to be part of the implementation process of an Early Identification and Family Intervention program is information. A lack of resources prohibits individuals from overcoming the negative stigmatizations, attitudes or beliefs they may hold towards deafness or hearing loss. While parents and caregivers received confirmation that their child was D/HH, it appears that there are limitations placed on what parents or caregivers should

do once they learn that information. There is a need to reach out to doctors, nurses and RHMs to gain a clearer insight into their knowledge, beliefs and attitudes towards deafness and Deaf individuals, as well as observe what information or advice is granted to parents. Interviews with health care professionals should none-the-less be pursued in the future.

The lack of services available for Deaf individuals and family members needs immediate attention. The California Department of Education (2013) adapted a chart acknowledging the “Sources of Support” for parents of Deaf children. In reading through the chart, another barrier to inclusion becomes visible; limited support networks (see Appendix VII). Of the six sources of support identified by the state of California, only one or two of them are available in Swaziland (“Family” and “Community Connections”).

The other fields, “Parent to Parent”, “Individuals who are D/HH”, “Information” and “Professionals” are much less accessible or even present. It is problematic that families of Deaf children are hindered from accessing these resources prior to that. Attention should be paid to the plethora of resources and support that could be made available to parents and caregivers, as illustrated in the charts in Appendix VII. An example of this would be to create family resources centers, parent support groups, mentorship programs, resource guides, as well as work on developing or enhancing job descriptions amongst professionals to encompass a broader range of services that are currently unavailable in Swaziland, such as Deaf agencies, audiologists and speech pathologists, to name a few.

There are four key components that need to be targeted upon initiating the Early Identification and Family Intervention program in Swaziland. These are:

1. Creating a sense of community encompassing Deaf and hearing individuals who identify with the values attributed to Deaf culture in Swaziland

2. Advocating for Deaf individuals to be recognized as members of a unique cultural group with SSL as a legitimate language;
3. The recognition and inclusion of Deaf adults as experts in supporting in program areas from design to implementation;
4. Production and availability of resources and services

CONCLUSIONS

The purpose of this study was to gain insight into the existing attitudes and beliefs held by parents and caregivers towards their Deaf children, and what strategies could be adopted to ensure greater inclusion of Deaf children into their families. The study sought to answer the question, *What interventions can be implemented in Swaziland in order to encourage the integration and inclusion of Deaf children into their families?* The main objective of this study was to understand what resources and assistance should be given to families with Deaf children as a means to encourage greater access to education and psychosocial support. This was addressed through the sub-questions, which aimed to better understand the current factors that prohibited the inclusion and integration of Deaf children into their families and other areas of society.

The findings answered the research questions, revealing that there are several areas where interventions could be developed to assist in bridging the communication gap, and spreading awareness on what it means to be Deaf in Swaziland. Specifically, creating interventions that would directly address language and communication skills are of utmost importance. Moreover, the findings addressed the research questions underpinning the study. This is evident in the data collected, depicting that considerations should be made to implement interventions that deal directly with the language and communication barriers that prohibit parent and child from

building stronger relationships. In addition to that, answers to the sub-questions emerged. Here, the questionnaire and interviews revealed the existing attitudes and beliefs of parents and caregivers of Deaf children in Swaziland. Although the study was limited to a small population pool, the information gathered served to highlight areas that can be further explored in future studies, to inform programs that seek to engage parents and caregivers.

Programs to open more opportunities for D/HH children in education and inclusion into society is needed. Legitimizing SSL as a relevant and necessary means of communication for Deaf people, and to encourage cross-cultural competence amongst family members and other members of society. Both parents and caregivers and their children, as well as the School for the Deaf would greatly benefit from the development of an Early Identification and Family Intervention plan. As there are very limited services in place offering assistance to families with Deaf children, the next step is to begin establishing some of suggested practices mentioned above. Greater community involvement is necessary in order for the ideal of inclusion to be realized, and not just its replica, which is what currently prevails in Swaziland.

Limitations

1. The small sample size in the interviews could not fully encompass all of the experiences and opinions of parents and caregivers of Deaf children.
2. Being an outsider to the community may have influenced the way interviewees answered questions
3. The inability to complete the healthcare professional interviews leaves a less well-rounded picture on the whole scope of the issues that need to be addressed

Future Research

In order to determine the depth to which stigmatization affects D/HH children could be further scrutinized or addressed. While parents and caregivers could make more effort to include their children. It appears that the attitudes and beliefs outside of the immediate family of a Deaf child might be the next area to address. Lastly, as the healthcare professional interviews did not

transpire, this is an area of particular interest that needs to be pursued, as it will take the support and teamwork of the Ministry of Health to help us achieve this particular initiative.

Useful methodology for future research would be to target the parents and caregivers more specifically when distributing the questionnaires, keeping record of who has or has not filled them out, and ensuring that all fields are filled out on them to gather accurate demographic information. In addition, being present when the parents or caregivers fill out the questionnaires would be advised to assist if there is language misinterpretation or misunderstanding that may otherwise prohibit them from filling out the form. In addition, the use of focus groups for the parents might assist in generating solutions to the problems addressed in this research. Home visits may also be an effective way to gain insight into the barriers that Deaf children face towards inclusion. However, these would have to be carefully planned as this method could also be disruptive, compromising the authenticity of home interactions.

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**APPENDIX I: LETTER OF CONSENT FOR PARENTS/CAREGIVERS
ENGLISH**

My name is Pamela Keilig and I am doing research in partial fulfillment of my Master's of Arts degree at the School for International Training in the United States.

The purpose of the study is to gather information on the challenges and experiences that both parents/caregivers and children face in understanding and communicating with a Deaf child, as well as establish what resources and initiatives should be made available to best assist parents/caregivers in raising their child and helping the child access education and reach their full potential in life. The term "cross-cultural" refers to understanding the differences in culture or behaviour that may lead to misunderstanding, as well a working to overcome any communication barriers. An intervention is an action taken to address an issue or problem working to find a solution. Further information on the study can be provided upon request.

Your involvement in this study requires your participation in an interview, whereby you will be asked a series of questions in a non-formal, discussion-based setting, and be encouraged to express your opinions on your experiences in communicating and interacting with family members.

I, _____ hereby consent to participate in the study Cross-cultural interventions for families of Deaf children in Swaziland. I understand that participation in this study is voluntary and that my choice to withdraw at any point will not result in penalty or loss of benefits to which I am otherwise entitled. Should I choose to withdraw, I can depart from the interview at any time without explanation. In addition, I have the right to refuse to answer any questions that make me feel uncomfortable. I acknowledge that confidentiality is of utmost importance, and that pseudonyms will be used to protect my identity. As the study requires video recording, I understand that recordings will be kept in a secure location at the School for the Deaf Primary, and will not be used for any purpose other than the study for which it was made. Upon completion of the study, all recordings will be deleted.

I have read the above and I understand its contents and I consent to participate in the study. I acknowledge that I am 18 years of age or older. I also give my consent to be recorded.

Should you wish to contact the IRB committee or SIT Graduate Institute for further information on your rights as a research subject, you may write to P.O. Box 676, 1 Kipling Road, Brattleboro, VT 05302-0676 or contact the IRB coordinator at irb@sit.edu.

Signature _____

Date _____

I would like to receive information regarding the findings of the research upon completion of the study [] _____

LETTER OF CONSENT FOR PARENTS/CAREGIVERS

SISWATI

Libito lami ngingu Pamela Keilig (Bongiwe Maphalala), ngilivolontiya lelihala e School for the Deaf Primary eSiteki. Ngisebentela kucedza tifundvo tami te Master's Degree lengitenta e School for International Training lesise Melika. Ngembonowami ngingatfokota ekwenteni lucwaningo kuze ngikhone kucala kusheshe ngibone nasekuhlanganyeleni nemindeni lenebantwana labakhubateke ngekungeva nangekungakhulumi eSwatini ekuhlanganyeleni nesikolo lesincane se Deaf. Lwati loluchubekako ngalolucwangingo lungatfolakala naluceliwe.

Inhloso yalolucwangingo kuhlanganisa lwati netingcinamba letibhekana nebatali nobe labanaka labantwana kanye nebantwana ekucondziseni lokukhubateka kwalabantwana kanjalo nasekucaleni kutfolakala kutsi yini tintfo letingatfolakala ekusiteni batali nebanakekeli ekukhuliseni bantwana babo nasekusiteni bantwana ekungeneleni imfundvo bafeze emaphupho abo emphilweni.

Luluhlelo lwelucwaningo lufaka kusetjentiswa kwelicumbu lelibheke embili/lelinenchubekela phambili, futsi ngitawutsandza kufaka umntwana wakho kulelicumbu. Labantwana batawubutwa luhla lwemibuto lolusakhulumo. Kute emabito lato setjentiswa lokusho kutsi kutawuba yimfihlo. Kwenteka kuloko ngicabanga kutfwwebula loluhlelo (video recording) kuze ngitoba nesiciniseko kutsi angishiyi lutfo.

SITATIMENDE SESIVUMELWANDO

Mine _____ ngiyamvumela umntwanami kutsi alungenele loluhlelo lwe kusheshe ubone nekuhlanganyela kwemndeni: Luhlelo lwemindeni yebantwana labangakhulumi nalabangeva eSwatini. Ngियाcondza kutsi kutsi kungenela lolucwaningo alubhadali nekutsi umntwanami angaphuma noma nini ngaphandle kwesijeziso nobe kulahlekelwa yinzuzonekutsi umntwana unelilungelo lekwalakuphendvula imibuto lengamgculisi. Ngiyavuma kutsi kugcina imfihlo yintfo lebaluleke kakhulu nekutsi kusetjentiswa emagama ludzinga kutfwwebula, ngiyacondza kutsi lemitfwwebulo itawugcinwa endzaweni lephephile esikolweni futsi angeke isetjentiswe kuletinye tidzingo ngephandle kwalolucwaningo lekwakhelwe lona. Ekupheleni kwalolucwaningo, konkhe lokutfwwebuliwe kutawucishwa.

Ngifundzile lokungetulu futsi ngiyacondzisisa lokukushoko futsi ngiyavuma kutsi umntwanami alungenele lolucwangingo. Ngiphindze ngiyavuma kutsi umntwanami atfwwebulwe.

Sidladla _____

Lusuku _____

**APPENDIX II: LETTER OF CONSENT FOR STUDENT INTERVIEWS
ENGLISH**

My name is Pamela Keilig and I am doing research in partial fulfillment of my Master's of Arts degree at the School for International Training in the United States.

The purpose of the study is to gather information on the challenges and experiences that both parents/caregivers and children face in understanding and communicating with a deaf child. Another goal is to help establish what resources and initiatives should be made available to assist parents/caregivers in raising their Deaf child and helping the child access education and reach their full potential in life. The term "cross-cultural" refers to understanding the differences in culture or behaviour that may lead to misunderstanding, as well a working to overcome any communication barriers. An intervention is an action taken to address an issue or problem working to find a solution. Further information on the study can be provided upon request.

Your child's involvement in this study requires participation in an interview, whereby he/she will be asked a series of questions in a non-formal, dialogue setting, and be encouraged to express his/her opinions genuinely for no more than 1 hour.

I, _____ hereby agree that _____ may participate in the study Cross-cultural interventions for families of Deaf children in Swaziland. I understand that participation in this study is voluntary and that my child may withdraw at any point will not result in penalty or loss of benefits to which he/she is otherwise entitled. Should he/she choose to withdraw, he/she can depart from the interview at any time without explanation. In addition, he/she has the right to refuse to answer any questions that may make him/her feel uncomfortable. I acknowledge that confidentiality is of utmost importance, and that pseudonyms will be used to protect my child's identity. As the study requires video recording, I understand that recordings will be kept in a secure location, and will not be used for any purpose other than the study for which it was made. Upon completion of the study, all recordings will be deleted.

I have read the above and I understand its contents and I accept my child's participation in the study. I acknowledge that I am 18 years of age or older. I also give my consent for him/her to be recorded.

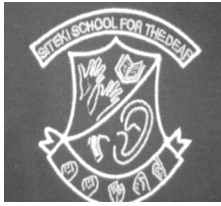
Should you wish to contact the IRB committee or SIT Graduate Institute for further information on your rights as a research subject, you may write to P.O. Box 676, 1 Kipling Road, Brattleboro, VT 05302-0676 or contact the IRB coordinator at irb@sit.edu.

Signature _____

Date _____

I would like to receive information regarding the findings of the research upon completion of the study [] _____

APPENDIX III: PARENT/CAREGIVER RESEARCH EXPLANATION AND QUESTIONNAIRE



School for the Deaf Primary
P.O. Box 135, Siteki L300
Tel/Fax: 23434241

RE: Early Identification and Family Intervention Program Questionnaire

Dear Parents,

The school is working to assemble information to improve the facilities and resources available to our students and their families. We are kindly requesting your support as we move forward with this initiative. We will be conducting research to help us develop the correct programming to aid in developing an Early Identification and Family Intervention Programme. An intervention is an action taken to address an issue or problem working to find a solution. The aim of this programme is to provide families with the information and resources needed to guide and assist families with Deaf children, as well as spread awareness on deafness in Swaziland. This will be achieved through better understanding where miscommunication may occur between parent/caregiver and the Deaf child.

In addition, programme areas will hopefully include assessment methods for identifying deafness in young children, providing counseling and support to families, and informing families on the best ways to communicate with their children as successful and expressive communication is essential to a child's social and educational growth.

Participation is not required, however, it will greatly benefit the current students at the school, as well as assist in paving the way for a brighter education for students in the future.

Should you choose, you may opt to participate in an interview which will provide the school and the researchers with a broader and deeper understanding of the challenges and experiences parents and caregivers face in regards to raising a Deaf child in Swaziland.

If you wish to contact the IRB committee or SIT Graduate Institute for further information on your rights as a research subject, you may write to P.O. Box 676, 1 Kipling Road, Brattleboro, VT 05302-0676 or contact the IRB coordinator at irb@sit.edu.

Thank you,

Early Identification and Family Intervention Program Questionnaire [ENGLISH]

Please tick [] if you would be willing to participate in an interview based on the information collected below _____

What relation are you to the child? _____ Mother/Father _____ Brother/Sister
_____ Grandparent _____ Aunt/Uncle _____ Legal guardian _____ Other

What is your gender? _____ Male _____ Female

1. At what age did you learn that your child is Deaf or hard of hearing? _____

2. How did you learn about your child's deafness or hearing loss?

3. How did you feel after learning this news?

4. What actions did you or another family member take after learning that your child was Deaf?

5. Did learning of their deafness change how you interacted with the child?

- a) Yes
- b) No

6. Do you believe there is a stigma on people who are Deaf?

- a) Yes
- b) No

Please Explain:

7. How did you learn about the Primary School for the Deaf?

- a) Clinic or Hospital (please provide the name) _____
- b) From a community member
- c) The radio, television or newspaper
- d) Other (please explain): _____

8. At what age was your child enrolled at the Primary School for the Deaf? _____

9. If your child was enrolled at the age of 6 or older, what challenges did you face in enrolling him/her earlier?
10. Had they been previously enrolled at another school?
a) Yes
b) No
11. Does your Deaf child interact with other children on the homestead or in the community?
a) Yes
b) No
12. What activities is your Deaf child involved in at home (circle all that apply)
a) Cleaning
b) Cooking
c) Wash clothes
d) Plays with other children
e) Other (please explain) _____
13. What behaviour does your child exhibit at home?

14. What methods do you use to communicate with your child? (circle all that apply)
a) I am learning/have learned Sign Language
b) Speaking/talking
c) Written communications (e.g. writing words on paper, etc.)
d) Miming/gestures/body language
e) Other (please explain) _____
15. I find communicating with my child difficult
a) Yes
b) No
16. Do you feel you have the support you need to raise your child?
a) Yes
b) No
17. Do you feel like you have a positive relationship with the school?
a) Yes
b) No
18. What support from the school would be helpful?

Please tick [✓] if you would like to receive information regarding the findings of the research upon completion of the study _____

**PARENT/CAREGIVER RESEARCH EXPLANATION AND QUESTIONNAIRE
[SISWATI]**



School for the Deaf Primary
P.O. Box 135, Siteki L300
Tel/Fax: 23434241

**LUHLELO LWEMIBUTO LWEKUSHESHE UBONE KANYE NEKUHLANGANYELA
KWEMINDENI**

Mtali,

Sikolo sisemkhankhasweni wekuhlanganiswa lwati ekutfufukiseni tidzingeko letisetjentiswa bafundzi betfu nemindeni yabo. Sicela kusekelwa lokukhulu sisachuba loluhlelo. Sitawuba nelucwaningo lolutasisita ekukhuphuleni kusita kuloluhlelo lesilisukumisile. Inhloso yaloluhlelo kutsi sinikete imindeni lwati netintfo letitobalusito ekucondizisa nelusita imindeni lenebantfwana labakhubateke ngekungakhulumi nekungeva kanjalo naskwandziseni lesatiso eveni lonkhe laka Ngwane.

Letindzawo letihleliwe titawuba netindlela tekubukisisa kukhubateka ngekungakhulumi nangekungeva ebantfwaneni, kuniketa lusito emindenini lephila nalabantfwana kanye nangekwatisa imindeni ngetindlelea letikahle tekuchumana kanye nebantfwana babo kuze umntfwana ngamunye anakeke nangekutsi bonkhe bantfwana babe nelitfuba lekufundza.

Kusebenta akukabhekeki kodvwa ke kungabalusito lolukhulu kubantfwana labakhona esikolweni kanjalo nasekusiteni ekuvuleni indlela leya emfundvweni lelichakazile yelikusasa lebafundzi.

Ekwengeteni, nawukhetsa, ungakhetsa ekubukeni licembu lelitoniketa sikolo nalabenta lolucwaningo ngelwati loluchakzile netingcinamba lababhekana nato batali nebanakekeli ekukhuliseni bantfwana labakhubateke ngekungeva ngekungakhulumi eSwatini.

Siyabonga,

**LUHLELO LWEMIBUTO LWEKUSHESHE UBONE NEKUHLANGANYELA
KWEMINDENI**

Kucelwa umake (√) nangabe utawutsandza kungenela kulelicembu kususelwa kulombiko lobutsisiwe ngentasi _____

What relation are you to the child? _____ Mother/Father _____ Brother/Sister
_____ Grandparent _____ Aunt/Uncle _____ Legal guardian _____ Other

What is your gender? _____ Male _____ Female

1. Wabona esigabeni seminyaka langanani kutsi umntfwana akeva/akakhulumi? _____
2. Wafundza njani kutsi umntfwana wakho akakhulumi/akeva?

3. Wativa unjani ngemuva kwekutfolela letitindzaba?

4. Nguyiphi imetamo lowayenta nobe leyentiwa ngulinye lilunga lemndeni wakho ekubeni kubonakale kutsi umntfwana akakhulumi/akeva?

5. Ngabe kufundza ngekungakhulumi/kungeva kwabanga lushintsho ebudlelwaneni bakho nemntfwana?

- a) Yes
- b) No

6. Uyetsembe kutsi kunelubandlulo kubantfu labangakhulumi labangeva?

- a) Yes
- b) No

7. Wati kanjani ngesikolo salabangeva/labangakhulumi (School for the Deaf)?

- a) Eklinikhi noma Esibhedlela (Sicela usho ligama) _____
- b) Weva ngelilunga lasenzaweni
- c) Ewayilesini, kumabonakudze noma ephephandzabeni
- d) Lokunye (chaza) _____

8. Umntwanakho watsatfwa aneminyaka lemingaphi esikolweni lesincane salabangeva (Primary School for the Deaf) _____

9. Wafakwa ebangeni lesingaphi nakefika kulesikolo lesingenhla? _____

10. Ngabe uke wafundza yini kulesinye sikolo?

- a) Yebo
- b) Cha

11. Ngabe umntfwana wakho longakhulumi/longeva uyakhona kuhlanganyela nalabanye bantfwana ekhaya nasemangweni?

- a) Yebo
- b) Cha

12. Ngutiphi tintfo letentiwa ngumntfwana wakho longakhulumi/longeva ekhaya (kipilitela konkhe lakwentako)

- a) Kuhlanta indlu
- b) Kupheka
- c) Kuwasha timphahla
- d) Kudlala nalabanye bantfwana
- e) Lokunye (chaza) _____

13. Uthsengisa luphi luhlobo lwekutiphatsa umntfwanakho ekhaya?

14. Ngutiphi tindlela lotsiebentisako ekuchumaneni nemntfwanakho? (kipilitela konkhe lokentekako)

- a) Ngiyafundzela noba ngisafundzela kukhuluma ngetandla
- b) Kukhuluma ngemlomo
- c) Ngibhala phansi
- d) Ngiyamumula/noba ngisebentise tandla
- e) Lokunye (chaza) _____

15. Ngitfolo bulukhuni ekuchumaneni nemntfwanami

- a) Yebo
- b) Cha

16. Ucabanga kutsi utfola lusito lolwanele ekukhuliseni umntfwana?

- a) Yebo
- b) Cha

17. Ucabanga kutsi budlelwane bakho nesikolo ngulobukahle?

- a) Yebo
- b) Cha

18. Nguluphi luhlobo lwekusitwa longalutfola esikolweni lolungaba lusito?

Kucelwa umake (√) nawutawustandza kutfolo umbiko macondzana nalolucwaningo naseluphelile.

APPENDIX IV: PARENT/CAREGIVER INTERVIEW QUESTIONS

Age of participant _____ Gender _____ Relation to child _____

Attitudes and beliefs parents and caregivers hold or express towards their Deaf children

1. What were you/the mother's experiences during pregnancy?
 - a. Were you ever sick?
 - b. Did anything happen to you that you think affected your baby?
 - c. Are there any other cases or instances of deafness in your family?
2. What did you think about the capabilities of Deaf or hard of hearing people before your child's birth? What do you think of their capabilities now?
3. Had you ever met a Deaf or hard of hearing person before?
4. What is your relationship between you and the child? What is the relationship between the child and other family members? Please explain.
5. Are there any barriers affecting your relationship with your child? What are they?
6. What are some myths or stereotypes regarding Deaf people?
 - a. What are the things that people or other parents say about having a Deaf person in the family? Are they positive or negative? Please give some examples
7. Is it a good or bad thing to take your child to school? Please provide three reasons.

Integration of Deaf children into their families

1. Is it easy to understand your child? What makes it easy/difficult?
2. How do you communicate with your child?
3. Does your Deaf child behave differently than hearing children (either in your family or part of the community)? How does the Deaf child behave?
4. What skills do you use to understand your child?
5. How do you correct your child when he or she has done something wrong?
6. What is the relationship between your child and the neighbour children?
7. How do you teach or impart knowledge and skills to your child? (e.g. Not to touch hot stoves, teach your child what respect is, etc.)
8. Can you tell me about your family?
 - a. What support do you have in caring for your Deaf child?
 - b. What support do you need?

APPENDIX V: STUDENT INTERVIEW QUESTIONS

Gender _____ Age _____ # of years attending school _____ Birth order _____

Attitudes and beliefs parents and caregivers hold or express towards their Deaf children?

1. Tell me about you and your family?
 - a. Who do you stay with when school is closed?
 - b. Do you have both parents?
 - c. Do you have siblings? Are they hearing or Deaf?
2. How do you find being with the Deaf community as compared to being with your family members?
3. What do you enjoy about being at home? What do you not enjoy about being at home?

Family-Child Interactions

4. How do you communicate with your family?
 - a. Do you understand them?
 - b. How do you tell them your feelings? (i.e. how do they know if you're upset, sick, happy, etc.)
 - c. Whom do you best communicate with?
 - d. Does anyone in your family know sign language? Have you tried to teach them? Why/why not?
 - e. How do you receive information?
5. What activities or chores do you do while at home?

APPENDIX VI: LETTER OF PERMISSION TO COLLECT DATA

The Government of the Kingdom of Swaziland



Ministry of Education & Training

Tel: (+268) 2 4042491/5
Fax: (+268) 2 404 3880

P. O. Box 39
Mbabane, SWAZILAND

3rd July, 2015

Attention:
Head Teacher:
School for the Deaf Primary School

Attention:
Good Shepherd Hospital Administrator


THROUGH
Lubombo Regional Education Officer

Dear Colleague,

RE: REQUEST FOR PERMISSION TO COLLECT DATA FOR SIT GRADUATE INSTITUTE IN VERMONT (USA) STUDENT – MS. PAMELA KEILIG

1. The Ministry of Education and Training has received a request from Ms. Pamela Keilig, a student at SIT Graduate Institute in Vermont (USA), that in order for her to fulfill her academic requirements at SIT Graduate Institute in Vermont (USA), she has to collect data (conduct research) and her study or research topic is: *Cross-cultural Interventions for Families of Deaf Children in Swaziland: Reframing Inclusion*. The population for her study comprises of fifty (50) parents and care-givers of the at least two hundred (200) learners from the above mentioned school; at least five (5) learners from the above mentioned school, and two (2) medical practitioners (one doctor and one nurse) from the above mentioned hospital. All details concerning the study are stated in the participants' consent form which will have to be signed by all participants before Ms. Keilig begins her data collection. Please note that parents will have to consent for all the participants below the age of 18 years participating in this study.
2. The Ministry of Education and Training requests your office to assist Ms. Keilig by allowing her to use above mentioned school and hospital in the Lubombo region as her research sites as well as facilitate her by giving her all the support she needs in her data collection process. Data collection period is one month.

Yours Faithfully,


DR. SIBONGILE M. MTSHALI-DLAMINI
DIRECTOR OF EDUCATION AND TRAINING

cc: Regional Education Officer – Lubombo
Chief Inspector – Primary
1 Head Teacher of the above mentioned school
Good Shepherd Hospital – Administrator
Dr. Ken Williams – Student Advisor



APPENDIX VII: QUESTIONNAIRE RESULTS TABLES AND FIGURES

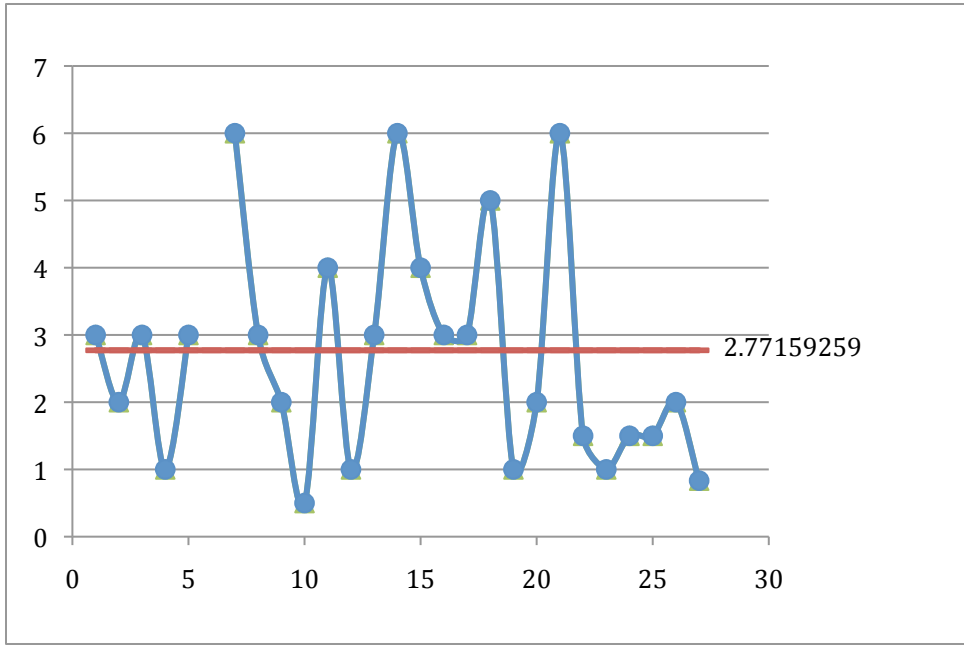


Figure 1: At what age did you learn that your child is Deaf or Hard of Hearing?

X-axis: Parent responses

Y-axis: Age of child in years

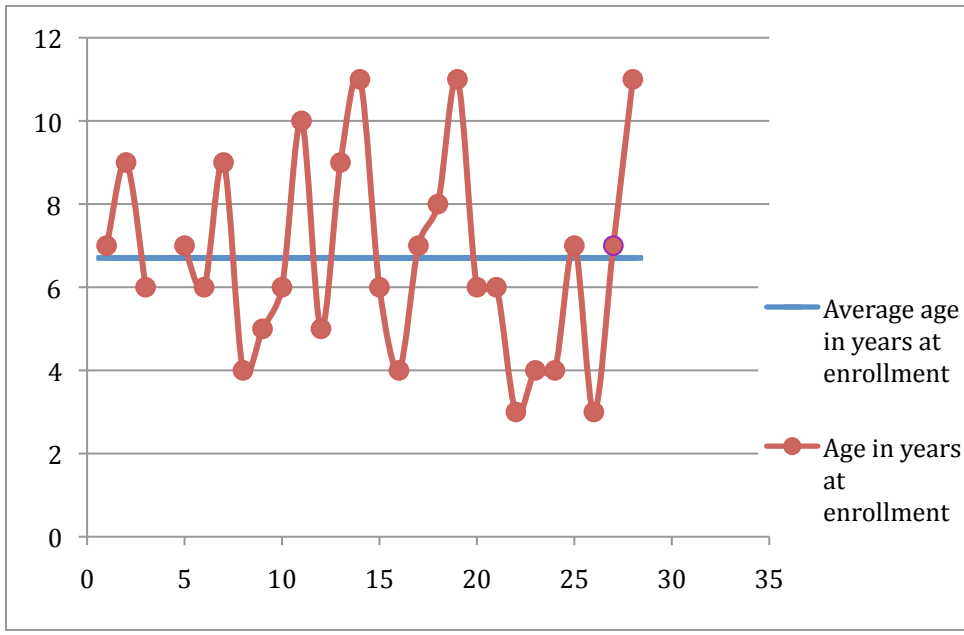


Figure 2: At what age was your child enrolled at the Primary School for the Deaf?"

X-axis: Parent responses

Y-axis: Age of child in years

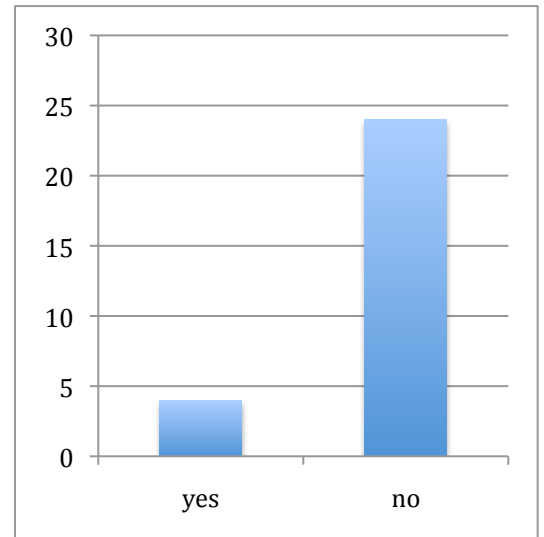
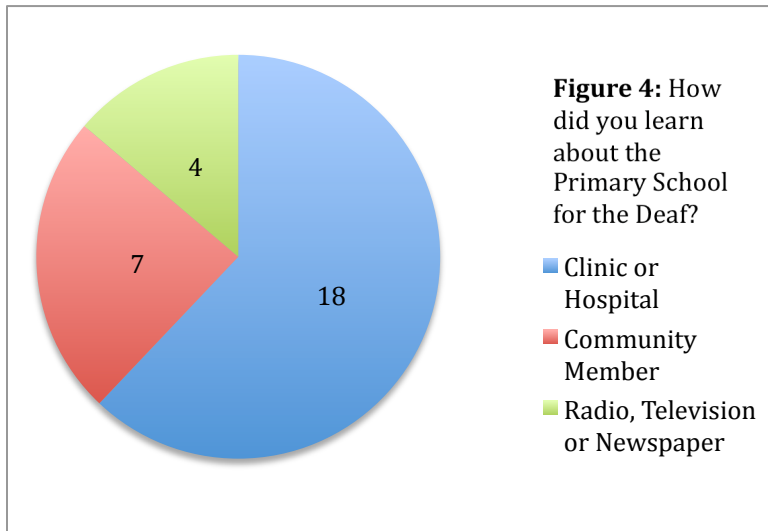
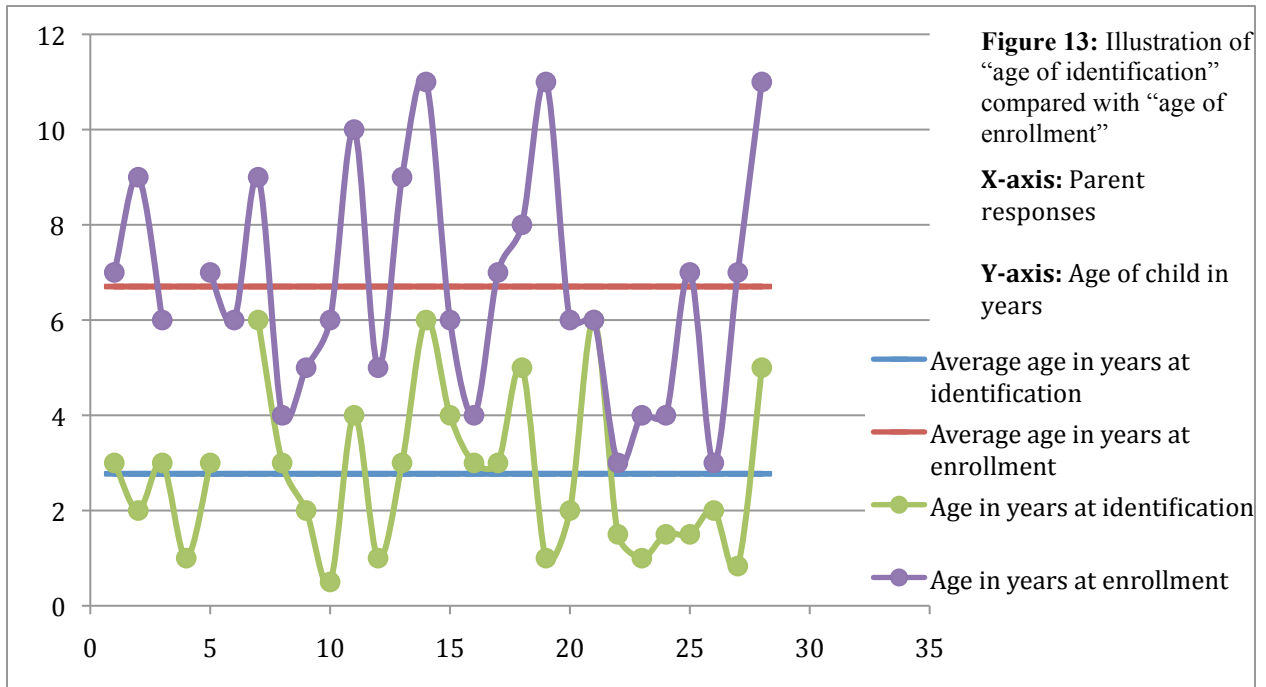
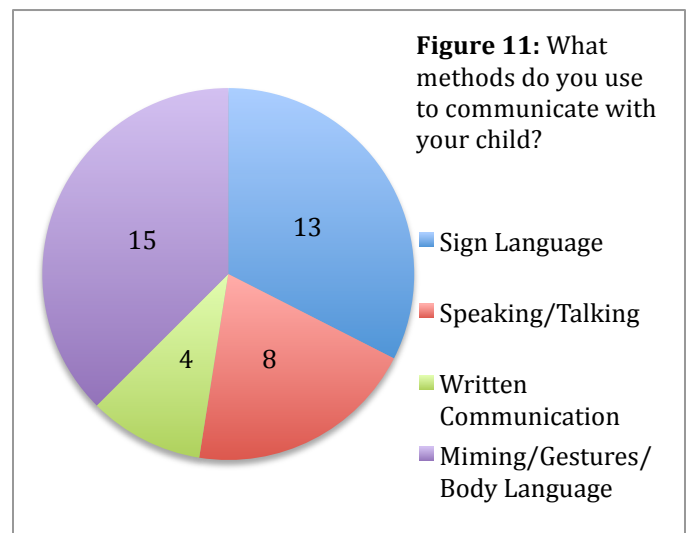
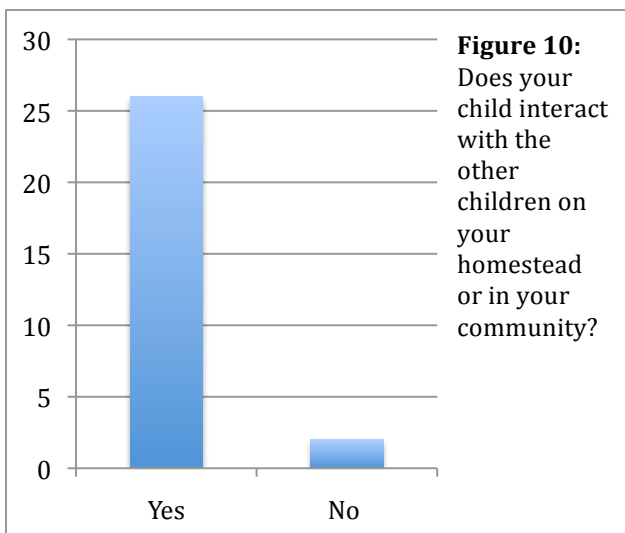
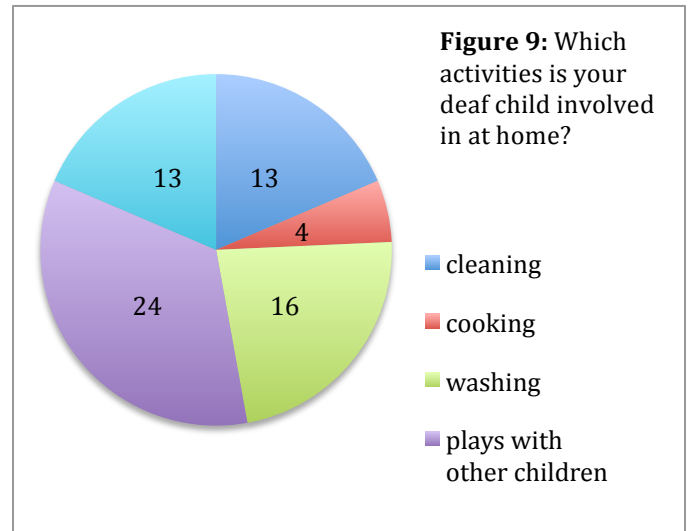
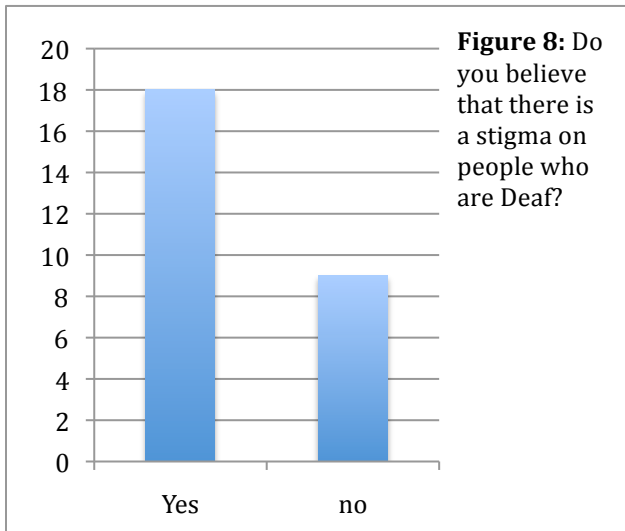
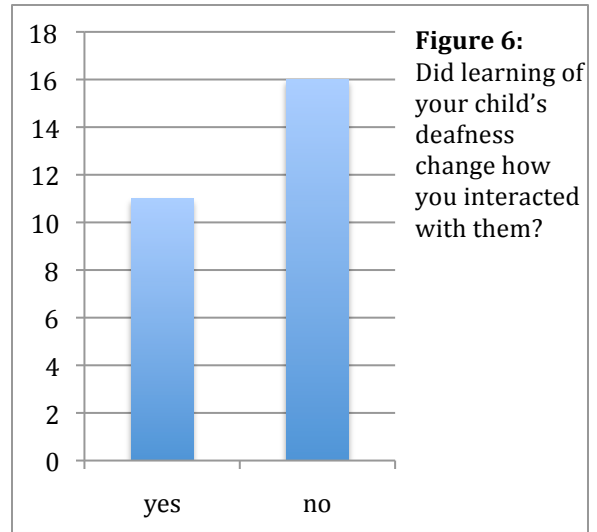
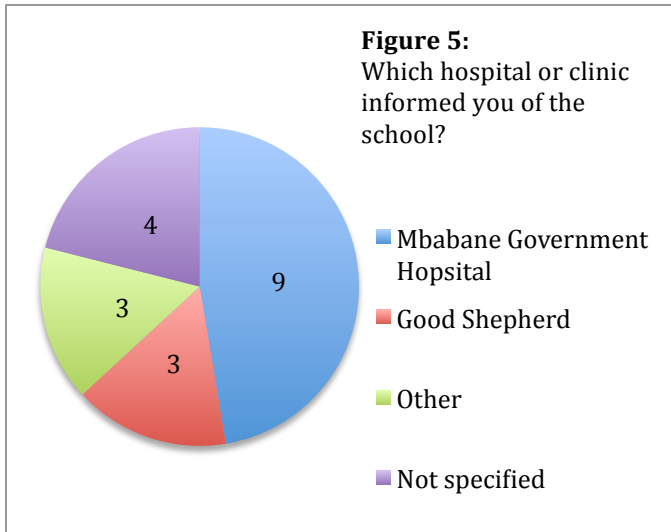


Figure 3: Had your child been previously enrolled in another school?



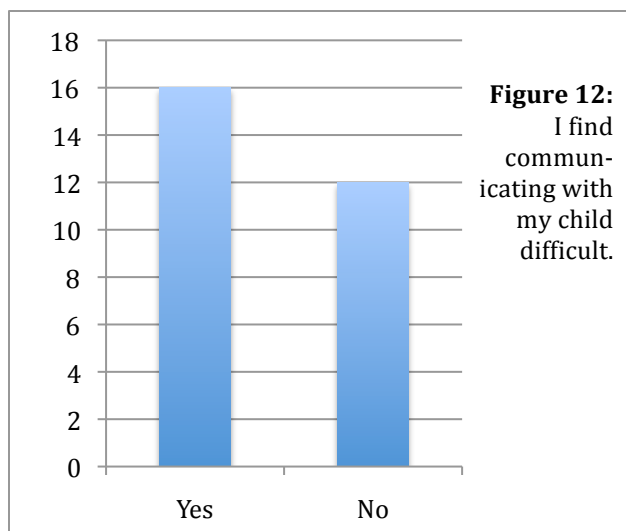


TABLE 1	
How did you learn about your child's deafness or hearing loss?	
Parent	Lack of Response
A, A2, N, M, L + S	I realised that my child had a hearing problem when he never responded when I called him, yet he was at a stage where he should recognise his name. I always had to pat him to get his attention. / he doesn't talk / He started not to respond when I called him /He wouldn't hear me calling him
J, Z, D + V	I use noisy toys to check if he heard them, but he never responded to any noise. / the child never reacted or responded to any noise, be it from a car, bus or truck or music from the radio., he just sat motionless.
B + X	He got to a child speaking age still not talking and as years advanced I started suspecting deafness/ He couldn't utter simple words that children who are learning to talk master first, like 'ncence' (please breastfeed me) or 'tata' (take).
	Illness or Health
K	Another problem is that he excreted pus through his ears and it troubled me.
	Confirmed by Medical Personnel .
E, T + U	I went to the clinic again to ascertain what the actual problem was and they confirmed my suspicions. They told me my child was Deaf. /He was 2 years old when I suspected that he had a problem. I took him to the clinic and they confirmed that he was deaf. /I took him to the hospital. It was there that they told me my child is deaf.

TABLE 2	
How did you feel after learning [that your child was Deaf or hard of hearing]?	
Parent	Feelings of Heartache
A, B, C, P, V + W	I was so hurt/ I was shattered/ I was depressed / So heartbroken/ I was so shocked/ I was so disappointed and hurt
G	It still hurts me.
H	I was so hurt and shocked. I always wondered what I would do, how I would help my child.
Religious Faith	
F	I was hurt but I chose to surrender everything to God.
Q	I accepted it as God's gift to us.
Acceptance	
S	I accepted the condition and nursed hope that my child would talk.
T, U + Z	I felt dejected but I accepted /My heart was broken, but I later accepted / I was hurt but I later accepted.

TABLE 3	
What actions did you or another family member take after learning that your child was Deaf?	
Parent	Sought Medical Advice
V	We went to Mbabane Government Hospital and they told us they could not assist the child.
B	We took the child to the hospital and the doctor there explained the deafness to be a result of being born to an HIV+ mother. Apparently, the mother's positive status resulted in the child's deafness.
N	We took the child to an audiologist at Good Shepherd Hospital
Q	We took the child to doctors who then advised us on the need to raise our voices when speaking to the child. He hears some things but others he doesn't hear.
E	I was the only one fending for my child. I knocked on many hospital doors seeking help but found none.
Sought Multiple Places for Support	
G + B2	I tried hospital doctors and also consulted traditional healers. /I tried taking the child to most hospitals and traditional healers
L, R + O	I took the child to the hospital and I also sought help from prophets. / We took the child to pastors for prayers and to the clinic / We took the child to the clinic and later to Mbabane Government Hospital but the condition remained the same. We eventually sought help from prayer warriors, still he remained deaf.
School for the Deaf	
C	I brought the child to the School for the Deaf.

TABLE 4	
What behavior does your child exhibit at home?	
Parent	Positive
A	<i>He is a very clean and neat child</i>
E	<i>He is an awesome kid.</i>
G	<i>Very respectful</i>
H	He is a peaceful and friendly child, sadly I can't communicate with him
P	Well behaved
R	He loves himself and enjoys playing with other children
T	Behaves like all other people
Negative	
C	<i>He is an obedient child but does get naughty sometimes</i>
N	He is so naughty.
Y	<i>He is neat, but short-tempered</i>
A2	<i>He is not friendly, prefers to be alone.</i>

TABLE 5	
What support from the school would be helpful?	
Parent	Sign Language
A, J, N, T, U + X	I wish to learn Sign Language so that I may be able to communicate with my child because most of the time language bars me from interacting freely with him. /I wish to learn Sign Language so that I may be able to communicate with my child /I wish to learn Sign Language to be able to communicate directly with my child
M, P, R + D	Learning Sign Language
Monetary Support	
I	I need financial help to pay fees and all other necessary school needs since the father is not working
N	I would also appreciate assistance towards paying school fees.
O	That the school may help me secure free scholarship because my child is brilliant and he loves school
Continued Education	
H, A2 + B2	I'm grateful for all the school does to educate my child on all issues since I can't communicate with him / for the school to teach my child life skills, good behaviour and respect / to learn to do things
C + F	That my child may go through school and be successful so that he may help me in the future. /get a good education, further his studies and get a good job in order that he may be of help to me.
Additional Services	
Q	That the teachers talk to children who are partially impaired so that they master both spoken and sign languages
K	I'm grateful to the school for providing proper meals to my child and for making sure he adheres to his medical needs. Takes meds at 7am and 7pm.
Y	An update on his social skills and how to handle him, especially when he is angry
B	The father does not support the child. I do everything single-handedly. I'm not sure if the school could be in a position to assist me to meet the child's needs, I'm not able to cater for all his needs on my own.

APPENDIX VIII: PARENT INTERVIEW FINDINGS

Table 6	
Hearing Parent Interview Results	
<p style="text-align: center;">Importance of Education</p> <p>Parent B: If you allow the child to go to school, he will be able to do everything. It is important to train him as normal kids. The child is hard working and can do everything that any other child can.</p> <p>Parent B: He feels at home at school because they are all the same, whereas at home he sometimes becomes angry due to the communication barrier.</p> <p>Parent A: School is good because [my child] is able to sign and teach the family sign language. He accepts himself as he is, and is able to communicate [with his peers], and he is able to clean because at school they teach everyone responsibilities such as working during the day.</p> <p>Parent C: Deaf children can do anything once they have an education.</p>	<p style="text-align: center;">Family Relationships</p> <p>Parent B: Relationship is good but at home there are barriers. She is able to hear through identifying what he needs. Sometimes he is too fast in communicating. They accept him as a member of the family.</p> <p>Parent C: Relationship is good with the child, and the family relationship is better now that they too have come to accept his deafness, especially since the child works to include himself in the family.</p> <p>Parent A: She feels as though she has no support. It would be helpful for her to be given the chance to receive education to know sign language and receive love and care from the family, so that she knows the child will be looked after if she is sick or dies.</p> <p>Parent B: here is no support from the family. It would be helpful to have money for toiletries and assistance in the further education of her child.</p> <p>Parent C: She receives support from the family –in the past, the family would give the car to take the child to the hospital</p>
<p style="text-align: center;">Communication</p> <p>Parent A: It is difficult because I cannot understand signs.</p> <p>Parent B: The child is often too fast when signing”</p>	<p style="text-align: center;">Attitudes and Beliefs</p> <p>Parent A: Cultural things, such as superstitions. They felt shame for having the child.</p> <p>Parent B: There is a lot of gossip that the mother is dumb, and has done wrong to anger the ancestors. She works to counsel herself that her child is a gift from God. It is now special to have a Deaf child</p>

Parent Demographic Table	
Parent	Characteristics
A	Female, age 54, hearing
B	Female, age 33, hearing
C	Female, age 42, hearing
D	Male, age 50, Deaf
E	Male, age 36, Deaf
F	Male, age 43, Deaf

Table 7

Deaf Parent Interview Results

Importance of Education	Family Relationships
<p>Parent E: When I first joined the deaf school I was 8 and it opened up a new world for me. When I went back home I cried because I had gained confidence from signing.</p> <p>Parent E: I wish that schooling for deaf children did not take as long as it did. I see the hearing children finishing school at a much more rapid pace than deaf children and its painful. My deaf child has had to repeat classes again and again as my hearing daughters continue to move through the system.</p> <p>Parent F: I was surprised to see signing for the first time. It was my first time really socializing at school.</p> <p>Parent F: When I came home, I didn't know how to feel about my daughter's deafness, but I accepted it because I am also Deaf. We wanted to start her at school right away, but the head teacher told us she was too young. So we brought her back when she was 4 years old.</p>	<p>Parent D: His grandmother realized he was deaf and told his mother that she shouldn't get rid of him, but that she needed to take care of him.</p> <p>Parent D: My mother didn't understand sign language very well, but my brother did so he would help interpret for me.</p> <p>Parent D: The children are very good at supporting each other and acting as interpreters so their siblings can feel included and assist in solving problems. I am happy to have both deaf and hearing children, and it was easy to accept them into my life. We can easily and freely communicate in my family. I am also able to communicate well with my brother.</p> <p>Parent E: When school closed, and I would go home, they would talk strongly. Luckily, I could write well because I had learned well at the school. Once we got a system down for writing it was very easy to socialize. I tried to teach my siblings sign language, but only my youngest sibling was successful.</p>

Table 8

Deaf Parent Interview Results Continued

Communication

Parent F: I didn't teach the same sign language as I would to adults. The best way for [my daughter] to learn was from copying other children. I would use some simple signs. Children communicate best with other children. But I would communicate also through pointing to things.

Parent D: It's really easy to counsel and advice my children, because we all speak sign language.

Parent F: As a deaf person it is better to communicate face to face.

Parent F: When they're children, I didn't teach the same sign language as I would to adults. The best way for her to learn was from copying other children. I would also use simple signs. Children communicate best with other children. But I would communicate also through pointing to things.

Parent D: I wish that it was law that family members would learn sign language, because my family for the most part is not able to communicate with me through the use of sign language.

Attitudes and Beliefs

Parent D: Sometimes they would say "no, you're hearing!", but then when they would see an interpreter they would understand. They would learn ways to get my attention, such as other ways to wake me up, rather than knocking on the door. The communities where my wife and I stay have also grown very welcoming and inclusive, and are supportive to my family.

Parent F: It's also difficult when it's just my wife at home when I'm not there, they give her a bit of an attitude. Well, it's not so much an attitude as it's an expectation of hearing culture. But I try to manage that, so that there's space for Deaf and hearing culture on the homestead.

Parent E: I think it also depends on awareness and whether a person knows someone who is Deaf, in terms of how they may treat deaf people. If they didn't grow up knowing someone, they may not have it in their heart to understand and may say hurtful things. I've seen the attitudes of some of my childhood neighbors change. When we were children, they seemed to hate me and had no interest in learning sign language. When I meet them now, they express interest in learning sign language so I recommend that they go to Mbabane or Manzini. It puzzles me a little why they want to learn sign language now.

Parent F: I remember one time the neighbor was looking for me, and couldn't find me and yelled that I was deaf and stupid. It was so loud that everyone heard. Another person in the community told me that she was saying bad things about me. The irony is that later she gave birth to a child who was deaf."

Final Reflections

Parent F: In order for Deaf and hearing people to be equal, people need to understand that Deaf people are capable in the same ways and work as hearing people. Deaf people can be teachers, so it's important that they have this awareness. That's why I teach hearing people sign language, because I want them to see that I am capable and to broaden their understanding of what deaf people can do. Many Swazis aren't aware that there are Deaf people all over the world, and that deafness is normal too. But spreading awareness takes time, so it must be little by little.

Parent F: The first advice I would give hearing parents of deaf children is to have acceptance of their child's deafness. Secondly, I would tell them not to worry because it is apart of God's plan. He made all people as they are, and should therefore be accepted. It would be great that the deaf could have the same opportunities to develop as the other people, especially given the king's vision of 2022. There isn't a Deaf college, and that would be amazing. There's simply too many barriers. It's important to continue advocating for these issues. It would be great to have the primary and high school working together to conquer these issues. When students move on to the high school I want them to remember the primary school and continue building an association between the two schools.

APPENDIX IX: STUDENT INTERVIEW FINDINGS

Table 9	
Student Interview Results: the Language Gap	
<p>Student 1: My father isn't very good at signing and so it often takes a while to figure out what he wants or is trying to say. If I am helping him with work, he'll ask for something, and I'll run and grab what I think he wants, then come back and he'll say "no" and we'll repeat this process until I finally grab the right thing.</p> <p>I communicate best with my youngest sister. She also is able to help solve problems, maybe my mother didn't understand what I was trying to say, so my sister is able to help explain and interpret for me.</p>	<p>Student 6: At home I have to change how I sign in order to be understood. Besides my sister, I have another sister who is able to speak sign language. We worked to teach our siblings some sign. This way its really easy to socialize and interact with my siblings. Just like at school, I'm free to express myself and be understood at home.</p> <p>It's nice too having an older sister who is deaf. When I was younger she would help interpret things for my mom and serve as an intermediary. It made communicating a lot easier.</p>
<p>Student 2: Yes. I've tried to encourage my family members to learn sign language in Manzini, but either they don't understand me or they just haven't taken the initiative. My father said he wanted to learn sign language, so I said I could go with him to Manzini, and he said he would plan a time when we could go, but he's always busy.</p>	<p>Student 4: At home, it's a bit boring. My mom wants to spend time with me, but it's hard because she's only just learning sign language, but it's getting better. But my younger sister knows sign language well</p>
<p>Student 5: Sometimes a friend will be talking with another person, even though I'm standing right there, they don't make efforts to include me in the conversation. Eventually I just leave. I guess it's hard to learn sign language.</p> <p>My siblings don't really know sign language, so they use village sign and gestures to communicate with me. They're always brief conversations though, never very long. When they start talking I'll just leave them and focus on doing things myself.</p> <p>Village culture of sign language is very weak. I'll try to write sometimes, but that also doesn't work very well, because I write in Deaf culture and sometimes its hard for hearing people to understand. Since I'm weak in writing, I leave it and just focus on signing as a means to communicate. I tried to teach other members of my family sign language, but they never really grasped it.</p> <p>My younger sister knows sign language the best and is the only one who makes sure that I am aware of what's going on. She will interpret for me. My father or aunt will maybe explain things on a shallow level, but the little girl will go on and on and give me every detail. I've spent time teaching my father the hand alphabet, but he continually forgot.</p>	

Student Demographic Table	
Student	Characteristics
1	Male, age 17, last born of 9 children, no Deaf siblings, grade 6
2	Male, age 17, 5 th born, no Deaf siblings, grade 7
3	Female, age 17, 2 nd born, one Deaf sibling, grade 6
4	Female, age 14, 1 st born, no Deaf siblings, grade 6
5	Female, age 18, 1 st born, no Deaf siblings, grade 7
6	Female, age 15, 6 th born, one Deaf sibling, grade 7
7	Male, age 15, 4 th born, no Deaf siblings, grade 5
8	Male, age 17, 1 st born, one Deaf sibling, grade 7

Table 10

Student Interview Results: Family Support

<p>Student 1: At school my life is good. What I don't enjoy about being at home is that I don't really get to socialize. I'll try to talk with my brothers and sisters but they always say that they're busy or studying. So I often go and sleep instead. It gets a little boring.</p> <p>I play soccer, and sometimes my parents don't give me permission, so I accept that and stay at home. Sometimes there will be big games in the community and I get to go to those as well. I enjoy watching the competitions, then I return home and it's a bit boring. I like going to the store too, to maybe buy some sweets. I often will meet other deaf people there and we can catch up on news. Then I return home and feel bored, and wonder what I could do, but life goes on. Sometimes I watch TV. I enjoy watching the news because there is a sign language interpreter at 7pm.</p>	<p>Student 4: Whenever I go out, my mom advises me not to talk to boys, and tells me to be careful and mind traffic – no accidents!</p> <p>I also gave up trying to teach my father sign language. It's better to focus on teaching my mother because I stay with her in her house. I also don't like my father very much. In 2013, my father didn't want me to stay in his house, I think it's because I am deaf. My parents also used to fight all of the time. My mother accepted my deafness and loves me. I don't think my mother would like more than one deaf child though. I think she is happy with just one.</p> <p>Otherwise, I don't really enjoy much at home, there aren't really any other kids to play with, and it's hard to have real conversations. It'd be nice to have the freedom to move around, but that's not the case. I just stay in the house for hours. I don't really have any friends while I'm at home, and I just try to remain patient.</p>
<p>Student 2: My family is nice, but they are hearing, so they talk a lot and do not understand much sign language. Sometimes I just hang out with friends who understand me better. I have two brothers and two sisters, and I am the only deaf person in my family. At home they'll use village sign that's very exaggerated. It's much nicer to be at the deaf school because I can socialize and be understood.</p> <p>It's easy to know the future of the hearing child too, because they will just keep paying for school, but after grade 7, it's important that the deaf child is also able to continue learning. But I know my father is trying so I respect his wishes. He also does a good job to advise me not to go around at night, and to stay safe.</p>	<p>Student 5: [My father] is the only one in my family that I really like. He raised me. Otherwise, it's hard to get along with everyone else. It's more difficult when my father is busy and goes off to work. I don't enjoy that. The other members of the family aren't good role models. They spread lies and make up rumors. When's gone I'm very bored, because I don't have any friends while I'm at home. I'll just sit by myself, because it's better than hanging out with kids who don't have good behavior.</p>
<p>Student 3: I don't like to be bored, so when I'm at home during the term break, I keep busy cleaning and helping out around the house. My sister will also help me with my studies.</p>	<p>Student 6: My family is very good at ensuring that I am caught up on what is going on around me, and that I am included. My mother works in Manzini, so she travels back and forth to our home. My gogo [grandmother] likes to take me places and keep me company</p>

Table 11

Student Interview Results: School and Creating a Sense of Community

Student 1: Being at the School for the Deaf is great because we can socialize, share news, and learn. There's also sport, so I have a good life.

Student 2: Sometimes I'm not always caught up on what's going on at home. That's why it's really nice at the Deaf School, because I'm in a place where people understand me, and we can make jokes. I think about that sometimes when I'm at home.

Student 3: In 2004, when I was 7 and my brother was 5 we first visited the School for the Deaf. Someone had told my parents about the school, so they were trying to decide whether they would send us there or not. The meeting went well, and we were going to join the school.

The nun told us to return in January at the start of the new school year. While my parents were sorting everything out, I was waiting in Nhlanguano as the months slowly passed by. 5 months later, it was finally January, and we made it back to the school. It was expensive!

Student 4: That first term I learned a lot –being at school really opened the world up to me.

Student 5: I joined the school for the Deaf at age 11 or 12. Before that I was at a hearing school. I was the only deaf person. The teacher would talk and talk, and it would all go over my head. I would just doodle to pass the time. The teacher decided it was best to just leave me be

APPENDIX X: SAMPLE NETWORKS OF SUPPORT

This chart, adapted from North Carolina's BEGINNINGS Program, shows some of the people and places from which parents may find support as they go through the coping process.

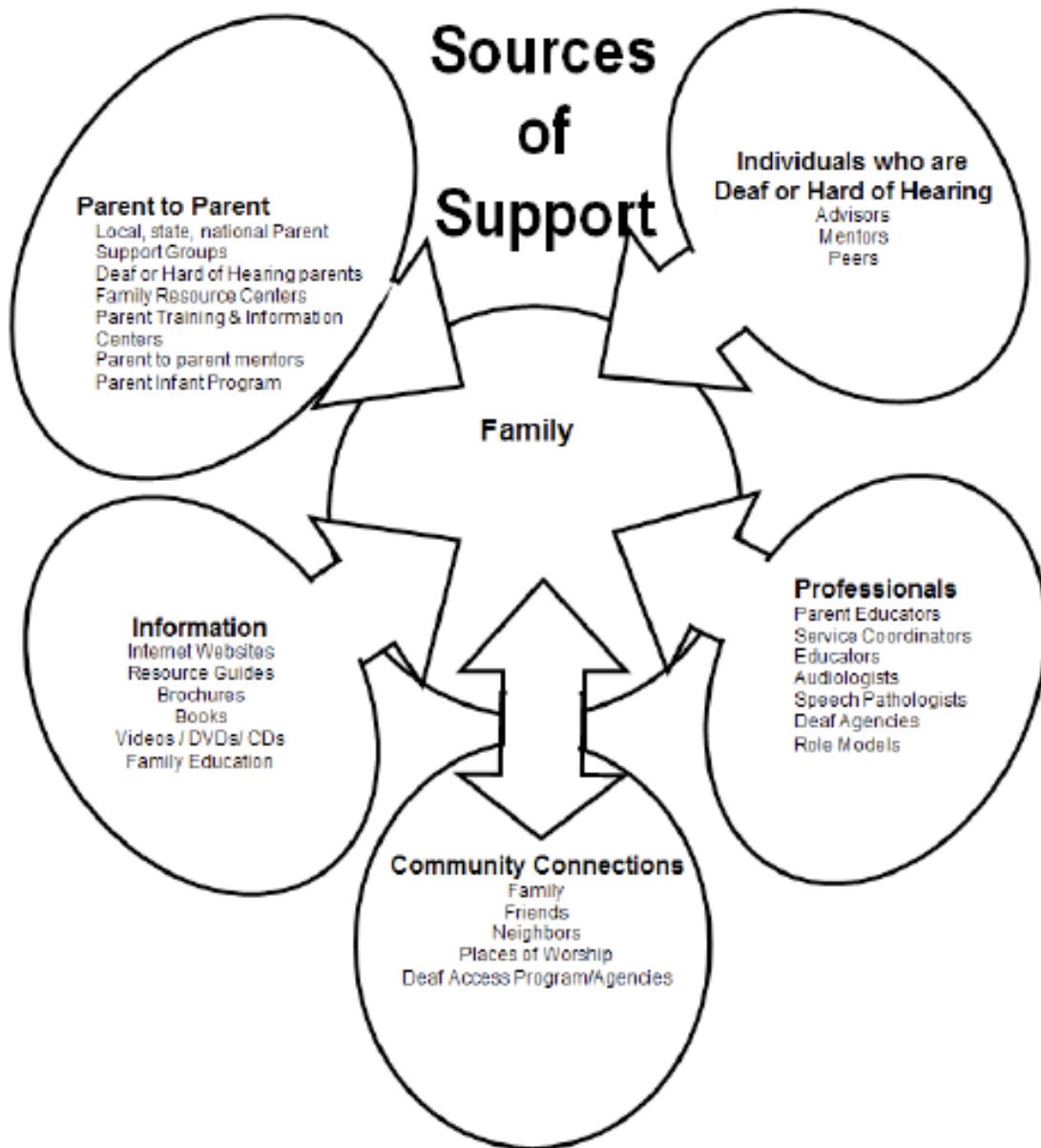


Diagram adapted from North Carolina BEGINNINGS (Joni Alberg)