<u>EMOTIONAL COPING AND LITERACY INTERVENTION DECISIONS: HOW HEARING
PARENTS GUIDE THEIR DEAF CHILDREN</u>

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1. Introduction

The purpose of this study was twofold: to explore who or what influenced hearing parents as they made decisions that promoted language acquisition and literacy learning in their deaf children and the emotions they felt as they made these decisions, as well as the emotional coping strategies they utilized as they made them. Upon learning their child is deaf, many hearing parents must scramble to make sense of a bewildering amount of information pertaining to special schooling programs, hearing aids, sign language, cochlear implants, cued speech, and other types of information related to deafness (Lane, 1999). Parents of deaf children must also deal with concurrent emotional reactions as they discover new information about deafness. Over 90% of deaf children are born to hearing parents (Buchino, 1990). These parents must not only cope emotionally with the discovery of their child's deafness (Calderon & Greenberg, 2003), but also with the emotional impact of discovering how deafness can negatively influence English language acquisition (Meadow-Orlans, Mertens, & Sass-Lehrer, 2003).

Studies have found that many pre-lingually deafened children and adults have numerous problems acquiring English language and English literacy skills (Luetke-Stahlman & Hayes, 1997). Indeed, many deaf adults do not achieve beyond a fourth-grade reading ability (Miller & Rosenthal, 1995; Moores, 1996). While hearing children learn to read by forming associations between their auditory information and corresponding printed symbols (Evans, 1999; Sacks, 2000), deaf children appear to be unable to make these auditory associations (Sacks, 2000).

Feher-Prout (1996) found that many parents, upon discovering that their child is deaf, move through emotional coping stages of shock, denial, anger, grief, and finally acceptance (among other stages). Despite the intensity of their feelings, decisions must still be made

regarding how their children will be educated. There is a great deal of pressure to make the right decisions, especially those regarding language acquisition (Meadow-Orlans, et al., 2003).

Statement of the Problem

It is important to better understand the factors that influence hearing parents' decisions to promote language acquisition and literacy learning in their deaf children, as well as the process by which hearing parents come to make those decisions, especially in the midst of various emotional coping stages. This is one way that counseling services for these parents can be improved and educational services for deaf children, especially in the area of literacy, can continue to develop.

Hearing parents may be overwhelmed by initial feelings of guilt and fear related to their child's deafness. They may feel confused about what to do, especially when they are presented with competing strategies for improving their child's language acquisition skills. Many report feeling stuck and unable to cope (Meadow-Orlans, et al., 2003). Additional research has suggested that everyday problems parents reported facing along with few social and financial resources of support predicted parental stress (Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2002). Research on how hearing parents specifically navigate environmental conflicts (such as school issues and obtaining services) and move through potentially adverse emotions toward effective decisions that promote language acquisition and literacy learning in their deaf children is needed.

Research Questions

This study explored hearing parents' emotional reactions to their children's deafness and the concerns they expressed while exploring the language acquisition and literacy learning options available to their children. The research questions of this study were:

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1) Who or what influences hearing parents in their initial decisions regarding language acquisition and literacy learning in their deaf children?

2) How do hearing parents' emotional reactions influence the initial decisions they make to promote language acquisition and literacy learning in their deaf children?

3) Who or what influences hearing parents in their subsequent decisions regarding language acquisition and literacy learning in their deaf children?

4) How do the emotional reactions and coping processes of hearing parents over time influence subsequent language acquisition and literacy learning-related decisions they make (if at all, and if any)?

2. Method

This study was a qualitative case study of eight hearing parents of middle school-aged deaf children. The study was conducted in the Mid-Atlantic region of the United States. The names of all participants and their children were changed, as were the names of the schools they attended. This section describes the eight participants that volunteered for the study, how they were contacted, how data were collected, and the circumstances surrounding their interviews. Data analysis design and procedures are then discussed. A concept map is also provided.

Participants/Setting/Terminology

Eight parents representing eight families volunteered to participate in this study. The researcher first obtained permission to collect data from the Human Subjects Review Boards of George Mason University, Gallaudet University, the Helen Keller Institute, and the Xavier Public Schools (XPS). Regarding XPS, Frederick Middle School was specifically targeted for the study. Three different XPS elementary schools, MacArthur, Sherwood, and Mason, all feed into

Frederick Middle School (see Table 1). MacArthur houses an oral deaf education program, Sherwood houses a cued speech deaf education program, and Mason houses a manual deaf education program. After working with administrators from Frederick Middle School and Smithville Middle School (a residential school not associated with XPS), it was possible to contact, on the basis of which school students previously attended, eight parents whose choices represented the variety of language acquisition options generally available to parents in the region. Kippinger Elementary School feeds into Smithville Middle School (see Table 1), but unlike Frederick, both are residential institutions, so the residential option was represented as well.

Table 1: Schools Most Mentioned in the Study

School Name	Type of Program	Feeder/Receptor School
MacArthur Elementary School	Oral	Feeder (feeds into Frederick Middle School)
Sherwood Elementary School	Cued Speech	Feeder (feeds into Frederick Middle School)
Mason Elementary School	Total Communication	Feeder (feeds into Frederick Middle School)
Frederick Middle School	Oral, Cued Speech, and Total Communication	Receptor (receives students from MacArthur, Sherwood, and Mason Elementary Schools)
Kippinger Elementary School	Total Communication	Feeder (feeds into Smithville Middle School)
Smithville Middle School	Total Communication	Receptor (receives students from Kippinger Elementary School)

Upon obtaining permission to conduct this research from the Human Subjects Review Boards, the researcher contacted the administrators at the Kippinger Elementary School and Frederick Middle School for assistance in contacting parents. The Helen Keller Institute, which oversees all research done in Kippinger Elementary School and Smithville Middle School, already had a procedure in place for contacting parents. The administrator in charge of the Deaf Education program at Frederick Middle School (in the XPS system), likewise suggested that she be allowed to contact the parents. Parents were sent both an introductory letter and a letter of

informed consent. Parents who might be interested were asked in the letter of informed consent to also answer preliminary questions. These data were used to identify which type of decision to promote language acquisition the participant made so that parents could be placed into rough categories according to their decisions (for example, parents who chose mainstreaming as an option to promote language acquisition, or cued speech, etc.). The purpose of doing this was to ensure that the researcher was selecting parents whose decisions represented, from as broad a range as possible, the options generally available to parents.

The letter of informed consent emphasized the fact that the specific type of intervention decisions the individual parents eventually made were not as important to the researcher as the process parents followed when making them. This was necessary both to avoid researcher bias (Maxwell, 1996) and to help the parents speak openly and honestly about their decisions during the interviews without feeling that they would be judged or criticized in any way for the decisions they made (Glesne & Peshkin, 1992).

It was intended that each individual parent selected for the interviewing process be the one who usually assumed the majority of the responsibility within his or her family for making decisions to promote language acquisition and literacy learning in his or her deaf children. However, it was also recognized that the parents who were eventually selected might simply have been those who could be most consistently available for the interviewing process. In any case it was made clear in the letter of consent (and later in the phone call or email made to establish a date for the initial interview) that the researcher strongly preferred to stay with the parent initially interviewed throughout the duration of the study, and not switch to another parent during the course of the study.

Parents who were themselves deaf or hard-of-hearing were not included in the study. Furthermore, it was originally intended that only hearing parents of profoundly prelingually-deafened children would be interviewed for the study because the impact of prelingual deafness on language acquisition is generally stronger as the level of hearing loss becomes more severe. However, when only eight parents responded to the letter of informed consent, the study was expanded to include parents of children with varying levels of hearing loss at birth instead of strictly profound levels of hearing loss. One final aim of the study was to only interview hearing parents who were not expecting deafness to occur in their children. However, the study was expanded to include two parents who adopted their children and knew that their children were deaf prior to the adoption, because the parents in both cases did not know of the extent of the deafness.

Once the eight individual parents that responded to the letter and volunteered to be a part of the study granted the researcher permission to contact them, the researcher then contacted these parents via email or by phone to schedule the initial interview. Using the data from the preliminary questions, the researcher then interviewed these eight parents twice in an initial and follow-up interview (and created transcriptions of each interview). Parents involved in the study were not interviewed along with their spouses (both the mother and the father together, for example) to avoid the possibility that one partner could influence or correct the other partner's responses to interview questions. The purpose of the follow-up interview was to clarify earlier answers on how specific decisions regarding language acquisition and literacy learning were made.

The researcher met with the parents and interviewed them using an interview questionnaire. Follow-up interviews were also conducted for purposes of clarification and to ask

the remainder of the questions on the questionnaire that were not covered in the first interview due to time constraints. Transcriptions were freely shared with parents in the second interviews, and their comments on the clarity of the transcriptions were also used as data.

The decisions the parents made to promote language acquisition and literacy learning in their deaf children varied widely, with some parents having chosen an oral program, others having chosen a manual one, and still others having chosen a mainstreaming option with signing programs, interpreters, cued speech, speech therapy, and combinations of these options (see Table 2). This variation allowed the researcher to analyze a wide variety of decisions and compare responses from the parents to see if the processes toward making them were similar or different, and if parents had different feelings and coping processes. Exploring the feelings of parents who made different types of interventions also offered insights into how coping processes and decision making processes changed in response to different types of challenges.

Table 2: Participant Information

Parent's Name	Child's Name	Initial Diagnosis (Parent's Report)	Later Diagnosis (Parent's Report)	Initial School Placement	Subsequent School Placement	Child's School Placement at Time of Inter-view
Melissa Andrews	Craig Andrews	Nothing wrong	Severe to profound bilateral loss (90% loss in both right and left ears)	Roberts Oral School	Mason Elementary School	Kippinger Elementary School
Darlene Lipton	Alisa Lipton	Mild loss	Moderate to profound loss (moderate-severe loss in right ear, between a moderate and profound loss in left ear)	MacArthur Elementary School	Mason Elementary School	Kippinger Elementary School
Karen Prell	Corrine Prell	Nothing wrong	Moderate to profound loss (profound loss in right ear, moderate-severe loss in left ear)	Murray Pre-school, Fox Valley Pre-school	Hilltop Elementary School, MacArthur Elementary School	Frederick Middle School
Mae Shackelton	Henry Shackelton	Profound Deafness	Profound deafness	Rainbow Road Pre-school	Southwest United School District, Mason Elementary	Frederick Middle School,

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					School, Kippinger Elementary School, Enigma School for the Deaf, L'Enfant Charter School, Orange School, Base School, Trinity School, Frederick Middle School	Forrest High School
Kate Terrace	Ben Terrace	Nothing wrong	Severe to profound loss (no substantial difference between right and left ears)	Blank School for the Deaf, Marymount County, Kippinger Elementary School	Kippinger Elementary School	Kippinger Elementary School
Diane Toffman	Isaac Toffman	Nothing wrong	Moderate to profound loss (severe-profound loss in right ear, moderate to severe loss in left ear)	Mac-Arthur Elementary School	Sherwood Elementary School	Frederick Middle School, Lake-shore Middle School
Derek Voss	Freddy Voss	Severe-profound loss	Severe-profound loss (profound loss in right ear, severe loss in left ear)	Kippinger Elementary School	Kippinger Elementary School	Kippinger Elementary School
Sarah Wheaton	Bailey Wheaton	Nothing wrong	Profound bilateral loss (>95 db loss in both right and left ears)	Sherwood Elementary School	Mason Elementary School	Frederick Middle School

Data Analysis Procedures and Design

Preliminary analysis of all interview transcriptions involved memo writing and color-coding to

isolate and identify emergent themes (Maxwell, 1996). Some of the memo writing involved

listing apparent categories of external and internal influences on parents' decision-making

processes that were emerging as the parents answered the questions from the interview guide.

Each category, after being identified in the memo-writing stage, was then assigned its own color.

Sections in the transcript related to that theme were highlighted in that color so that the

researcher could quickly scan through a transcript and find data that pertained to a particular

category.

Grids were then used to "fracture" the data (Maxwell, 1996, p. 78). One of the major purposes for the grids was to make it easier to sort data across cases according to various themes. Sometimes an answer a parent gave could be applied to several categories, and in those instances where much overlap among the data in particular categories occurred, color coding became difficult. Thus identical data could be listed under various grids with different theme headings, making it easier to explore all possible relationships between and among themes, both within and across cases.

Each grid was labeled with the parent's coded name so that during cross-case data sorting, it would always be clear which parent had supplied a particular piece of data. This was done by taking the sections of a transcript that pertained to a given theme and placing each sentence in its own box on the grid so that it could be identified easily. Then page number on the transcript which the sentence appeared was placed after the sentence on the grid so that it could be located again in the transcript easily if needed. Finally a theme heading was assigned to the grid. Particular care was taken to keep track of the original contexts from which various themes arose in order to avoid the problem of what Maxwell (1996) referred to as "context stripping" (p. 79). This was not only done by recording the page number that the sentences on the grids originally appeared, but also by maintaining the color coding system originally used to identify emerging categories of influences upon decisions. While it was difficult to use color coding to show categorical overlap on the transcripts themselves, this was more easily seen within the grids, especially since particular words or phrases could be colored to show other categories in which they appeared. Page numbers recorded in the grid (that the sentences appeared on in the original transcript) were also often colored to show where certain themes recurred.

These themes were used to construct concept maps (see Figures 1 and 2), which were then used as a part of a contextualizing strategy to explore possible relationships between themes (Maxwell, 1996). Data from the memos and the concept map was used to further explore relationships, comparisons, and contrasts between sets of cases, and also to explore general processes and tendencies in parents' feelings and thinking between groups (Maxwell, 1996; Wolcott, 2001).

New displays of categorized themes and subcategories were expanded across participants to look for patterns across cases and isolate types of concerns and emotions specific to those concerns. Coping processes in parents and their possible links to specific decisions to promote language acquisition and literacy learning in their deaf children were analyzed. Hypotheses that developed were used to further develop the concept map and move from a narrative and descriptive stage of data analysis into an exploratory stage. Results are written up by utilizing data from the transcripts, memos written on the transcripts, and relationships discovered and displayed on the concept map. A complete listing of data analysis procedures is shown in Table 3 below.

Table 3: Data Analysis Procedures

Order of Completion	Procedure
Step One	Transcripts for the first round of interviews are coded to keep names of participants, schools, and identifying information confidential
Step Two	Transcripts are organized into general categories Categories are color-coded
Step Three	Memos and notes are written discussing possible links between categories and cases
Step Four	Categories are assigned to grids and given thematic headings Data that recurs in various themes are assigned to corresponding

	grids
Step Five	Categories that recur across cases are identified and isolated
Step Six	Second round of interviews begins Steps one through five are repeated for these transcripts
Step Seven	Concept map is created from themes that recur across cases (see Appendix D), and possible relationships between them are displayed
Step Eight	Results are written up by utilizing data from the transcripts, memos written on the transcripts, and relationships discovered and displayed on the concept map

Observation That There is a Problem with Child's Language Development — 1

Emotions (1):

Suspicion, Uncertainty

The Influence of the Medical Community/ Deafness and Medical Issues:

The Early Discovery of Deafness

Pediatrician Misdiagnosis and the Discovery of Deafness in Later Testing

Medical Conditions in Addition to Deafness

Beliefs/Decisions about Using Hearing Aids and Cochlear Implants

Doctors Perceived to be Helpful and Unhelpful (Beyond Pediatricians) — 2

Emotions (2):

Shock
Overwhelmed
Naivety,
Trust
Disappointment
Anger

Books and Research/ Parents' Understanding of Language and Reading — 3

Recognition Early Years are Important for Language Acquisition — 4

Literacy and Language Challenges — 5

Emotions (3-5):

Concern

The Influence of Deafness-Related Educational-Placement Agencies and Knowledgeable Professionals:

Regional Disability Services

Knowledgeable Professionals

Administrators' and Teachers' Transfer Recommendations

The Military — 6

Emotions (6):

Naivety
Disappointment
Trust
Growing Distrust
Resistance

The Influence of the Schools:
Site Visits

Simultaneous Attendance

Parent-Infant Programs

Home Visits from Teachers

Class Size

Distance from School

Speech Therapy
Child's Peer Group/Socialization Issues

Child's Interpreting Needs

School Politics/ Reputation/Quality of Teachers

Children's Issues with Reading, Writing, and Homework

Relationships with Administrators/ Teachers

Children's Feedback

Self-Contained and Mainstreamed Classrooms — 7

Emotions (7):

Disappointment
Dissatisfaction
Trust
Growing Distrust
Resistance
Wariness
Weariness

Figure 1: Concept Map (Part 1)

Lack of Trust in Schools/ Doctors/ Not Always Following Advice of Schools/Doctors 8

Emotions (8):

Distrust
Resistance

The Influence of the Deaf Community

Deaf Power/Anti-Hearing Problems

Total Communication and Voice Off Conflicts

Parents Consult the Deaf Community or Wish They Had

Deafness as a Disability versus Deafness as a Language Issue

Emerging Deafness-Related Identity Issues 9

Emotions (9):

Repulsion
Attraction
Concern

The Influence of Family Members/ Others in the Community

Parents Consult with Other Family Members

Parents and Families Find Signing Beneficial/ Signing within the Family

Negative Issues Associated with Signing

Parents' Other Children Limit the Amount of Time That Can Be Spent with Their Deaf Children

Single Parenthood/ Family Dissolution/ Negative Background Influences

Others in the Community 10

Emotions (10):

Support
Frustration
Hope
Fear
Stress
Repulsion

Influence of Faith/ Support of the Church Community 11

Emotions (11):

Support
Hope

Parents Receive No Counseling 12

Emotions (12):

Ambivalence

Wanting Children to Be Able to Function in the Hearing World 13

Emotions (13):

Determination

Parents' Feelings about Their Recent Decisions 14

Emotions (14):

Satisfaction
Confidence
Hope
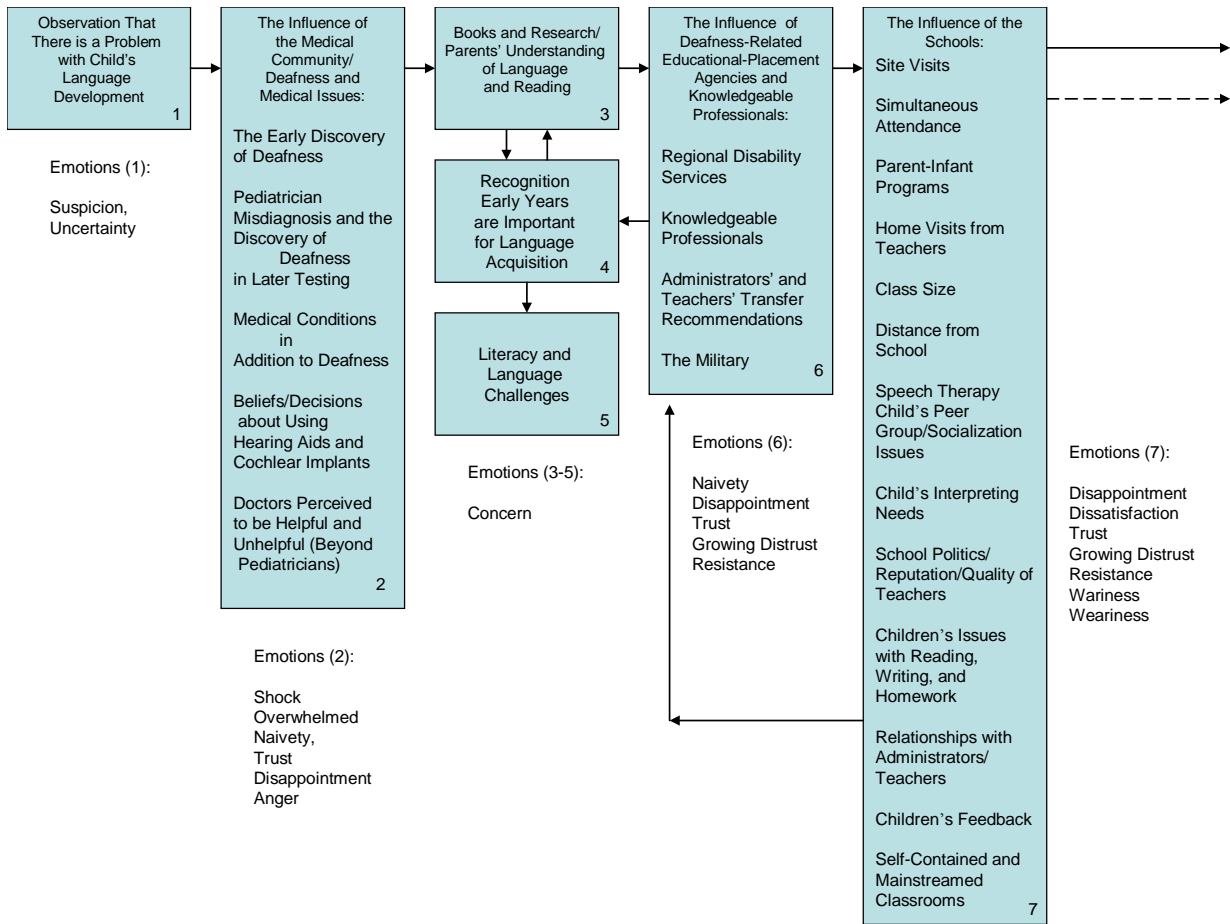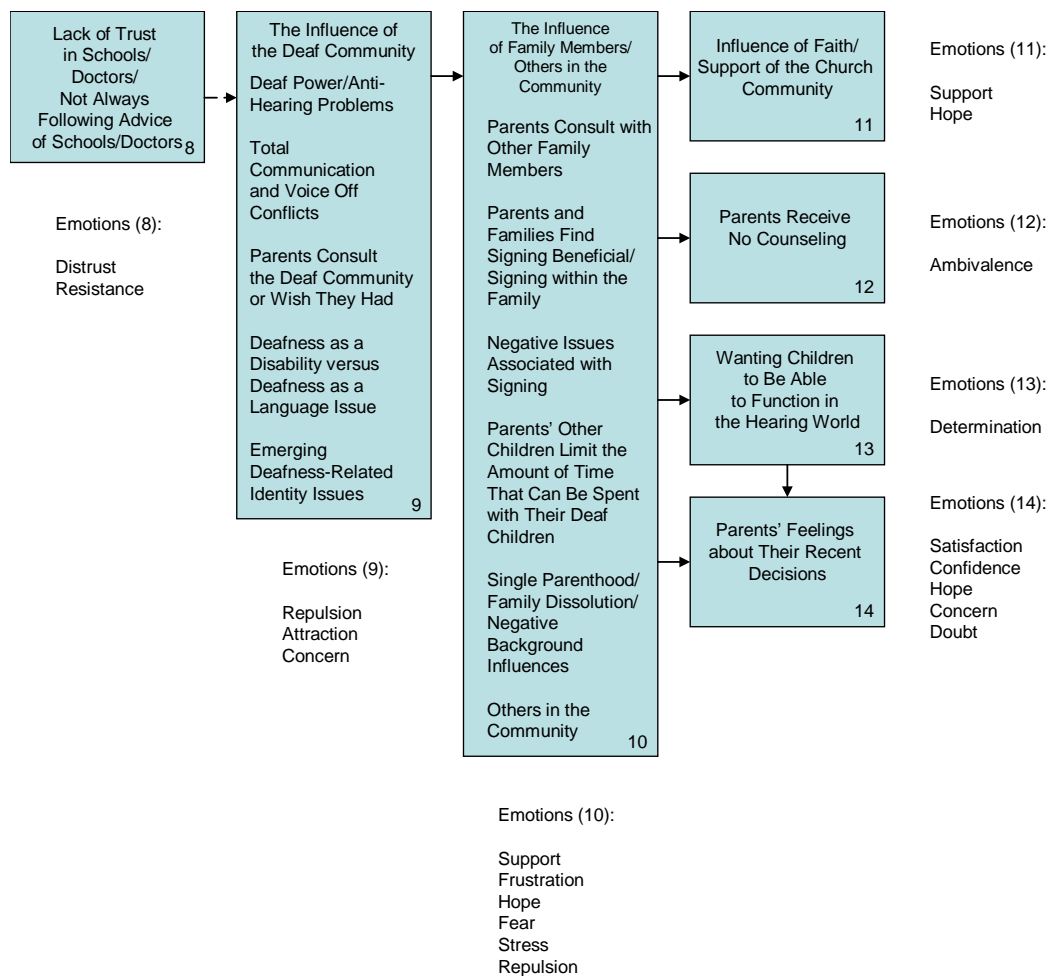Concern
Doubt

Figure 2: Concept Map (Part 2)

3.Conclusions

Overall Conclusions of the Study. The most significant findings of this study were: the finding

that pediatrician misdiagnosis of deafness occurred in every case a parent depended upon a

pediatrician to make such a diagnosis and that doctors were most often perceived as unhelpful

when parents believed these doctors either withheld or could not provide information and not

when they failed to be emotionally supportive. Also significant was the finding that three of the

four parents that reported using Regional Disability Services (RDS, an office of Xavier Public

Schools charged with locating disabled children and consulting with parents within—but not

outside of—the Xavier Public School System) also reported dissatisfaction with these services, and some of the reasons listed included one parent feeling that she had not been exposed, either deliberately or not, to all of her options while another felt the organization was promoting its own agenda over the welfare of her daughter.

Furthermore, four parents did not report using RDS, because they lived outside of the geographical area RDS provided services to. One parent reported that the military was not able to inform her of the quality of the programs in a geographical area, and in another case (where the parent's child had always attended Kippinger Elementary School) the parent reported he had never heard of services outside of Kippinger Elementary School or Smithville Middle School. This implied that various schools and placement services were not reporting on all options available, or else could not.

Another significant finding was that simultaneous attendance in various programs heavily influenced initial decisions parents made about educational-placement because it allowed them to compare programs, and both language acquisition and literacy learning delays in their deaf children heavily influenced subsequent decisions most parents made to transfer their children to new programs. Once these transfers were made, socialization and opportunities for developing social skills emerged as one of the most influential factors on parent's decision-making processes.

Two parents also reported that they faced what they perceived as anti-hearing extremism from some members in the deaf community and from certain programs, one faced what she perceived to be anti-signing extremism, and another noted a program appeared to have been designed to diminish negative stigmata society often connects to deafness. Overall, these types of perceptions influenced parents decisions to either send their child to or keep their children in

those programs, but did not appear to interfere with the parents' general willingness to seek out advice from the deaf community. Several parents also reported feeling confused by conflicting advice from various programs, especially on the issue of not using voice and signing simultaneously.

Finally, parents reported that they found much support and guidance in their friends and families and in their faith in God or a higher power. While family support appeared to be strong during initial decisions made about educational-placement and approaches, conflicts were reported in several cases among family members during subsequent decisions. One source of tension in two cases appeared to be the issue of sign language and how well parents and immediate family members learned to use it, but the tension appeared to manifest among members of the family other than the deaf children. The finding that the parents received no emotional counseling for deafness-related issues is perhaps not surprising in light of research done by Meadow-Orlans, et al. (2003) but what is significant in this study is the report of most parents stating they didn't feel they needed emotional counseling, and that it was their children, not them, who would bear most of the burden of coping.

To address these findings, suggestions for future practices included improving testing procedures used by pediatricians or at least providing parents with more information on where more accurate testing could be conducted. Also suggested was the publishing of criteria and guidelines regarding how educational-placement agencies help parents to determine which program is best for their children. A final suggestion for future practices was the creation of orientation programs for schools receiving diverse groups of deaf students previously educated in programs using diverse approaches. Such a program could help deaf children from diverse

language backgrounds, along with their parents, to learn to use strategies from programs they had not yet been exposed to for the purpose of increasing social opportunities.

Further research was also suggested into how the use of cued speech fits into the way that deaf children learn language through social contexts. Further research was also suggested on the topic of how hearing parents' perception of anti-hearing extremism coming from certain members of the deaf community and from certain educational programs might also interfere with the social contexts necessary for learning language. Finally, additional research was also suggested regarding the topic of conflict resolution between hearing parents and various medical specialists, educational-placement counselors, teachers, and administrators.

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*Note: This paper is a summary of a 286 page dissertation under the same title. For a more

complete picture of the participants, their backgrounds, and an in-depth discussion of all

findings, this work can be found at: http://gradworks.umi.com/33/94/3394589.html.

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