To the Graduate Council:

I am submitting herewith a dissertation written by Vicki L. Wolfe entitled: "An Investigative Study Identifying the Factors which Influence Parents as They Make Educational Placement Decisions for Their Children Who are Deaf." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Education, with a major in Leadership Studies in Education.

George W. Harris, Jr., Major Professor

We have read this dissertation
and recommend its acceptance:

Accepted for the Council:

Associate Vice Chancellor and
Dean of The Graduate School

AN INVESTIGATIVE STUDY IDENTIFYING THE FACTORS WHICH INFLUENCE PARENTS AS THEY MAKE EDUCATIONAL PLACEMENT DECISIONS FOR THEIR CHILDREN WHO ARE DEAF

A Dissertation

Presented for the

Doctor of Education

Degree

The University of Tennessee, Knoxville

Vicki L. Wolfe

May 1999

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DEDICATION

This work is dedicated to my loving parent's George and Virginia Lawrence. They taught me how to find peace in the midst of a struggle, beauty in simple living, and new life through God's Son, Jesus Christ.

ACKNOWLEDGMENTS

I would like to begin by thanking my husband, Derick, for his tremendous support and encouragement throughout my doctoral studies. I realize that your own personal dreams were put on hold so that I could accomplish my own. You will always have my unconditional love and confidence. Special gratitude goes to our daughter, Yemy, who has patiently waited for "mom to finish school" and who has reinforced my belief that children who are deaf can accomplish great things.

To my doctoral chair, Dr. George Harris, I am truly grateful. Your guidance and commitment during my years of study were priceless. Also, to Dr. Malcolm McInnis, Dr. Sandra Twardosz, and Dr. Olga Welch, I owe a special word of thanks for your insight and encouragement while serving on my doctoral committee.

Gallaudet University also deserves special recognition for providing the grant funding to complete this research study. I am indebted to Dr. Carol Marchel for auditing my research study and to Melba Wilkins for her expertise in editing. Lastly, I would like to recognize all my friends at the Postsecondary Education Consortium for their positive influence in my life. Special thanks to Melinda Kerr, Lisa McFall and Pat Tate for your unwavering friendship and ability to enjoy life to the fullest.

ABSTRACT

This study examined the educational decision-making processes of parents with middle school age children who are deaf. Both qualitative and quantitative research methods were implemented to gain a better understanding of the resources families utilized when making educational decisions for their children. Parents who had chosen a wide range of communication and placement options for their children were invited to participate in the study. Seventeen families living in remote areas of Georgia, Kentucky, Louisiana, and Tennessee participated in personal interviews within their homes or their children's schools.

All families completed a questionnaire consisting of a demographic section and a Likert Scale, prior to the interviews. Through the use of a semi-structured interview format, the parents were asked to describe their experiences as their children transitioned through the following stages: the age of identification (hearing loss), the transition into elementary school, and the transition into middle school.

Data analysis yielded several inter-related themes common to families during critical periods of transition. The majority of families experienced a period of shock and grief once their children's hearing loss was documented. When seeking to learn about deafness and related issues, the parents utilized several resources: the parents (themselves), family and friends, medical

professionals, and educational professionals. The degree to which families utilized these resources and their interaction with various support services was directly related to their individual parenting styles. Three patterns of parenting emerged from the data: Trusting Self, Trusting Others/Trusting Self, and Trusting Others. When asked to give advice to other families with young children who are deaf, parents suggested exploring all communication and placement options, becoming a parent advocate, and practicing patience.

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CHAPTER I

INTRODUCTION

"She does not think anything is wrong with her and so we just have kind of gone along on this nice journey together." (-P5 Pretest)[1]

Parents of children who are deaf face important placement decisions for their children as they journey through the educational system. Although the initial placement decision carries extreme importance, parents and educators should recognize it as only one of the first steps along the educational continuum.

As a result of both federal and state legislation, a mandatory, yearly review and examination of a disabled child's current educational placement gives protection for the rights of children who are disabled. Aside from the annual reviews, transition periods from elementary to middle school, middle school to high school, and high school to work or postsecondary education comprise critical periods within the child's educational development. Do parents have the resources and tools necessary to ask knowledgeable questions and make informed choices about their childrens' educational placement? If they answer yes, then what resources do they utilize? If they

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[1]Pseudonyms were used for names, school systems, and places throughout the study.

answer no, then who assists parents in making these decisions and who has accountability for the overall progress of these children?

An Overview of the Study

This study sought to discover the factors which influenced the educational placement choices made by parents for their middle school age children who are deaf. It identified the resources they utilized when making these decisions, and explored the various parenting styles which emerged as families made educational choices. As I gained a better understanding of the processes which parents went through when making these decisions, the positive and negative factors affecting their choices emerged.

The study involves a total of 17 parent interviews conducted in predetermined remote areas of Georgia, Kentucky, Louisiana, and Tennessee. I included in the research sample parents who had chosen a wide range of communication options, as well as educational placements for their children. A brief questionnaire consisting of a demographic section and a series of rating scale statements were mailed to all participating parents prior to the interviews. Data obtained from the questionnaires and parent interviews were analyzed by the use of both quantitative and qualitative research methods in order to gain insight into the educational decision making processes of parents for their children.

Qualitative Research

Because qualitative researchers seek to understand certain phenomena and gain insight into certain processes associated with specific populations, we must carefully acknowledge our own personal experiences and how personal events effect the way in which we interpret individual stories and experiences of others. With this principle in mind, I offer a glimpse into my life in order to provide understanding for the framework from which my knowledge of deafness and parenting has emerged.

My Perception of Deafness

My first experience of meeting an individual who is deaf happened in a shopping mall parking lot when I was ten years old. A man approached us with a small white card which had the manual alphabet printed on one side and on the other side these words: **"I am a deaf mute. I provide for my family by selling these cards. The cost is $1.00. God Bless You."** My mother quickly handed the gentleman one dollar and we hurried into the shopping mall. Sensing my confusion, she offered a brief explanation about the handicapped and how we should help those less fortunate than ourselves. That explanation closed the matter for my mother: yet, I can distinctly remember experiencing a sick, uneasy sensation throughout the day and even into that night as I lay awake in my bed. I recall feeling such pity for this man and gave thanks that I had not been born deaf. I kept that

card for the longest time. Over the years the card has become lost and eventually the feelings I associated with it have also disappeared or changed.

Ten years passed, and I found myself in undergraduate school majoring in the field of elementary education. The summer before entering my junior year of college, I volunteered to work at a camp for inner city children living in New York City. Little did I know that the events which occurred over this summer would have such a powerful influence on my future career path and overall life decisions. About three weeks had gone by when the campers and counselors gathered for evening chapel services. The order of events proceeded as usual; however, something made this particular night different. A young woman using sign language stood in front of the group next to the song director. Her graceful movements and facial expressions immediately caught my eye, and I became mesmerized throughout the entire service.

Once I realized that she was a sign language interpreter, I began scanning the room trying to locate the individual who was deaf. My eyes quickly rested on a young African American girl around eight or nine years old. She was a beautiful child. As she watched the interpreter, her face beamed with anticipation and excitement. Nevertheless, her reassuring nods and nonverbal cues which seemed to express "Yes, I understand" struck me most. The child actively participated in the worship service. She was "included" not "excluded."

That night my perception of deafness changed from one of pity to one of respect and intrigue. Drawn to this unique culture, I knew at that moment that I would never remain content until I had embraced it to the fullest. After completing my degree in elementary education, I enrolled in graduate school and majored in the field of deaf education. After graduate school, I began teaching elementary age children who are deaf. Times of utter joy as well as utter despair marked these years. These children possessed intelligence, creativity, and capability; nonetheless, I found myself frequently frustrated by their low academic performance, lack of self motivation, and limited parental involvement. The unsurmountable amount of paperwork required for special education constantly pulled me away from the students and instruction which added to my sense of frustration. More than once, I caught myself thinking "How much could these children learn if I did not have the demands of completing paperwork and the restrictions of an eight-hour school day?" Little did I know then that I would have the privilege to answer this question on a daily basis.

Four years later, on August 19, 1995, our plane touched down on American soil. Our five-year-old-adopted daughter, Yemy, who is profoundly deaf, was so excited to finally be reunited with Daddy once again. Yemy and I had remained in Colombia, South American two weeks longer than Dad, since he had to return home to fulfill work obligations. Since Yemy had no formal language, we basically communicated through pictures and simple

gestural signs. We looked at the pictures of Dad, our home, and her new bedroom. Soon she would experience them firsthand, and that prospect thrilled us.

One of our greatest joys has been to watch our daughter grow and mature into a confident, young girl who loves life and has the ability to communicate her feelings, ideas, and understanding of the world around her. My role as a parent of a child who is deaf has altered my role as a teacher of the deaf. The experience has caused me to reflect on my years in the classroom and evaluate my attitudes and actions, as well as teaching methods. With all honesty, some components I would enact differently, while at the same time, some components I would not change. Those in the field of deafness must undergo this type of self-refection and willingness to change before they can make positive advances in the future. On the other end of the spectrum is my role as parent, which I am still learning about. This role has served to heighten my awareness of the tremendous influence each individual brings to the educational table and how this influence can either strengthen and support the educational process or weaken and undermine it.

My husband and I have faced numerous struggles when making educational placement decisions for our daughter. Have we made the right decision? What if "they" are right and "we" are wrong? Reflecting back over the last three years has caused us to wonder how other parents handle

these tough educational decisions. Do they have a support system to assist them during these times? What happens to families living in isolated areas of the country? In keeping with these thoughts, the present research study resumes. Periodically throughout the study, I will revisit these questions and try to explain how my experiences have influenced the manner in which I interpreted the research data and how our family has changed through the insight other parents have so willingly shared.

The Statement of the Problem

Within the field of deaf education, professionals and service providers often quickly express their opinions with regard to the appropriate educational placement options for children who are deaf. These discussions, frequently marked by controversy, span from the earliest beginnings of deaf education to the present. Abundant research supports the sundry of ideological platforms adopted by professionals and service providers within the field.

This study endeavors to move beyond the "professionals" and into the everyday lives of families who face the serious educational decisions for their children who are deaf. By exploring the resources used by families and the concerns they have with regard to their child's education, perhaps those working in the field of deafness will develop a better understanding of their role as professional and service provider. Until educational professionals

recognize and appreciate the needs, concerns, and experiences of parents, they cannot sufficiently address the problems existing in deaf education. Ritter-Brinton and Stewart (1992) state, "We must not assume that there is an elixir for families of deaf children" (p. 89). They stress the importance of the family's influence on the development of the child who is deaf and call for service agencies to use the family as a primary focus of intervention. If the profession truly wants to make positive changes for the nation's children who are deaf, service providers must view parents as valuable resources and be given an active voice. As Strauss & Corbin (1994) so eloquently express:

> ***"We have obligations to the actors we have studied: obligations to 'tell their stories' to them and to others--to give them voice--albeit in the context of their own inevitable interpretations" (p. 281).***

Purpose of the Study

The study proposes to increase understanding among educators, other professional service providers, and families about the information needs and concerns of parents when making educational placement decisions for children who are deaf. By addressing the following objectives, I developed a realization of the educational decision making processes of parents who have children who are deaf, the factors which positively and negatively impact these decisions, and the parents' role in their child's education. Comparisons

between parents who have chosen residential school placement for their children and parents who have chosen one of the public school placement options were also explored.

Objectives of the Study

1. To describe the factors, through the use of information obtained from participant questionnaires and personal interviews, which most significantly influenced parents' initial placement decisions, as well as the transition periods into elementary and middle school,
2. To list and describe, through the use of information obtained from participant questionnaires and personal interviews, the resources and support systems parents of children who are deaf utilized as they encountered periods of transitions.
3. To record and interpret, through the use of the questionnaires and personal interviews, the responses of parents as they describe the positive and negative aspects of their children's past and present educational placement/s. Additional responses include the children's current academic, social and emotional level of functioning.

Importance of the Study

Research addressing the factors contributing to the educational placement options of parents with children who are deaf and the resources they utilize, remains extremely limited. Educators, professional service providers, as well as other parents, can benefit greatly from information which focuses on the personal experiences and concerns of parents who are in the midst of their child's education. The information obtained from parents can assist school systems in building better parent-professional relationships, increase support for other parents of children who are deaf, and offer suggestions for how Local Education Agencies (LEA) can better serve families with children who are deaf. I asked parents who participated in the study to respond to questions addressing the following topics: 1) awareness of the laws which protect individuals with disabilities and their families, 2) the resources available to families with children who are deaf, and 3) the positive and negative influences which have impacted their children's quality of educational services.

Responses to these questions can assist professionals in understanding the support needs of families and may act as a catalyst for strengthening the networking systems among parents, professionals and other service providers. Parents faced with making their first educational placement decision or those in the midst of a transition period (i.e., elementary school to middle school), can also benefit from the past

experiences and valuable insights of other parents with children who are deaf. Because, the majority of deaf children in America, including a large percentage of residential day students living at home, researchers must collect information focusing on the family dynamics of school age children who are deaf and their families (Moores, 1996). Currently, limited research exists addressing this specific population.

> ***" It is true that the needs of families change throughout their deaf child's development, but the importance of identifying and serving those needs does not change " (Ritter-Brinton & Stewart, 1992, p. 89).***

Assumptions

1. All participants in the study will supply the researcher with information which reflects their personal experiences when making educational placement decisions for their children.
2. All participants will understand the questions asked on both the questionnaire and during the taped interview.
3. A total of 17 parents, living in remote areas of the southeast United States, with middle school age school children who are deaf will respond to the researcher's request for participation in the study.

4. Participating school systems will contact and invite all parents, within their particular program who have middle school age children who are deaf, to take part in the proposed research study.

Limitations

I limited the study to a small sample of parents, with children who are deaf, living in remote predetermined geographic areas within the southern region of the United States. The information obtained from these participants was specific to this population and may not be generalized to other populations without appropriate caution. Although I invited both hearing parents, as well as parents who are deaf, to take part in the study, the first 17 families to meet the criteria for participation were all able to hear. The fact that all of the parents were hearing did not allow me to draw comparisons between both parent groups.

Participating school systems were expected to contact all parents, within their program who have middle school age children who are deaf, and invite them to take part in the study. I had no guarantee that the schools distributed the information to all parents with middle school age children who are deaf. In the unlikely event that certain parents were targeted for participation, and others were not, the results from that particular school/program may not yield a true sample of the targeted parent population.

Definition of Terms

Several important terms were used in this study and are defined as follows:

Audiogram. A graph on which results of an audiometric evaluation are charted to indicate the person's ability to hear tones at each of the presented frequencies.

Auditory Brain Stem (ABR). A painless test which involves the measurement of electric responses recorded from the hearing nerves and brain by means of small, disk-like electrodes secured behind each ear and on the forehead

Cochlear Implant. A multichannel device which implants electrodes into the cochlear and stimulates the nerve endings. In certain cases, this technique has been known to increase the individual's ability to hear and recognize sounds.

Day Classes. Classes for students who are deaf located in a public school setting where the majority of children have normal hearing. Instruction occurs within a self-contained class for children who are deaf, within the regular education classroom, or a combination of the two.

Day School. A school located in urban areas which serve only students who are deaf. The students commute to and from school daily.

Deaf. An individual whose hearing is disabled to the extent of 70 dB or greater.

Educational Placement Options. The wide range of schools, programs, and other settings which offers educational services to children who are deaf.

External Validity. The extent to which the research findings can be generalized to other populations.

Grounded Theory. A constant comparative method of inquiry where theory is 'generated' from data sources in order to study the processes which a target group moves through as they relate their own personal experiences over time (Strauss & Corbin, 1994).

Individualized Education Program (IEP). An individualized plan developed by the Multi-Disciplinary Team for all children receiving special education services. The plan must include current level of performance, instructional goals, educational services and placement, as well as the criteria for determining how instructional objectives will be met (Hallahan & Kauffman, 1988).

Internal Validity. Internal Validity is the "degree to which the explanations of phenomena match the realities of the world" (Schumacher & McMillan, 1993).

Interpreter. An individual who facilitates communication between persons who are hearing, deaf, or hard of hearing through the use of the deaf or hard of hearing person's primary mode of communication.

Mainstream Programs for the Deaf. Public school programs where children who are deaf are integrated with their hearing peers.

Manual Communication. Communication occurring through the use of body movements, hand shapes, gesturing or an established form of sign language.

Multidisciplinary Team (M-Team or IEP Team). A deliberation among appropriate individuals for the purpose of determining eligibility for special education services, developing recommendations for educational placement and reviewing educational progress.

Oral Communication. Communication occurring through the use of the speech mechanisms.

Parent. The individual/s who have legal custody of a child and who serve as the parent representative on the child's Multi Disciplinary Team.

Residential School for the Deaf. A school serving students who are deaf within commuting distance to the school, as well as those from farther distances who reside as residential students. Residential students live on campus during the week and generally return home on weekends, holidays, and during the summer. These schools offer both academic and vocational training.

Remote. Living outside of large urban areas as outlined by the United States Census Bureau (see page 51).

Resource. Any person and/or material which has assisted or continues to assist parents when making educational placement decisions for their children who are deaf.

Organization of the Study

This study consists of five chapters. Chapter 1 introduces the reader to the main focus of this study--to explore how parents make educational placement decisions for their children who are deaf. This chapter also discusses the rationale for conducting this study and how my own personal experiences blend into the process of interpreting and recording the stories of other families.

Chapter 2 provides a review of relevant literature including: a historical perspective of the development of educational programs for children who are deaf, a comparison of program options in urban and rural areas, and a review of resources which are beneficial in assisting families during periods of transition. Chapter 3 focuses on the research design and methods of data collection and analysis. As a researcher, I attempted to provide the reader with a detailed description of how I gathered and organized information and the steps I implemented to decrease researcher bias. Chapter 4 includes my interpretation of the data through the presentation of emerging themes and patterns. This section also offers a glimpse into the lives of families raising children who are deaf, by giving

voice to their experiences, hopes, and fears. By capturing their thoughts on the challenges facing deaf education, I trust others will learn from the mistakes of the past and take positive steps to ensure a better future for all children who are deaf.

Chapter 5 contains a summary of findings and recommendations for individuals interested in the field of deafness. The advice given to young families with children who are deaf was taken from the actual interview sessions with parents. I chose to conclude this chapter with quotes which contrast the parents' initial reaction to deafness with their present aspirations for their children's future.

CHAPTER 2

REVIEW OF LITERATURE

". . . guess that is my wish that everyone would be more open-minded and understand that what might work great with this kid might not work with this one ." (-P8 Pretest)

Historical Perspective of Placement Options

Prior to the nineteenth century, no evidence existed of any organized attempt to provide an education to individuals who were deaf living in the United States (Moores, 1996). Affluent parents often chose to send their children who were deaf to schools located in Europe. Through these ties with Europe, individuals in the field of deafness can better understand the development of education for the deaf in the United States.

In 1817, Laurent Clerc and Thomas Hopkins Gallaudet established the first permanent school for the deaf in the United States. Clerc, a deaf teacher from Paris, worked at the Royal National Institute for the Deaf. Thomas, a congregational minister, had graduated from both Yale and the Andover Theological Seminary in Massachusetts. Thomas became interested in the education of the deaf as a result of working with a nine-year-old girl who was deaf, Alice Cogswell. Her father, Dr. Mason Fitch Cogswell became

instrumental in recruiting Clerc and Gallaudet for the purpose of establishing the first permanent U.S. school for the deaf in 1817, The American Asylum for the Education of the Deaf and Dumb (Van Cleve, 1996).

In 27 years from 1817 to 1844, only 7 schools for the deaf were established; then, from 1844 to 1860, one new school was added per year (Moores, 1996). Most of the schools from 1817 to 1844 were residential in nature and a large percentage were located in remote areas within the individual states. State legislature, social stigmas, and the sharing of facilities for both the deaf and blind contributed to the trend of isolating residential schools from mainstream society.

The first long term day schools for the deaf were established in 1869 with the opening of the Pittsburgh Day School and the Boston Day School (Moores, 1996). In contrast to the residential schools where students lived on campus, students attending day schools went home after the completion of the academic day. The early schools for the deaf, whether residential or day schools, predominantly utilized manual communication methods (i.e., sign language or finger spelling) for instructional purposes. The influence of the oral method of communication did not achieve its greatest gains in changing the direction of American education for the deaf until the late nineteenth century. Not only did the oral method of communication increase the educational placement options for children who were deaf, it also ignited

the debate over preferred communication methods for the deaf. The Clarke Institute for Deaf Mutes, founded in 1867, was one of the leading oral schools during this time.

As the controversy over the manual and oral methods of communication continued to grow, schools for the deaf began to be identified by the communication philosophy with which they adopted and practiced. This categorizing of schools and programs, based on communication methodologies, ushered in the twentieth century and continues as a source of tension in the field of deaf education (Jordan, 1996). As the American population, geographic areas, and economic resources from the years 1800 to 1900 steadily increased, programs for the deaf continued to grow in number, variety and quality (Moores, 1996). By 1900, 57 residential schools for the deaf had been established within the United States, and the number of day school programs for children who were deaf had also increased (Randall, 1993).

Although educational placement options for children who were deaf continued to expand from 1900 to 1950, the majority of the children attended public residential schools for the deaf. Children who were deaf attending urban day school programs typically came from immigrant families and received training in the oral method of communication. Movement away from residential school placement for the deaf began soon after World War II.

Factors which contributed to this gradual decline in the percentage of children attending residential schools include the following: an influx of children who were deaf due to the population explosion and rubella epidemic, which resulted in increased enrollment in alternative types of programs for the deaf; better transportation; and the high costs of constructing new residential facilities (Moores, 1996). Consequently, very few residential schools for the deaf were built in the country after 1950. The opportunity to choose among educational placement programs existed in a few urban areas since the mid-1800's; nonetheless, most communities had no local school programs or classes for children who were deaf until the early 1960's (Moores, 1978).

According to Davis (1986), the period between 1960 and 1980 was marked by major changes in the availability of educational programs for children who were deaf. She believes five factors contributed to the development of more local programs for children who were deaf:

1. the improvement in hearing aid technology,
2. the expansion of knowledge about language acquisition of children,
3. the rubella epidemic of 1963-1965,
4. the federal legislation that focused on the rights of handicapped individuals to a public education, and

5. the general movement toward recognition of minority and individual rights.

Federal Legislation

One of the most significant factors which contributed to the expansion of program options for individuals who were deaf during the twentieth century was the passing of legislature protecting the rights of individuals with disabilities. In November 1975, Public Law 94-142 (The Education for all Handicapped Children Act) was passed by the United States Congress. This law required state and local agencies to provide appropriate educational services for disabled children and youth from the ages of 3 to 18. One of the major components of this legislation, which influenced the educational placement options for children who were deaf, involved the least-restrictive environment provision. This section of the law states that, as much as possible, handicapped children should be educated with non-handicapped children. According to Luetke-Stahlman & Luckner (1991), *"School systems should provide a continuum of services that facilitates student movement from one type of service to another as the need arises" (p. 45).* Another important feature of the legislation required the development of an annual Individualized Education Program (IEP) for all children receiving special education services (Cantor & Cantor, 1995). The IEP, developed by a

Multidisciplinary Team (M-Team or IEP Team), determines the individual needs of the student, the specific support services required, and the available educational placement options. The actual team may consist of a number of various individuals, depending on the specific needs of the child. According to the Individuals with Disabilities Education Act of 1997, the IEP Team means a group of individuals composed of: 1) the parents of a child with a disability, 2) at least one regular education teacher of such child (if the child participates in the regular education setting), 3) at least one special education teacher, or where applicable, at least one special education provider of such child, 4) a representative of the local educational agency, qualified to provide or supervise the provision of appropriate special education services, 5) an individual who can interpret the instructional implications of evaluating results, 6) at the discretion of the parent or the agency, other individuals who have knowledge or special expertise regarding the child, including related services personnel as needed; and 7) whenever appropriate, the child with a disability. Parents of the child with a disability serve as equal members of the Multidisciplinary Team and must be informed of their protected rights under the law.

The passage of Pubic Law 99-457, in September 1986, extended the age of eligibility for special education services to include children from birth to three and their families. PL 101-476 extended the period of eligibility for

special education services to age 21. The enactment of PL 94-142 and subsequent re-authorizations (including PL 101-476 and the Individuals with Disabilities Education Act [IDEA] of 1990 and 1997), reflects a continuing evolution in the approach to educating individuals who are deaf (Moores, 1996). Residential schools and day schools are no longer the only placement options for parents to consider. Other types of educational options available for children who are deaf include: Day classes, resource rooms, itinerant programs, private schools, and home schools. As the quantity of educational placement options for children who are deaf continues to increase, questions of effectiveness and quality must also be addressed. More specifically, do all parents have access to these types of programs? Do differences exist between urban and remote settings with regards to program availability, quality of service, and student population?

Urban Special Education

Most of the earliest American schools and programs established for children who were deaf were located in remote areas of the country. At present, the majority of state residential schools, day schools, and public day programs are situated in or near large metropolitan areas within each state. Generally these types of settings offer early intervention, preschool, elementary, and secondary programs. Although some residential schools

have programs in place that allow students to interact with their hearing peers, the majority of integrated programs occur in the public school setting.

Due to the critical mass of students located within urban and metropolitan areas, day schools and public day programs tend to have a significant number of students who are deaf or hard of hearing. A large percentage of students who are deaf also exists in residential schools which enroll students from both the surrounding metropolitan and regional service areas. Because of the concentrated number of students who are deaf, residential programs generally have better support services, facilities, transportation, funding resources, and more specialized staff.

While urban areas have many advantages in terms of educating students with disabilities, they also have some common disadvantages. According to Helge (1984a), urban settings tend to have high turnover rates among special education directors and other supervisory positions when compared to rural school systems. This turnover can be especially difficult for teachers and other service providers who must frequently adapt to new or inconsistent management styles and policies. Another disadvantage of urban settings is that the community structure often becomes depersonalized except within inner-city pockets of distinctive ethnic groups. Even though residential schools for the deaf pride themselves on building a strong sense of community, students living on campus may not have the same

opportunity, as children living at home, to fully acclimate to their parents' local community. Finally, special education programs located in urban areas may experience more problems with discipline, crime and violence.

Rural Special Education

Rural schools comprise the majority of the nation's school systems and remain extremely diverse (Helge, 1984a). With the passing of federal legislation, rural schools have been forced to address the educational needs of children with disabilities within the local school system. Helge's 1980 study (as cited in Helge, 1984a) examined the percentages of special education services offered to students with disabilities before and after the passing of Public Law 94-142. Of the 75 rural school districts surveyed, 25 percent offered some type of service to hearing-impaired students prior to the legislation. After the passing of Public Law 94-142, the percentage of districts offering services to the hearing-impaired rose to 60 percent.

Rural school districts serving students who are deaf often face unique problems. Due to the low incidence of deafness, these districts lack the critical mass of students needed to ensure proper grade level placement (Moores, 1996). Often teachers are required to teach a small group of children with varying degrees of hearing loss and at multiple grade levels. Other problems which may plague small rural districts include: a lack of

qualified personnel, inadequate transportation, and reduced funding. In Helge's (1984a) study of rural special education districts, similar problems of qualified personnel shortage and limited funding were also noted. In addition, the study by Helge (1984a) cited high turnover rates among special educators, professional isolation, poor student motivation and a lack of ethnic diversity among students as common problems facing rural education. A study conducted in 1990 by Stone (cited in Wengerd, Hayes, & Luetke-Stahlman, 1995) found that the teachers' turnover rate in rural areas is 30-50 percent annually, and the most common reason for teachers leaving their positions centered around feelings of isolation. In rural districts of the United States, many of the educators who provide services to students with disabilities do not have specialized certification or training in deafness. Consequently, many educators are issued "emergency certification" in order to fill positions requiring a special educator (Helge, 1984a). Wengerd, et al. (1995), surveyed teachers serving students who are deaf and hard of hearing in twenty-five rural school districts in three Midwestern states. The researcher asked participants to report the problems and concerns they encountered while working in rural settings. Represented among the 44 percent of survey participants were teachers from resource, self-contained, regular education and itinerant positions. Examples of the problems reported by survey participants included: the wide age range of students, geographic

isolation, multiple teacher roles, teacher burnout, isolation from the educational system, lack of deaf role models, and unqualified assessment personnel.

Interestingly, some rural districts had employed or contracted individuals who did not possess teacher certification (i.e., speech language pathologists and school counselors) or persons who lacked the appropriate certification to teach children who were deaf or hard of hearing. If the professionals and service providers working with these students who were deaf had no specialized training in the area of deafness, how could they adequately inform parents about the education placement options for their children? Furthermore, were they equipped to assist the parents in assessing the individualized needs of the children as they transitioned from one educational level to another?

Rural school districts, however, are not without certain advantages when compared to urban settings. On the positive side, rural districts often have a relatively high trust factor, close family ties, a sense of community, and a willingness to volunteer in helping individuals with disabilities (Helge, 1984a). Another conceivable advantage of working in rural settings is that special education teachers often have the same group of students over a period of several years. In this classroom environment, teachers may enjoy watching the children grow and mature from year to year and often develop

a special bond with pupils (Wengerd, et al., 1995). Obviously, the reverse could be true as with most situations dependent upon the individual teacher/student relationship.

Educational Placement Options for Children Who Are Deaf

United States statistics for 1994 indicated that approximately 9,000 children who are deaf attended residential programs for the deaf, 3,704 attended day schools for the deaf and 30,347 were enrolled in some type of local public school program (Moores, 1996). The educational placement options available to families of children who are deaf have changed drastically over the course of United States history. As the range of educational programs for children who are deaf has increased, have professionals and other service providers accepted responsibility for providing parents with the information necessary to make informed educational decisions for their children?

The educational continuum for children who are deaf spans from the age of identification to early intervention and continues through the numerous transition periods (elementary school to middle school, middle school to high school, and high school to work/postsecondary education). This study traced the educational placement decisions of parents from the time their child's hearing loss was first documented to the transition period

from elementary to middle school.

According to Donald Moores (1996), five basic school programs available for parents of children who are deaf include (pp. 16 -18):

1. Residential schools
2. Day schools
3. Day classes
4. Resource rooms
5. Itinerant programs

Furthermore, as many as twelve variations of the these five basic placements may exist in any of the fifty states. The array of educational options may be limited when geographic service areas are taken into consideration.

As mentioned previously, families residing in geographic areas where services for children who are deaf are severely limited, may experience a reduction in availability of educational options. Brantlinger and Guskin (1987) noted that parents of children with low-incidence disabilities and/or those who reside in rural areas of the United States experience problems with accessing suitable services for their children. Urban areas generally offer a wide range of educational programs for children who are deaf. In contrast, more remote areas are frequently less affluent and characterized by limited personnel in specialized fields, less educational expenditure per/child and fewer community resources.

Due to the remoteness of some areas and the low pay scales, school districts have difficulty recruiting qualified professionals within the school systems. State support for special education teacher positions is often based on the number of students with a specific disability in any given service area. Since deafness is a low incidence condition, schools in remote places, located outside of large urban areas, may be less likely to employ educators with the specific credentials necessary for teaching children who are deaf. The responsibility for teaching these students often shifts to the general special education teacher or another professional who lacks adequate training in the field of deaf education. Traditionally, national centers for deafness, parent advocacy groups, and other potential resources available to families with children who are deaf are located in urban areas. Families from remote areas may also have fewer contacts with other members of the deaf community, as well as other families with children who are deaf. If the problem of limited resources continues, who serves as a support system for these families as they make important educational decisions for their children who are deaf?

A study conducted by Bernstein and Martin (1992) surveyed 128 parents of children attending residential schools for the deaf. The parents were asked to indicate how they had obtained information about the educational placement options for their children and the reasons for choosing

this placement. The results of the study indicated that 72 percent of the parents had received some information pertaining to educational placement options for children who are deaf. However, a large percentage of these parents reported that the information they received was limited to one specific placement option. In many of the cases, the discussion of multiple placement options never occurred. These findings suggest some professionals and service providers within the field of deafness may not provide parents with sufficient information regarding the educational placement options for their children.

The most common factors which influenced parents placement of their children in residential schools included: a better education, inadequate public school services, peer/social interaction, communication, and trained teachers/staff. Ninety-one percent of the parents reported that their children transferred from another type of program into the residential setting. The reason most commonly cited for the transfer was inadequate local school programs. The Bernstein and Martin study did not specify the reasons why parents felt the public school programs had not sufficiently met their needs. The term "inadequate" could describe negative aspects of an existing program or failure to offer specific services. In fact, some rural schools do not provide programs for the deaf beyond the elementary grades. Parents

faced with this situation may choose to send their children to residential schools in order to complete middle school and/or high school.

Calderon & Sidman-Bargones (1998) conducted a study which investigated the outcomes of the Early Childhood Home Instruction (ECHO) early intervention program for young children who are deaf and hard of hearing. Children who had graduated from the ECHO training program were tracked several years later in order to measure the success of the family intervention. As the children exited from the birth to three programs, the majority of parents choose to enroll them in deaf education programs which stressed a total communication approach to instruction with an emphasis on Signing Exact English.

Interestingly, although many of the parents were presented with various communication and program choices upon graduation, they chose the same type of educational approach and communication methodology implemented during the ECHO early intervention program. Even though these parents chose programs similar to the training and instruction introduced during the early intervention program, many of the families did not stay with one particular type of educational setting and method of communication. By the time of the follow-up study, approximately 50 percent of the children had enrolled in at least one other type of educational program, and several others had attended two or more placements utilizing various types of signing systems.

The reasons why parents made changes in the type of educational placement program and communication methods for their child were unclear. The researchers suggested the following possible explanations for the programmatic and communication shifts: rural families may relocate to places offering better programs and services; an increase in the parents' knowledge and understanding of the various educational options for children who are deaf; or the families may have experienced instability within the home. Future research is warranted in order to gain a better understanding of the processes which parents go through when making these educational placement and communication decisions as well as the rational which leads to the changes and shifts from existing programs.

Transition Periods

According to Blacher 1984, the stress level of families who have children with disabilities can fluctuate along with chronological periods or key transition periods in the child's life. When parents discover their children have a severe to profound hearing loss, they may find themselves experiencing feelings of denial, grief, anger, or depression (Luterman, 1979; Moores, 1996; Vernon & Andrews, 1990). Since at least 90 percent of children who are deaf are born to hearing parents, who often have had no prior contact with a person who is deaf, these feelings can become especially

strong. Moores (1996) identified four periods of extreme stress which families with children who are deaf may experience: identification of the hearing loss, entrance into formal schooling, the beginning of adolescence, and early adulthood. During the period when the childrens' hearing loss is identified, many parents struggle with their own feelings regarding deafness and at the same time, have to make important communication and program placement choices for their children.

A study conducted by Meadow-Orlans, Mertens, Sass-Lehrer and Scott-Olson (1997) surveyed 404 parents of 6 and 7 year-old children who are deaf or hard of hearing attending a wide variety of educational programs across the United States. Parents rank ordered the degree of helpfulness of each support service they had utilized since the childrens' diagnosis of a hearing loss. The top five ranked support services listed by parents as "extremely helpful" or "very helpful" consist of: teachers, spouse, therapist, other parents, and deaf adults. Only 19 percent of the respondents listed medical doctors as "extremely helpful" and only 20 percent listed doctors as "very helpful."

Studies such as these tend to focus on the service delivery of families during the early intervention years. Once the elementary placement and communication options have been decided, however, the focus of existing research shifts to measuring the childrens' progress, examining individual

communication and/or teaching methodologies, and evaluating the diverse types of programs available to children who are deaf.

Family support programs/resources should center on the needs and concerns of parents at all levels of their child's education (Brinton & Stewart, 1992). Once the child completes preschool, parents may take advantage of family directed services more readily. Many families have had the opportunity to adjust to their personal feelings about their childrens' deafness as well as develop some basic skills related to deafness issues. Research exploring the home and school environment during transitions into adolescence, is relatively nonexistent. For this reason, this study has asked participating parents of middle school age deaf children to make comparisons between the elementary years and the middle school years. Through conversations with families, I collected data which examined the similarities and differences between elementary and middle school programs/settings as well as the aspects of their childrens' current middle school placement which they are most satisfied/dissatisfied.

Summary

In 1992, Ritter-Brinton and Stewart conducted a survey which examined parental understanding and motivation when deciding on a particular sign communication system for their children who are deaf as well

as the quality of service delivery they received. When the researchers asked parents to report on the resources offered by professionals which they considered most helpful, parents indicated the following: unbiased opinions, honesty, resource materials, and the freedom to make their own decisions without pressure from the professional/s. Resources offered by professionals which parents considered to least helpful included: insufficient deaf role models, limited written information, and failure on the part of professionals to describe the full range of communication options/alternatives. The Ritter-Brinton and Stewart study suggested parents of children who are deaf want a full range of program options presented to them when making important educational decisions for their children. They value honesty, access to resource materials (books, articles, videotapes, etc.), as well as exposure to other individuals who are deaf.

When comparing urban and rural resources/programs for children who are deaf and their families, it appears that parents living in rural districts of the United States are at a greater disadvantage. Aside from families being isolated from larger programs serving students who are deaf, their networking and resource capabilities with others in the field of deafness may remain extremely limited. The field of deaf education has much to gain from further investigation into how these families, living in remote sections of the United States, cope with the responsibilities of raising a child who is deaf

and the challenges they face when making important education decisions as their child transitions into middle school. Research should include parents of children who are deaf from a wide range of geographic areas, and it should encompass the entire life span of its subjects. Historically in deaf education, the majority of research has centered disproportionally on infancy and early childhood (Moores, 1996). As Fairchild (1980) so poignantly states:

> ***"We should address this issue squarely and decide how to best provide all parents with accurate information about the services they can expect. So many times parents simply 'burn out' for lack of reward and assistance" (p. 1009).***

CHAPTER 3

METHODOLOGY

"I don't think any parent is 100 percent sure they are doing the right thing." (-P 24)

Introduction

This section describes the methodology of the study. It also outlines the steps taken to develop the theory supporting the research. I first contacted parents with middle school age children who are deaf and invited them to participate in my research. Once the parents met the criteria for participation, I asked them to complete a brief questionnaire containing demographic information about their child and a series of Likert Scale items.

Next, I conducted personal interviews with the qualifying parents to record their experiences over time when making educational placement decisions for their children. The study explored these decisions from the age of identification through the transition periods into elementary and middle school. Through the process of utilizing Grounded Theory research methods, emerging themes and various styles/patterns of parenting emerged from the data. The process of developing theory allowed me to gain a better

understanding of the challenges facing families with deaf children living in remote areas of the United States.

Research Methods

Grounded Theory

Because this study sought to better understand the "process" that parents go through as they make educational placement decisions for their children who are deaf, I implemented a qualitative, grounded theory approach to the research. The Grounded Theory method is a systematic discovery of theory from data obtained in the social domain (Brown, Maxwell & Browning, 1990). Glaser and Strauss first introduced this particular method of conducting qualitative research in The Discovery of Grounded Theory, (1967). According to Strauss and Corbin (1994) the work by Glaser and Strauss had a threefold purpose:

1. To offer a rationale for theory that was generated and developed through interplay with data collected during research projects (i.e., Grounded Theory);
2. To suggest the logic for and specifics of grounded theories;
3. To legitimize careful qualitative research.

Strauss and Corbin explain that after approximately two decades, American sociologists did begin to see the significance and value for the

more precise and systematic conceptualization that constitutes theory. As a result of this heightened appreciation for the Grounded Theory method of research, other sociologists, scholars, and graduate students from a vast array of professions have benefitted from this methodology. In order to more fully appreciate the contributions which Grounded Theory has made to the field of education and how I utilized the method as a viable research tool when studying the educational decision making processes of parents of children who are deaf, one must first have an understanding of what Grounded Theory is, the techniques used in deriving the theory, and the components of the theory.

What is Grounded Theory? The following definitions offered by Schumacher & McMillan (1993) and Strauss and Corbin (1994) offer a more detailed description of the qualitative research method known as Grounded Theory.

> ***"Grounded Theory relates abstract concepts to propose a theory as an explanation of the phenomena. The theory is "grounded" in that it is developed from the data, in contrast to testing a theory from the literature. The relationships between two or more concepts generate a theory. Data are presented to describe each concept and its relationship to other concepts." (Schumacher & McMillan 1993,*** p. 509).

"A constant comparative method of inquiry where theory is 'generated' from data sources in order to study the processes which a target group moves through as they relate their own personal experiences over time "(Strauss & Corbin, 1994).

I continued to develop the theory throughout the course of the entire study by utilizing the following research techniques and by addressing the various components of the theory as outlined by Strauss and Corbin (1994).

Techniques for Deriving Grounded Theory.

1. Making constant comparisons
2. Systematically asking generative and conceptually related questions
3. Obtaining theoretical sampling
4. Implementing systematic coding procedures
5. Establishing guidelines for attaining conceptual density and processes or changes in patterns of action, as well as consequences and related actions

Grounded Theory/In My Own Words. A qualitative approach to research allowed me to describe in great depth the feelings and reactions of parents when their children were first diagnosed as deaf, and the experiences they faced as their children progressed from elementary into

middle school. The data I obtained from the personal interviews were reported in the participants' "own words" through the process of audio taped recordings and transcriptions. The text of the interviews served as the primary source for interpreting and analyzing the data. By reading and re-reading the transcripts, I identified thematic data by noting common "threads" which emerged from the individual stories. According to Schumacher and McMillan (1993), a *"Theme Analysis describes specific and distinctive recurring qualities, characteristics, subjects of discourse, or concerns expressed" (p. 508).* Once I recorded and coded these themes, I formulated a time line to trace each parent's actions as he/she made communication and educational placement decisions for his/her child.

Three styles of parenting emerged from the 17 parent time lines: 1) Trusting Self, 2) Trusting Others/Trusting Self, and 3) Trusting Others. I compared these parenting styles with the interrelated themes which emerged from the initial transcript analysis. In turn, the relationships between the emerging themes and the styles of parenting generated theory "grounded" in the research data. The development of theoretical concepts led to a more thorough understanding and appreciation for the educational decision making processes of parents when raising children who are deaf.

Research Questions

I addressed the following questions during the data collection phase of this research project.

1. Who were the initial contacts for parents which provided them with advice/information concerning the educational placement options for children who are deaf?
2. What were the major factors which influenced the parents' initial educational placement decision for their child?
3. Did the same factors which influenced the parents' initial placement decision play a vital role during the transition period from elementary to middle school?
4. As the parents reflect on their child's educational history, what resources or support systems do they consider the most valuable?
5. What aspect/s of their child's current educational placement are parents most pleased with? most displeased with?
6. What advice do parents of middle school age children who are deaf have to offer to other parents with young children who are deaf?

From these general research questions, I developed a more detailed list of questions which appeared in the participant questionnaire and interview guide. During the process of developing the questionnaire and interview guide, I asked other colleagues within the field of deafness as well as other qualitative researchers to review the items on both

instruments and offer constructive feedback. This collaborative effort with other professionals proved very effective in adding information which I had overlooked, deleting unnecessary educational jargon, rewording the questions to encourage a better participant response, and highlighting potential philosophical bias inadvertently present in the wording. After I completed the final editing, I pretested both the questionnaire and the interview guide on parents of children who are deaf (refer to page 59). By exploring the various parental perspectives and concerns with regard to these questions, I gained insight into the factors which influenced their educational placement decisions and into the key resources/support systems families living in remote areas of the southeast United States utilized.

Research Design

This study consisted of two phases. Phase I of the research study included a participant questionnaire which contained the following: a demographic information section and a Likert Scale (Table 1 & 2).[2] I asked all participants to complete the questionnaire prior to Phase II of the study. At the beginning of each interview, I allotted time for the participants to ask questions about items on the questionnaire which they found unclear.

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[2]Tables 1 and 2 are included in Appendix A

I purposely decided to collect the completed questionnaires on the day of the interview so that I would enter the session with no personal background information about the parents. I followed this procedure to protect against potential bias or assumptions I could have drawn based on the parent's occupation or level of education.

The purpose of the Likert Scale, included in the questionnaire, was to provide an overview of the major areas of satisfaction and/or dissatisfaction among families parenting children who are deaf. Because the majority of parents tended to respond in the Strongly Agree or Agree category, overall areas of dissatisfaction were not noted. Therefore, I chose to use the data collected from the participant interviews as my primary means of analysis. I felt the personal interviews more accurately reflect the experiences of the parents and provide clear distinctions between the major areas of satisfaction and dissatisfaction among parents. For individuals interested in the reviewing the responses from the Likert Scale, I presented the results in the Appendix section. Since many of the parents chose not to disclose their occupation and/or educational background, I was unable to provide a summary report on these statistics.

Phase II of the study consisted of a semi-structured interview, combined with both open and closed form questions, which I implemented during the scheduled interviews with parents. Although I used a

semi-structured interview format during the interview, I allowed for further exploration into areas that warranted additional investigation. In these instances, I simply asked "Tell me more about ____?" or "How did that make you feel?" The use of both a predesigned questionnaire and a semi-structured interview format allowed me to address the research questions which guided the study while at the same time allowed some level of flexibility and latitude when asking the questions. When parents inadvertently responded to a question that I had not yet asked, I chose to skip over that question/s and continue to the next. The scheduled interviews took place during the Spring and Fall of 1998.

Reliability

Reliability in qualitative research refers to the "consistency of the researcher's interactive style, data recording, data analysis, and interpretation of participant meanings from the data" (Schumacher & McMillan, 1993). I implemented several design strategies to enhance the consistency of my research methods, to minimize threats to reliability, and to enable other researchers to discover similar outcomes. These strategies included: 1) Defining My Role as Researcher, 2) Selecting a Population Sample, 3) Describing Strategies for Data Collection, and 4) Reporting Strategies for Data Analysis.

Defining My Role as Researcher. My role as researcher was to listen and record the stories of parents and to understand how they make educational placement decisions for their child. My personal background in the field of deafness, combined with my experiences as a parent of a child who is deaf, fostered empathy and understanding toward the challenges they faced. My role was not to judge the choices and decisions of parents or to sway them to my own personal preferences and philosophical preferences.

Selecting a Population Sample. I provided a detailed description of the methods used to locate parents for participation in the study and the role which school systems played in these efforts. I also supplied specific demographic information, relating to the children who are deaf.

Describing Strategies for Data Collection. I discussed precise descriptions of the data collection techniques such as the research packet, questionnaire, interview guide, and interviewing methods and placed these items in the Appendix. During the actual data collection phase of the project, I implemented several techniques for establishing reliability: verbatim accounts, low-inference descriptors, multiple researchers (see page 68), participant review, and reporting of discrepant data.

Reporting Strategies for Data Analysis. I gave explanations how information gathered from the study was mechanically recorded,

condensed, formed into categories, and coded for emerging themes and patterns.

Internal Validity

Internal Validity is the *"degree to which the explanations of phenomena match the realities of the world" (Schumacher & McMillan, 1993).* In more simple terms, it is the extent to which my interpretations of the data and the participants' interpretation of the data agree. In order to increase internal validity, I incorporated the following techniques: 1) usage of participant language, 2) conducting field research, and 3) documenting researcher bias. I minimized threats to Internal Validity by: 1) describing how research participants were contacted and chosen for participation in the study, 2) documenting the experiences of the families from the age their children were identified through the transition into middle school, 3) soliciting parent reactions to my interpretation of the data through verbal summaries, and 4) by exploring possible rival explanations by comparing the study results with existing literature and by acknowledging discrepant cases during data collection and analysis.

External Validity

In qualitative studies, the researcher's intent is not to make generalizations of the findings but to offer an extension of understanding

(Schumacher & McMillan, 1993). This "extension of understanding" allows others to explore how the results from one study may assist in the understanding of similar situations in subsequent research. In order for other researchers to come to a full understanding of the group characteristics studied, I developed a demographic table for displaying information about the families. I also discussed the historical experiences of the families throughout the study. I compared factors such as geographic location, type of school placement (residential or public), and communication methods among families. Finally, the stories shared by these families will expand existing literature that focuses on the decision making processes of parents raising children who are deaf.

The Population Sample

For the purposes of this research project, I chose parents with children enrolled in middle school during the Spring and Fall of 1998 as the main focus of study. The children of these parents were not allowed to participate, in any manner, during the interview sessions. I chose this population because the parents had moved beyond the initial placement decision and had several years of experience working with the Multidisciplinary Team at their child's school. The elementary years were behind these families and others in the field of deafness need to learn

how parents were handling their child's transition into early adolescence. Has their decision making pattern shifted from elementary to middle school? What resources did these parents utilize when deciding on the child's educational placement for middle school?

The targeted population for this research project included parents of middle school age children within remote areas of Georgia, Kentucky, Louisiana, and Tennessee. Due to time constraints and traveling distance, I focused on parents living within a 5 hour driving radius of The University of Tennessee, Knoxville. In the state of Louisiana, I chose the state capital as a reference point and kept all interviews within a five hour driving radius of Baton Rouge.

Defining Remote Populations

According to the United States Census Bureau, one of the following criteria must be met in order for a family residence to be classified as rural:

- Parents must live in a town or city with a population of 2,500 or less as recorded by the United States Census Bureau.
- Parents must live on a "rural farm" (places which earn $1,000.00 or more of agricultural products per year).
- Parents must live in areas with less than 1,000 people per square mile (unless the territory eliminates an enclave or closes an indentation in the boundary of an urbanized area).

Although a large percentage of the parents who initially indicated a desire to participate in the research study resided in "rural areas" as defined by the United States Census Bureau, I quickly realized that many families who did not fall under the rural classification lived in under served "remote" areas of the country. For example, a family living in a place with a population of 2,750 would not have qualified for participation in the project under the existing Census Bureau classification for rural areas. After much discussion with staff at the United States Bureau of the Census located in Washington, District of Columbia and the Office of Demographic Studies at Gallaudet University, these individuals suggested that I consider including families living in areas classified as "Other Urban" for participation in the project.

The classification "Other Urban" included towns with populations greater than 2,500 but excludes large urbanized areas, central cities and urban fringe areas. For this reason, I allowed families living in "rural areas" as well as those living in areas classified as "Other Urban" to take part in the study. I replaced the term "rural" with "remote" in order to compensate for the change in classification. I used a computer-generated list of places, separated by individual states, provided by the United States Bureau of the Census to determine whether a potential participant's address fell under one of the classifications mentioned previously.

Documentation of a Hearing Loss

At the outset of the study the definition of a person who is deaf was defined as: one whose hearing is disabled to an extent (70 dB or greater) that precludes the understanding of speech through the ear alone, with or without the use of a hearing aide (Moores, 1996). Since four of the families indicating a desire to participate in the study had chosen to pursue cochlear implants for their children, the above definition was no longer adequate. These families viewed the cochlear implant as one of the resources which they had utilized during the course of their children's education. To exclude this population, based solely on the fact that their children at some point in time may begin to understand speech through the use of the implant, would have discriminated against this particular parent group. In order to level the playing field, I adopted the following definition: **a deaf person is one whose hearing is disabled to an extent of 70 dB or greater**. All parents participating in the research study provided a copy of their children's most recent audiogram or other official documentation in order to verify that their children had a severe to profound hearing loss.

Participating School Systems

I contacted potential subjects in the following manner: residential schools were asked to send information packets to all parents of children

who are deaf currently enrolled in middle school during the Spring and Fall of 1998. Since the individual counties within public schools often have fewer numbers of students who are deaf, I asked them to send out the information packet to parents within their system or to contact the families by telephone. Parents contacted by telephone, could either request a participant packet from the school system or call my office at The University of Tennessee, Knoxville to receive the information. Once a school system agreed to participate in the study, I asked them to send a formal letter to the researcher stating the terms on which they agreed to take part in the research project.

I sent an information packet containing a letter of support from the participating school system, a study information sheet describing the details of the research project, a letter of informed consent, and a response card by the schools to all parents with middle age school children who are deaf. (See Appendix B.) One month after sending out the packets to school systems, I made follow-up telephone calls or faxed a reminder letter to all participating schools to ensure they had sent out the information packets in a timely manner and to encourage them to send in their letters of agreement, if they had not already done so. Once the letters of agreement arrived at my office, I filed them under the respective school system and recorded their agreement on the appropriate information list.

Parents interested in volunteering for the study were asked to return the postage paid response card to my office at The University of Tennessee, Knoxville. A completed response card contained the following information: the parent's name, address, telephone number and a convenient time to be contacted. Since some of the more remote counties often have fewer numbers of students who are deaf, I gave them the option to contact the parents by letter (as mentioned previously) or by telephone. Parents interested in the study, who were contacted by the individual school system via telephone, could either request an information packet from the school representative or were given a telephone number where I could be reached personally.

Notably, some parents learned about the study by word of mouth. Since deafness remains a low incidence population, individuals with ties to the field of deaf education often form networks and share information among themselves. Consequently, other professionals, support service providers, and parents who had knowledge about the study may have mentioned it to other parties without directly contacting the researcher, or a particular school system. This type of sampling phenomenon is known in qualitative research as the "snowball effect" (Patton, 1990). In these cases, interested parents were given my name and telephone number so they could contact me directly or in some instances individuals simply

requested a packet of information and forwarded it to the prospective parents. Of the 17 families participating in the interview, I located only one parent through this type of sampling effect.

All participating school systems as well as parent participants were informed that at the conclusion of the research study they would receive an information packet containing the following items: a summary of the research findings, a list of national, state, regional, and local resources pertaining to deafness related issues, and a listing of various parent resource organizations/advocacy groups.

A total of 17 parents from the targeted states participated in the study. The interviews included families whose children were attending residential schools for the deaf or other types of public school programs for the deaf. I conducted the interviews within the parent's personal residence unless the parent preferred an alternate site. Of the 17 families that I interviewed, 14 chose their personal residence as the interview site, and 3 chose their children's school. For purposes of confidentiality, only the parent/s and I were allowed to participate in the audio taped interview.

Data Collection

By utilizing the methods described earlier, I did not ask the individual school systems to reveal confidential names of parents to me, as the

researcher. Accordingly, all parents interested in participating in the study self-disclosed their name, home address, and telephone number when completing the response card or calling by telephone. As the response cards arrived at my mailing address at The University of Tennessee, Knoxville, I recorded the time and date of delivery. All parents who returned a response card received a letter which expressed appreciation for their interest in the study, the criteria I would use to determine eligibility, and the expected time frame for contacting them. After checking to see that the corresponding school system had sent in their letter of agreement, I began contacting the parents to assess whether they met the criteria for participating in the study. The criterion for participation constituted the following:

1. The parents must reside in remote areas within a 5 hour driving radius of Knoxville, Tennessee. (In Louisiana, the 5 hour radius was set from the state capitol, Baton Rouge).
2. The parent's child must have a documented hearing loss of 70 db or greater.
3. The parent's child must be enrolled in middle school during the Spring or Fall of 1998.

To the parents who failed to met the specified criteria, I sent a letter thanking them for their willingness to participate in the study and expressed

my regret that they failed to meet the established criteria for participation. Once I determined that the parents met the above criteria for participating in the research project, I scheduled the date, time and place for the interview. I also asked for specific directions to the site the parents had chosen.

During these initial telephone contacts I began to build relationships with the parents. I immediately answered any questions they had about the study and conveyed in simple, conversational terms that the purpose of the project was to "listen to their stories." For myself, I found these initial conversations very valuable at building rapport with the families and aleving any fears about the unknown aspects of my work. The unknown can be scary, and I distinctly remember how I personally dreaded those initial telephone calls. Would they meet the criteria? Will I bother them? What if they say no? After contacting the families, I felt that each parent was very gracious and seemed truly willing to assist in my research study.

I selected eight parents with children attending residential programs and nine parents with children attending public school programs to participate in the study upon meeting the established criteria. In the event that a parent withdrew from the study, I decided to select the next qualifying parent from the withdrawing participant's state and program choice (residential or public). None of the parents who agreed to participate in the interviews withdrew from the study. I excluded names of the

parents, their children, the schools which their children attended, and personal references to specific people or organizations from the research results. Since many states have only one residential school for the deaf and could be easily identified, I did not report the type of programs listed by individual states. Instead, I chose to form two broad categories (residential and public) which represented all of the schools, across the four targeted states, where the children were currently attending.

Pretest

I performed a pilot study consisting of five parents in order to evaluate and further develop my research techniques. I chose five parents of middle school age children to pretest the questionnaire and interview instruments. (See Appendix C.) In most cases, researchers use the information collected from the pretest to correct any major flaws in the questionnaire or interview technique. After completing the pretest, however, I did not feel that either the questionnaire or interview guide required any major alterations which would significantly change the direction of the study. In fact, after finishing these initial interviews, I recognized possible themes beginning to emerge from the pretest as well as some of the major "characters."

In order to verify these suppositions, I spoke with my doctoral committee, several colleagues, and an experienced qualitative researcher

and asked them to review the questionnaires and transcripts obtained from the pretest. After much discussion, we agreed that the participant questionnaire and interview guide did not require any major changes and that the data obtained from the pretest interviews contained a wealth of valuable information. For this reason, I reported and analyzed the data collected from the first five families in the study. All demographic information, presented in the form of Tables, includes data collected from all 17 interviews. Nevertheless, in keeping with my original proposal design, the data analysis section (Chapter 4) separates the results of the five pretest interviews from the findings of the proceeding 12 parent interviews.

Questionnaires

One week prior to the interviews, each participant received a questionnaire via the United States Postal System. I asked the participants to have the questionnaire completed and ready to return at the scheduled interview. With the questionnaire I included a letter to the parents encouraging them to complete the questionnaire, and reminding them to have all specified documentation available (consent form and audiogram, etc.). The date, time, and place of the interview was also confirmed in the letter. I took the opportunity to reiterate that only the parents and I would

be allowed to participant in the actual interview session. I did indicate that if possible, I would like the opportunity to meet with their children after the close of the interview. I made this request for several reasons: First, many of the parents expressed a desire for me to meet with their children. Many of the children were naturally curious about my scheduled visit to their home or school and wanted to talk with me. In fact, many of the children had numerous questions for me to answer. Second, I wanted to interact with the children with whom the parents spoke about during the interviews. I have always liked to "put a face with a name" and meeting the children really made the experience more personable and enjoyable.

The follow-up letter, mentioned earlier, proved very resourceful. All but one of the participants returned their completed questionnaire on the day of the interview. The one exception was due to a last minute scheduling change which resulted in the questionnaire arriving late. In this instance, the parent mailed the completed questionnaire to The University of Tennessee, Knoxville on the next business day after receiving it. All but three of the parents had documentation of their child's hearing loss available at the interview. After obtaining the necessary documentation, they forwarded the information to my office. Fortunately, all parents were home when I arrived for the interview, and all of the parents made certain that no children were present during the taped interviews.

Interviews

Upon arriving at the interview site, I took a few minutes to "chat" with the parents and build on the rapport established through our prior contacts. I also talked a little about the study and answered any questions they had about my research. Before starting the actual interview, I collected all necessary documentation (questionnaire, consent form, and audiogram). In order to keep myself organized and focused, I made a checklist of all the items which needed to be collected before leaving the interview site. During this time, I also answered any questions they had with regard to the participant questionnaire.

Before turning on the tape recorder, I explained that my role as a researcher was to ask questions, to clarify/summarize their responses, and to listen to their experiences as a parent. I went to great lengths to make sure they understood that we would be meeting only "one time" and they would not receive a copy of the verbatim interview transcript. For this reason, I asked the parents to make corrections, at any time, if I misquoted or misunderstood them. I also explained that at the close of the interview I would attempt to summarize their responses to each question on the interview guide. Summarizing their responses allowed the parents to "listen" to my interpretation of their stories. I gave them the opportunity to add information which had been overlooked and/or to correct inaccurate facts.

If more than one parent was present at the interview, I encouraged both of them to take part. Of the seventeen interviews, four included both the husband and wife, twelve included the mother only, and one involved the grandmother (legal guardian). When quoting portions of the interview involving both parents, I identified the person speaking in brackets (see page 77). If both parents participated in the interview, I chose to give them a "combined voice" unless they specifically expressed disagreement with each another.

During the actual interview, I worked hard at maintaining eye contact with the person speaking and took as few notes as possible. When I found it necessary to take notes, I generally prefaced my writing with a comment such as, "Let me write this down. I want to make sure I get all the information," or "Ok, I'll jot that down so I can come back to it later." I chose to limit my note taking so that any unnecessary distractions would be minimized and so that I could better focus on the parents as they spoke. Knowing that I would have to summarize the parent's responses to each question at the close of the interview served as an incentive for keeping me focused and attentive. As I began to summarize the parent's responses at the close of the interview, I was very pleased that they felt the freedom to stop me and interject comments, clarify statements, and correct any misinformation or misunderstandings on my part. I always concluded our

session with the following question: "Is there anything else you would like to add before we complete the interview?" The parents who responded to this questions did so for the following reasons: to clarify statements they had made during the interview, to add information which I had not addressed in the interview, to acknowledge their appreciation for the opportunity to share their experiences as a parent of a child who is deaf.

I would sum up the overall mood for the majority of the interviews as an "extremely personal, relaxed conversation." For the most part, parents wanted to share their stories. I think the fact that I have a child who is deaf fostered a certain level of trust between myself and the parents. On more than one occasion a parent would say, "Well, you understand; you have a deaf child too" or "I don't have to tell you how hard it is to be a parent of a deaf child." Because the interviews summoned personal feelings and family memories, the parents displayed a wide range of emotions throughout the interviews. Simply stated, we laughed together and we cried together. In the situations where parents became too emotional to continue with the interview, I turned off the tape recorder and we took a short break.

After we completed the interview and I turned off the tape recorder, I usually visited with the parents and answered any questions that they had. Most of the families expressed interest in the adoption of our daughter and

how she was doing. Others just wanted to show me around the house and offer refreshments. Many times I had the privilege of meeting their children who are deaf. We usually talked about how school was going, hobbies, and life aspirations. I must admit these conversations with the children are some of my most treasured memories. These conversations gave me the opportunity to encourage and praise the children and watching their children interact seemed to please the parents. I believe parents naturally want to see their children's self-esteem grow and have a desire for others to affirm the accomplishments of their children.

I know these exchanges with the children encouraged me as a parent. Although the families had faced many struggles, they were surviving and their children were adapting to the transition into adolescence. Regardless of any existing problems, the families seemed to have a realistic yet hopeful attitude toward the future. This type of exchange between myself and the families underscored the "bi-directional" nature of conducting qualitative research. During the process of conducting the research, I realized that my research had an affect on the lives of others while at the same time the research was ultimately changing me.

As suggested by the research auditor for the study, I always found a quiet place to stop after each interview to jot down notes to myself, as the interviewer, and to record my thoughts and impressions of the visit. At a

later date I transferred these notes into the summary section attached to each interview transcript. I also kept a personal notebook to record information about the data collection and analysis process, topics and references for future exploration, and other miscellaneous material. The data entry phase and the informal analysis of the project began as soon as I completed the first scheduled interview. I gave transcribers the audiotapes accompanied by a letter of confidentiality and instructions for typing/ formatting the data into text.

Data Analysis

I analyzed the data obtained from the participant questionnaires by utilizing descriptive statistical techniques. I used a frequency distribution to provide a visual representation, in the form of percentages, of the following facts: 1) selected demographic characteristics relating to the parents' children who are deaf, and 2) parents' responses to the Likert Scale items on the questionnaire. I compared the responses from the Likert Scale items with the information I collected from the interviews in order to verify and/or cross-examine emerging themes.

I analyzed textual data obtained during the parent interviews through a process of coding, of clustering of concepts, of making comparisons, of drawing contrasts, of partitioning variables, of noting relationships, and of

building a logical chain of evidence. After transcribers completed each interview, I listened to the audiotape to ensure that they had correctly recorded the information. Whenever the transcriber could not understand a portion of the interview, they were instructed to draw a blank line with a question mark next to it. The final editing of the transcripts allowed me to fill in those blanks and familiarize myself again with the data before writing the interview summary.

I adapted the interview contact summary used in my study from from the work of Miles and Huberman (1994) and included the following information: 1) an outline of the educational placement history for each parent's child (type of program, age of entry and the duration of attendance), 2) my reactions and feelings about the interview, 3) potential bias which I may have brought to the interview, 4) the climate and demeanor of the parents, 5) emerging themes, 6) quotes from the parents that particularly "stood out," 7) the source from which the hearing loss was documented, and 8) a listing of the extracurricular activities of the child who is deaf. I also went through each transcript and noted in the margin where the questions from the interview guide began and ended. These notes allowed me to pinpoint portions of the text more easily. Since I knew that the researcher auditor would be receiving the transcripts after the summary section was finished, I frequently posed "questions for thought" that we needed to discuss at our next meeting.

I also transferred the notes which I had written to myself directly after the interview to the summary section. This process worked well to keep all documentation relating to the interview organized and accessible. Finally, I recorded the interview techniques that seemed to work well and ways to improve on the ones that were not effective.

Research Auditor

An experienced qualitative researcher functioned as an "auditor" during the data analysis phase of the study. This individual had the responsibilities to ask specific questions relative to the research design and methods utilized throughout the study. Schwandt & Halpern (1988) suggested six levels of attention required of the audit:

1. Are findings grounded in the data? (Is sampling appropriate? Are data weighed correctly?)
2. Are inferences logical? (Are analytic strategies applied correctly? Are alternative explanations accounted for?)
3. Is the category structure appropriate?
4. Can inquiry decisions and methodological shifts be justified? (Were sampling decisions linked to working hypotheses?)
5. What is the degree of researcher bias (premature closure, feelings of empathy?)

6. What strategies were used for increasing credibility (second reader, adequate time in field, peer review)?

The collaborative effort between the researcher and auditor offered a more comprehensive approach to testing the findings and conclusions of the study. I accomplished the verification process by providing a list of analytic "check points" so that the external reviewer could determine whether the sampling, measurement, and analyses leading to the main conclusions and explanations withstood the most common sources of bias and error (Miles & Huberman, 1994). After receiving a completed, edited version of the interview transcript, the research auditor read the transcript and wrote a summary statement consisting of the following information: 1) initial reactions to the interview, 2) emerging themes, 3) parent quotes that "stood out," 4) comments to the researcher for improving the interview techniques, and 5) questions which needed to be clarified at our next meeting.

I scheduled meetings with the research auditor in order to review the transcripts and to compare our notes and interview summaries. During these meetings, our discussions generally centered on the interview techniques, evolving themes and patterns, the interpretation of data, and the exploration of potential researcher bias. I feel that the relationship we developed was both personable and professional and allowed us to speak

openly and honestly about the strengths and weaknesses of the study, which in turn created a system of accountability and credibility.

Grounded Theory Analysis

Utilizing Grounded Theory Methodology, I made constant comparisons within the interactive context of data collecting and data analyzing. From these comparisons, I identified patterns and processes of action/interaction among the various participants. In turn, I carefully examined these patterns and processes of action/interaction for possible links with specific conditions and/or consequences which surfaced from the emerging themes within the data. I assigned each pattern a specific code which I transferred to the summary section.

As I began to delve more thoroughly into the data, I devised informal, handwritten charts to note emerging themes and patterns. I divided the first chart into broad categories separated by each question on the interview guide. I recorded important key words, phrases and concepts which surfaced from the data under the respective category and color coded for easy recognition. Eventually, I collapsed the broad categories into smaller more manageable groups. I found the hand drawn charts which I developed beneficial for several reactions: I prefer "hands on" activities; it strengthened my familiarity with the data; it provided a visual representation

of the data; and the information was extremely portable (no computer required).

Because the study focused largely on the decision making process of parents when choosing an educational placement, I went through each transcript and sequenced the events that lead up to the first initial placement and all subsequent placements up to middle school. A chronological time line proved very valuable when I began to conduct cross-case analysis.

The two strategies of cross-case analysis which were I utilized include: 1) variable-oriented strategies, and 2) case-oriented strategies (Strauss & Corbin, 1994). The first approach entailed careful inductive coding among the cases (i.e., parent interviews) which in turn yielded recurring themes or variables. The second approach shifted back to the individual cases so that I could identify specific patterns/styles of parenting. Both of these strategies allowed me to see how the parenting decisions were similar/different and served to pinpoint variables which altered the decision making process. I gave special attention to the parents' attitudes and their reactions to the individuals serving as resources to their family along the decision making continuum. Parental responses to each question on the interview guide were counted and categorized into major themes/patterns. The top ranking responses are presented in the data analysis section (Chapter 4).

I feel that effective theoretical coding was enhanced by the theoretical sensitivity which I brought to each interview. I could more easily empathize with the personal experiences of other parents because of my own awareness and appreciation for deaf culture, educational placement options for children who are deaf, and parent advocacy issues. Additionally, my role as researcher-theorist became more theoretically sensitive as I scrutinized the literature to discover possible theories relevant to the emerging theory developed largely through the continuing examination of the research data (Strauss & Corbin, 1994).

Confidentiality and Ethics

In order to protect the privacy of the families participating in the study, I assigned a code to each parent which I recorded on the corresponding participant questionnaire, field notes, and all transcribed materials. Only I had access to the list of the names that match the individual parent codes. I kept this list with other confidential information (i.e., consent forms) in a locked cabinet at The University of Tennessee, Knoxville. I required the data transcribers and the data auditor to sign a letter of confidentiality (Appendix D) prior to receiving any confidential information pertaining to the study. When applicable, I blacked out the names of parents and replaced them with the parent code. I asked all

transcribers to replace names with initials when typing the text. When quoting parents within the research text, I replaced proper names with pseudonyms to protect the privacy of individuals and school systems. Prior to conducting the interviews, I obtained informed consent from all research participants in accordance with The Human Research Committee of The University of Tennessee, Knoxville.

Summary

Many times I would leave the interviews totally exhausted. I felt as though I had peered through a mirror of past, present, and future scenarios on the education of deaf children. At times, I found myself questioning our family's past decisions relating to our daughter's education, pondering our present circumstances, and worrying about the ones to come. In an effort to deal with these feelings, I talked at length with my husband, close friends, and colleagues. Through these conversations, I began to readjust my focus and was reminded of the appropriate place that self-reflection plays in qualitative research. I gradually began to understand that my role as a qualitative researcher allowed me to see the beauty that each family brought to the canvas of life and how the experiences in my own life contribute to the ever-changing landscape known as "The Education of Deaf Children."

CHAPTER 4

ANALYSIS

"Don't ever look back and regret, always know that you make the decisions you make based on the knowledge that you have today."

(-P8 Pretest)

Overview

This chapter focuses on the journey of parents as they make educational decisions for their children who are deaf. Their journey begins with the parents identifying their children's deafness and continue through the children's transition periods into elementary and middle school. The actual "words" of the participants, as they describe their personal experiences of parenting a child who is deaf, form the core of the study. In spite of efforts to acknowledge and lay aside personal bias, my own background and "frame of reference" have no doubt entered into the interpretation of their stories. I have tried to remain true to their experiences and attempted to give a balanced account of their journey. Some individuals may interpret the information in different ways, if they choose. Regardless of one's interpretation, I believe others will gain an appreciation for each

family's willingness to share their hopes and fears as they parent a child who is deaf.

Organization of the Chapter

Chapter 4 is divided into two sections: Part I: Transition Periods and Part II: Patterns of Parenting. Part I consists of three separate categories: Age of Identification, Elementary School, and The Transition From Elementary to Middle School. I incorporate into each category the interrelated themes or "common threads" identified by the families as they described these periods of transition. Although all 17 parents expressed common themes, distinct differences within the interrelated themes gradually unfolded. I describe these variations to encourage an awareness of the diversity among families and how their differences influence the educational setting.

Part II provides an outline of the three styles of parenting which surfaced from the data: 1) Trusting Self, 2) Trusting Others/Trusting Self, and 3) Trusting Others. I discuss the unique characteristics of each pattern and make comparative analysis across groups. As I contrasted the decision making processes of the families, two contextual categories emerge: 1) The Time Factor and 2) The Control Factor. Each family's parenting styles was directly related to their awareness and understanding of "time" and "control." For some parents a sense of time and control played a major role

in their approach to decision making, while for others, time and control held little significance.

As mentioned in the methodology section, the five parents involved in the pretest "set the stage" for the 12 subsequent interviews. For this reason, I chose to highlight quotes from the pretest interviews when introducing each new theme and/or pattern. Even though I continued my search for new themes within the 12 remaining interviews, I found none. Consequently, the data collected from these additional interviews serve to verify the pretest themes, broaden the depth and density of these themes, and expand the styles of parenting.

The Context

Parents of children who are deaf find themselves on a journey marked by "constant change." Parent #11 shared her frustrations: *"Sometimes I cry because it is so hard. . . . I am tired of having to do things different. I cry because we don't have the normal, everyday life, you know" (-P11).* Families spoke repeatedly about the instability they faced throughout the first five years of their children's lives. This period of change began with the initial diagnosis of a severe to profound hearing loss and continued until the child entered preschool and/or kindergarten. "What does it mean to be deaf?" "How will this affect our family?" "How will our child communicate?" "Where will our child attend school?" These questions represent some of the

issues families encountered when discovering their children were deaf. Parents faced the ominous task of coping with their children's deafness, while at the same time, making critical educational choices.

PART 1: PERIODS OF TRANSITION

Age of Identification

Initial Reactions

The majority of the families expressed shock and disbelief over the documentation of their children's hearing loss. Consequently, parents had many unanswered questions about the appropriate plan of action to pursue. Parent #8 described her reactions as the audiologist explained the results of her child's audiogram: "*She had to look me in the eye and say 'Your child has a severe to profound hearing loss.' That was the last thing I heard .*" *(-P8 Pretest)* Another family experienced a similar reaction: *[Father speaking] "Yes, it was shocking." [Mother speaking] "We didn't want her to be deaf and then we decided we got to. What do we do about it? Where do we go from here?" (- P4 Pretest)*

Although the majority of parents expressed a sense of loss and dismay when discovering their child's deafness, a few actually experienced relief to finally have an official diagnosis:

We had to go back later for the brain stem test. She [the audiologist] said that he was indeed hearing impaired. So we all went out to eat lunch and celebrate. Because we knew what it was. (-P1 Pretest)

He was not responding to the sound and it was getting so loud that it was hurting me . . .. My response, instead of going "Oh, my child can't hear," I felt myself being real proud. "I told y'all." (-P8 Pretest)

As the families began the process of coping with their children's disability, they often sought the advice of others when trying to learn about deafness. What resources were available to families as they sought information about the following?:

1. The medical aspects of deafness
2. The communication options available for children who are deaf
3. The educational placement options for children who are deaf.

Resources

Four categories of resources and support systems utilized by families, materialized from the textual data: 1) the parents (themselves), 2) family/ friends, 3) medical professionals, and 4) educational professionals. Parents considered many of the resources extremely valuable and at times referred to

them as "life savers." Parent #12 spoke highly of the early intervention program on behalf of her son:

> *They got down to the "nitty gritty." They had an excellent program to get us going. If we had not had that to get us started, to educate us on all the methods, John [the child] would not be where he is now. (-P12)*

Although some of the resources proved beneficial, not all parents considered the information helpful. In retrospect, some of the parents expressed their regret over listening to the advice of others. Parent #10 expressed: *But now looking back, I can see that there was a lot of things let go there [the local county school system] that should not have been. Knowing what I know now, things were not done right. (-P10)* Parent #8 shared her family's experiences with the cochlear implant:

> *So we decided to go to Alabama and have the testing done to see if he was even a candidate. We did that, they wanted it. Then they [sic] whole community got together to raise money because this was very expensive and it was not covered by insurance at that time. . . . We did that and that was horrible. It was a horrible, horrible, decision, and I just hate to look back at that. (-P8 Pretest)*

Themselves. Frequently the parents, themselves, sought out advice from others when learning about deafness, modes of communication, and school placement options. The majority of the

parents first detected a hearing problem and quickly obtained medical advice. The following statements, made by parents when they first suspected a hearing loss, are followed with recommendations given by medical professionals:

We noticed when he was about 8 months that he did not hear so we took him back and forth to the pediatrician. We did go to an audiologist within a month or two. . . . He [the audiologist] tested his hearing and said he could hear, that he was not language delayed. It was because we were bad parents. We didn't make him talk. (-P1 Pretest)

When Allen was nine months old, we first suspected. I called his regular pediatrician and they sent us to an ENT (ear, nose, & throat physician). They started doing the brainstem testing and all of that. We knew there was a problem from their testing. (-P10)

At 14 months old, I had told the doctor I thought something was there . . . ; He said "No, he is a boy. Boys are slower and he is your third child." (-P9 Pretest)

She was a year old and I took her to the health unit for a physical and they did a hearing test. She was sitting on my lap and they dropped a book . . . took a pot and were banging it. She did not respond at all . . .; so the nurse said, "You see the same thing I

see, don't you?" The lady said, "Do you have an ENT?" She said, "We are making an appointment right now." (-P16)

After their children's hearing loss was diagnosed, a few of the parents began to research deafness and related issues, such as communication and school options, on their own. One parent went to the local board of education and petitioned for a teacher of the hearing impaired:

"We started her at South Haven Elementary. I went to the board trying to get a teacher for her" (-P4 Pretest). Yet another, began contacting social organizations which had a reputation for helping children with disabilities: *"I got on the phone and looked through the phone book and called Shriners. . . . I knew The Scottish Rites Hospital helped handicapped people. I thought surely someone can tell me something" (-P21).*

Family and Friends. In many cases' friends and family members became instrumental in furnishing the parents with references to professionals and other service providers working with children who have disabilities:

[Mother speaking] There was nobody there, and we had to go to Lexington; we had to start finding places to call. Where do you start? The only thing we knew about was, somebody in your family knew about. . . . [Father speaking] John got us in touch with Children's Hospital. (-P8 Pretest)

I had a friend I was working for at the time and she knew Doris and she contracted her for me. She contacted me and then we went through the state and got everything set up and she started coming in for in-home visits. (-P14)

Medical Professionals. Due to the emphasis on early language intervention for young children who are deaf, parents had to quickly choose a method of communication for their children. At the same time, they had to gather information about the types of school programs available to children who are deaf. Some parents looked to the medical profession for assistance and guidance when making these decisions. In most of these instances, the parents did not have all possible options presented to them.

As in the case of Parent #4, the only choices given centered around manual communication methods. A discussion of the possibility of implementing an oral approach never occurred: *"They [speech therapists at the County Mental Health Clinic] came out and told me we had two selections and which one do you prefer? We made our choice between cued speech and sign language." (P4-Pretest)*

In many situations, individuals in the medical field maintained a bias towards one particular communication or school program option. Once again Parent #4 related how she felt pressured into choosing a particular educational program instead of being " informed" of all possible placements: "*Dr. Smith was pushing us for that direction [talking about the state school*

for the deaf]. He was telling us we needed to think of Susy [their child] and we didn't need to think about us." (-P4 Pretest) Other parents experienced the same type of "slanted" viewpoint by medical professionals:

> *We went to an audiologist to do the ABR and then the ENT was called once they showed a mild [progressive] loss. That is what he told us. This child needs to go to a deaf school and learn sign language. (-P12)*
>
> *They referred me to an audiologist and she was 14 months old when we got the hearing aids. I asked her, "What do I do?" She said, "Take her home and teach her, just talk to her. Put the aids on her and talk to her." After a while I got frustrated because we could not communicate. (-P21)*

Some individuals within the medical profession acted immediately on the parent's suspicions of a hearing loss while others tended to ignore their concerns. Throughout the study numerous incidences transpired when professionals behaved carelessly and assumed a condescending attitude toward the parents. For this reason, many of the parents adopted the attitude "professionals don't know best":

> *When trying to get him diagnosed, I think sometimes we backed off because we assumed the fact that they had bigger degrees . . .; they knew more and actually they did not. (-P1 Pretest)*
>
> *I don't have a paper in front of me of research but my gut feeling says to me that my child was not understanding you. So I*

think I have the right to go on that and the professional wants to be the professional. Maybe he can do the research. (-P8 Pretest)

She turned two in September . . .; we went down there and they gave her a liquid medication that did not put her to sleep and she went wild and crazy so we had to reschedule. I went back and I walked in and said, "You better do it right or I'm not coming back" and they gave her, instead of listening to me, half and it didn't do nothing but wire her up . . .; they tried to put electrodes on her but she ripped them off. I went home with hives because it was such a horrible experience [doctor attempting an Auditory Brain Stem test]. (-P11)

Educational Professionals and Service Providers. When families turned to the education profession for advice, some received a wide range of options to explore:). *"We visited the three schools that they gave us. We visited all three of them." (-P18 Pretest--reference to an oral county program, total communication day program, and an oral day school).* Parent #10 expressed admiration for the school administrator who gave her guidance and counsel: *"It is not like she was saying, 'You have to come here.' She gave us the options. She showed us different ways of learning." (-P10)*

Other parents, however, were presented with limited choices: *"We were not given many choices [referring to programs for the children who are*

deaf] . . .; this is what we've got . . .. Looking back, I would liked to have had a choice." (-P1 Pretest) Parent #9 felt that local county politics influenced the manner in which educational professions presented program options: *"The governor of the state said they would give them money to start a program in each of your counties and that is when all the deaf were pulled out of the deaf schools. The county needed numbers and my child became a number." (-P9 Pretest)*

Regardless of the resources families utilized, parents frequently mentioned feelings of confusion and uncertainty when making important educational decisions for their children. Parent #6 described her anxiety as she thought about sending her child to school at an early age: *"It seemed to happen so fast. They were talking about the Smith County Day School. I wasn't too sure . . .; he was just 2½. He had just been potty trained. You can't just have my baby." (-P6 Pretest)* Parent #8 shared her family's reasoning for initially choosing an oral program for the deaf: *"I mean we are dealing with a child who is very young and we don't know exactly the extent of the hearing loss so we chose to go with an oral program." (-P8 Pretest)*

Because of the confusion they experienced, Parent #24 and Parent #11 had a difficult time recalling the early intervention services which their child had received:

> *Well, I guess I talked with the audiologist in Karington that did the hearing, the hearing test, gosh, I can't remember. Somehow I got*

referred to the SkyHigh Program and I really don't remember who that was through. (-P24)

We had so many different dealings with so many different people and to be honest with you I was in a fog. I don't know if I can tell you exactly what happened because I pretty much woke up every morning and took a deep breath and waited for the evening to come. (-P11)

Elementary Years

The Mulitdisciplinary Team

When the time came for the children to enter a formal training program, members of the Mulitdisciplinary teams met to discuss the individual needs of the children and to determine the appropriate school placement. After the initial placement, the teams held annual meetings to review the children's performances and evaluate the effectiveness of the current placements. Parents often referred to these meetings as the "Big M-Team." Parent #5 recalled the first Multidisciplinary meeting: *"So we had the big M-Team meeting [italics added] . . . they all agreed so ever since then they contracted services." (-P5)*

Some parents described the M-Team as being calm and very productive while others indicated their frustration and distrust of the process. The following statements present a stark contrast between parents who had

positive experiences working with the M-Teams and those who had negative encounters:

We have never had a bad M-Team. I mean, I have talked to other parents who have nightmares. It is like they get broad sided . . . I mean they are told your child is not appropriate at this and it's like they get kinda hit [italics added]. (-P5 Pretest)

There have been times when we get in positions where the board didn't want to come up with a teacher and I'd "take the beating" and always use the threat of an attorney if I have to. My child would get an education and she would get it in her school system. (-P4 Pretest)

They were wonderful. Any questions that we had they explained everything. They showed us what the IEP meant and what they were going to try to do from this date to the following date of the next year. (-P13)

It was horrible. They were very rude, defensive. They wanted him here. They wanted to put him in, like I said, in a classroom with mentally handicapped kids. There is nothing wrong with his mind, he can't hear, but there is nothing wrong with his mind [italics added]. There is nothing that he can't do. (-P 14)

Most of the families, by the elementary years, possessed a better understanding of the medical aspects of deafness, had chosen a

communication option for their child, and gained an understanding of the various educational placement options for the deaf (i.e., residential, day school, county program, or home zone school). After the children entered elementary school, parents turned their attention to the development of the IEP.

During the elementary years, the context of "constant change" moved past early intervention issues to programmatic related matters. Although change continued, the parents began to express concerns over the "unpredictable" nature of their changing circumstances. Many of the parents felt their children's educational program was subject to change from year to year. Parent #11 discussed her frustration with the unpredictable nature of their child's education:

> *But you can never sit down and relax because you know the next year is coming. And even though you start out the year and you kinda take a couple of breaths, we still know that next year is coming. (-P11)*

Parent #14, whose son currently attends 6th grade, talked about her concerns for the upcoming school year:

> *And then, I made an inquiry about the 7th and 8th grade . . . I am going to run into the same things over there and Beth [coordinator for the hearing impaired] told me that the parents are going to have to make the teacher get up and do her job . . .. "That is my job to make that*

teacher do hers? I don't pay her." I mean all the time, it is going to be an uphill battle. (-P14)

Socio-Political Issues

Due to the low incidence of deafness, many school systems struggle to find qualified administrators, teachers, and support service providers. Limited funding, budgetary restrictions, and low pay scales often result in understaffed school programs serving students who are deaf. Two families expressed their resentments over high-ranking, county administrators whom they felt lacked the qualifications of an effective leader:

[Mother speaking] I don't think he has compassion for the children. It takes somebody who has the knowledge, knows what they are doing, and knows the law and all that. But above all, I think it has to be somebody who has the heart and I don't believe he does. I would start with him and I'd kick his butt out. I would tell him, "You know, either you start thinking about the kids first or take a hike." [Father speaking] It's called politics [italics added]. (-P11)

They are very aware of their restraints money wise, personnel wise, facility wise. I find they are not generally thinking of my child in the meetings. I don't understand why people in the IEP work for the school system, but I have always

been able to get what I felt like he needed or close enough (child is attending oral, public school program). (-P12)

One parent described the difficulty rural counties face when searching for qualified teachers for students who are deaf: *"They are still looking for a teacher of the hearing impaired. See, he really needs it, but of course it is such a rural community. It is hard to get anybody." (-P10)*

Another problem, which can negatively impact school systems, is the lack of standards for assessing the competencies of support service providers. Parent #9 discussed how the absence of standards opened the door to hiring unqualified staff such as sign language interpreters:

They did not have qualified interpreters and I do not understand how it is state per state. No one tests the interpreters. There were some deaf children who went in who knew more sign language than the interpreters. (-P9 Pretest)

Parent #11 also shared his frustration with the school systems lack of standards for sign language interpreters:

The school and the school board does what it has to do to get by. . . . I will go up there and say, "I want to be an interpreter. I can sign a little bit." If they have an opening they will throw me in there. (-P11)

All schools, whether residential or public were subject to these socio-political concerns. Nevertheless, parents whose children attended public

schools had the most concerns about high teacher turn over and inadequate support service providers. The high teacher turnover rate witnessed by families could be linked to smaller public school programs in remote areas of the country. Furthermore, because residential schools do not necessarily require the service of sign language interpreters, inadequate support services may not be a problem. Parents whose children attended residential school did, however, note concerns over limited staffing in the student dormitories or cottages:

> *What I dislike most . . . I guess a lot of times the kids are not always thought of first. Maybe something political comes into it and they kinda forget that they should be doing what is best for the children not necessarily what is best for whoever . . . the top dog [child attends residential school for the deaf]. (-P24)*
>
> *It's like they don't have enough money to staff as many people as they should for the amount of kids that they have (referring to dorms at the residential school for the deaf). (-P3)*

Academic Setting

Parents also mentioned concerns related to their child's academic performance and instruction during the elementary school years. Families concentrated on the educational goals of their children and often linked program satisfaction with teacher effectiveness. In other words, if the

parents considered the teacher competent, they were generally accepting of the school system administration and at times compromised on some issues of disagreement. On the other hand, parents unhappy with their children's teacher expressed frequent criticism of the school system. In turn, parents often displayed inflexibility when resolving differences with the school.

Parent #1 described her satisfaction with the teacher's capability to administer various tests designed to measure a student's educational performance. Although she disagreed on the effectiveness of some tests, the parent never made a formal complaint. Instead she chose to focus on the teacher's strengths and minimize the weaknesses:

> *The last two teachers he had in Jefferson County were really good, very good teachers. So they used the Stanford Achievement Test for the state hearing impaired. They used the KTA, which I don't particularly care for, but it helps a little bit. They have got a signing test that they gave him . . .. They go over all the testing where he is at and what he is doing. (-P1 Pretest)*

Parent #8 could have filed a complaint since the school system failed to provide sign language interpreters for parents interested in the regular education mainstream program. Instead, the mother commended the teacher's efforts and stressed the positive aspects of her child's placement:

> *She [the teacher] was so excited, she understood that she was getting a child with no speech and also she realized that he had no signs, but*

was willing to try it . . .; the good thing was that Jimmy had pretty much one on one instruction for kindergarten, first, second, and third grade because he was with her. He could not go out into the classroom because there was no interpreter. (-P8 Pretest)

Parents who experienced negative encounters with teachers became critical of the system and expressed frustration over the *"We visited the three schools that they gave us. We visited all three of them." (-P8 Pretest--reference to an oral county program, total communication day program, and an oral day school incompetency of the staff.)* Parent #6 considered transferring her son to a previous school placement because of her displeasure with the classroom teacher:

That first year was a disaster. It was nothing. I mean he was so bored he would sit there and unravel his socks. She [the teacher] was trying to say he was Attention Deficit Disorder. I was like, I think we just need to get him back to the Smith County Day School. (-P6 Pretest)

Parent #11 voiced disregard for her child's teachers because of the low expectations set in the classroom. She did not feel this type of teacher was an anomaly:

I can guarantee you that teacher will never ever, ever, teach my child again as long as I am on this earth. She is wrong; she does not need to be in there because <u>she is one of the ones</u> [italics added] with the

attitude: "They just can't do it, put them over there in the corner. . . . They can't learn nothing, you know, let's just babysit them all day." (-P11)

The Transition from Elementary to Middle School

Similarities and Differences

Limited research exists focusing on the transition from elementary school to middle school, for students who are deaf. In order to learn more about this time period, I asked families to respond to the following topics: similarities and differences between elementary and middle school programs, aspects of their children's current program which most satisfied/dissatisfied them, and concerns about their children's present educational plan (academic, social, and emotional). Parents felt that the greatest differences between elementary school and middle school centered around: 1) Facilities, 2) Scheduling, and 3) Student responsibility.

Facilities. Typically, students attending some type of public school program commonly transferred to different school locations as they progressed from elementary to middle school. The majority of public school systems serving children who are deaf established programs at designated elementary, middle and high school locations. The students were transported to and from school on a daily basis.

Parents in this study, whose children attended one of these public school programs, had to prepare their children for the move to a new facility when entering middle school. Some parents expressed concerns over the middle school's location as well as the student body size. Parent #14 explained:

"It is really in a bad neighborhood [long pause]. I am really scared" (P14). Parent #11 expressed her concerns: "*Now all of the sudden she is moving to a school where the children are the size of adults and what was a little alarming, um its well fenced, I was please about that." (P11)*

Parents whose children attended residential schools shared similar apprehension as their children transitioned into the middle school facility:

> *It was a different cottage entirely, a different school, and it was just a new thing for Danny to have to adjust to. I think now that the year is ending that he pretty much adjusted to that and he knows that is what he is going to have to go back to in the fall when school starts back again. (-P3)*

In a few situations, parents expressed great exasperation when the county system failed to establish a self-contained program for middle school age students who are deaf:

> *We don't have that facility. We just have one self-contained classroom that the kids go to. . . . He is either with the older kids or*

younger kids, not those his age. So he picks up things not appropriate for his age level. (-P25)

Scheduling. Parents also reported differences in their children's class schedules when contrasting elementary and middle school. For the most part, elementary students in both residential and public schools remained with one special education teacher and/or regular education teacher throughout the entire school day. When entering middle school, however, the students were required to switch classes and/or teachers based on the subject matter taught:

The sixth grade they didn't work at all. There was too much confusion. I think, I think that did not help and then here he was moving around changing classes, changing teachers that first year. But I am glad they went back to a single teacher class. (-P8 Pretest)

From 5th to 6th there is a new way of doing things. He has experienced the change of class but this is new. He has to grow up and learn that he must be where he needs to be at this time and that. (-P10)

She [the teacher] knows about Danny's problems and knows what he needs to work in and during the fifth grade he changed classes some. Like to other teachers like say for science or math or something . . . but we talked with the principle and the lady from the

M-Team. . . . It might be better for Danny if he don't have to just change classes a lot. (-P3)

Student Responsibility. Finally, parents felt elementary school teachers typically "babied" the students, whereas in middle school, the teachers expected the children to take more personal responsibility for individual work assignments. One parent talked about her child's transition into the sixth grade: *"In elementary school you are cuddled and cradled until you are reminded about your assignments and stuff, where in middle school your are responsible for yourself." (-P6 Pretest)* Parent #16 remarked:

I think it may be a bit stricter. Elementary they are small and cute and they are young and they are still like babies and they are growing up. I think they are going to have more responsibility, that will hit Stacy hard. (-P16)

Interestingly, the three areas of change which the parents described (facilities, scheduling, and personal responsibility) centered around issues any normal hearing child might face. Parent #5 spoke of the similar experiences of both her son (hearing) and daughter (deaf) as they transitioned into middle school:

I think the biggest thing in middle school--I don't think it has anything to do with the hearing-impaired program and I went through it with my son who will be a junior in High School–it is the loss of [parental] control in middle school that is different. They are trying to put more

responsibility on the children and when they are not as responsible as they should be at times it is like the parent is the one who feels that. (-P5 Pretest)

Areas of Satisfaction

When asked to describe the aspects of their child's middle school program they were most pleased, the majority of parents indicated: 1) Teachers, and 2) Opportunities for Participation in Organized Sports.

Teachers. Parents were most pleased with their children's middle school teachers. They viewed the educator as hard working, caring, and knowledgeable in the field of deafness. Although the overall response of parents appeared very positive towards the middle school teachers, some expressed dissatisfaction. In a few instances, parents reported misgivings about the teacher's skill and qualifications.

Parent #8 quickly expressed respect for her child's current teachers: *"I have felt like I have walked in with a group of people who knew my son, who actually knew what he was doing." (-P8 Pretest)* A similar response came from Parent #3: *"I am satisfied with the way his teacher, Ms. Jones, has really been wonderful. She seems to really be interested in Danny; you know, making him do everything and making him do it right." (-P3)*

Parent #16 said, *"I like the teachers; they like to teach those children. They have to be firm; they have to, you know; you can't be too lenient.*

Limits you know." (-P16) Finally, Parent #24 commended the teachers for their genuine concern for the students: *"You asked me about the school . . . I guess the teachers. I think they really care about the kids; I mean I can see that. (-P24)*

A number of the parents, whose children participated in a mainstream setting, spoke highly of the regular education teachers as well. The teachers "were willing to go the extra mile" to make their child feel welcome and comfortable in the regular education classroom: *"Frank [the child] is very fortunate to have good regular education teachers who have been at Frank's side and willing to go the extra mile." (-P13)* Parent #4 expressed her appreciation about the regular education teacher: *"I am most pleased with her teachers. They go an extra effort to make her secure in the classroom, to make her take part in the classroom." (-P4 Pretest)*

Parent #11 shared similar thoughts: "*I have to say Ms. LeBlanc was the best teacher, regular education teacher. . . . She was kind, she was very cooperative and didn't treat them any different than anybody else." (-P11)* Another parent acknowledged gratitude over the regular education teacher's support for her son:

> *The staff [in regular education] is great. They are very supportive. If he needs anything special, he gets it. They are very supportive if you need anything they try to go out of their way to help. (-P12)*

Organized Sports. Parents also noted satisfaction with the organized sports programs offered in middle school. They felt these activities helped their children develop a positive self-image and encouraged socialization with both deaf and hearing peers. Parent #9 discussed the increase in her son's maturity level once he began participating in organized sports: *"He interacts. He is on the deaf basketball team, self esteem. I have seen him grow unbelievably. He is like a different person." (-P9 Pretest)*

Several other parents indicated satisfaction with their children's involvement in organized sports:

> *The Calcasieu Middle School have invited Greg and one of the other students here to be on their long distance cross country track team . . .. Greg has been the manager on the football team and he plays basketball. His is in boy scouts. He is involved in lots of things. (-P6 Pretest)*
>
> *She has so many good qualities. She is very outgoing. She is involved in many activities. . . . Well, there is basketball. She took an interest in it in 6th grade. She always has like [sic] swimming. Cheerleading . . . this year she want to play volleyball, cheerlead, and play basketball [parent laughs]. She is very athletic . . .. She has been on the track team for a couple of years. (-P24)*
>
> *He is going to be the manager of the football team and the basketball team. He had gone to the coach cause that is where all*

his friends are and that is what he wants to do . . . what his friends do. (-P12)

Areas of Dissatisfaction

Parents indicated two areas of dissatisfaction when discussing their children's middle school program: 1) Low academic expectation and 2) Behavior problems.

Low Academic Expectation. While most parents appreciated the dedication and care of the classroom teachers, many families expressed discontentment with the academic level of expectation for their children. The majority of parents felt the teachers had not pushed the children to reach their maximum potential. In fact, some parents believed the teachers frequently "lowered the standard for the deaf." Repeatedly, parents mentioned their disappointment in the low reading expectations for children who are deaf:

I guess the thing that dissatisfies me seems to be such a accepted rule that deaf people only have a reading level of 6th grade. That bothers me. I have a problem with that. If you tell children that you can only do this and this is as far as you can go. Or if you tell anyone that . . . then that is all they will shoot for. (-P6 Pretest)

I want to be concerned over reading but they assured me over the years that is how it is with most deaf kids . . .; They say, "Ma'am

you don't understand," but starting this year it sunk in that most deaf kids don't read well. It's like you have to be a genius. It is something that is in the genes or something. (-P23)

Parent #25 and Parent #23 felt their children were not being "encouraged" to reach their fullest academic potential: "*I am not satisfied because I think he can do more than that if he is pushed because he is a child who needs to be pushed." (-P25)*

I know it is a good school but it is just my feelings, not no one elses, it is not hard enough [italics added]. I'm not blaming them no. . . . One told me that they just going to put them in there and pass them on through. What are you going to do in 6th and 7th? He is in 1st or 2nd really, so why should you keep moving them like that? (-P23)

Another parent expressed concerns over the academic standards expected for her daughter who is deaf in comparison with those required for hearing children in the same peer group:

I think academically she in not challenged. I am concerned that she may not. . . the curriculum at the deaf school may not parallel with public so she may not be getting what her hearing peers are getting. (-P21)

Behavior Problems. An increase in behavior problems was also cited as a major area of dissatisfaction among families. Parents whose children attended both public schools and state schools for the deaf, expressed

worries and concerns about the verbal, physical and sexual misconduct of students in middle school: *"There are some behavior problems in the hearing-impaired classroom. At times pretty severe, not real severe, but at times." (-P1 Pretest)* Parent #4 added:

> *Probably the only thing I don't like about the school is that sometimes the students can be really rude. Um, you know you have to discipline them when they are like that, separate them, from the other kids. (-P4 Pretest)*

Although the majority of parents shared the same concerns about middle school, parents whose children lived in the dormitories at residential schools tended to be more outspoken about issues of misconduct while their children remained separated from them:

> *These kids come from all over. You have to imagine your child home on the weekend but some kids are out in this world doing just what they want and they have people do things to them. It is like you can hope and trust in God but you can't be there twenty-four, seven. (-P23)*
>
> *I know that no school is perfect and this school is no exception. One little girl that rode the van got expelled. Come to find out a boy crawled in through her window and they were in bed together. I said, "Oh yea?" (-P16)*

PART II: STYLES OF PARENTING

When parents faced making important communication and educational placement choices for their children, three styles of decisions making emerged from the data: 1) Trusting Self, 2) Trusting Others/Trusting Self, and 3) Trusting Others. The first two styles surfaced during the pretest phase of the study while the third style materialized from the remaining 12 interviews. A breakdown of the number of parents included in each group is as follows:

1) Group #1- a total of six parents

2) Group #2- a total of six parents

3) Group #3- a total of five parents

Although I compared demographic data, such as age of identification, communication method, and school placement, among the children represented under each parent group, I found no distinct differences. Under each of the three styles of parenting, two broad categories emerged from the data which demonstrated the differences in parenting styles. The first category (The Time Factor) discussed the relationship between the parent's sense of time and their actions when making educational decisions. Some parents sensed tremendous pressure to "act quickly" while others, although aware of the importance of time, did not feel "compelled" to make decisions promptly.

The second category (The Control Factor) involved the degree to which parents' considered themselves in control of the educational decision making process. Parents' who felt "in control" of a situation generally exhibited more confidence and goal oriented behaviors. On the other hand, parents who felt a lack of control over their circumstances, exhibited a more passive, impressionable parent role.

Group #1- Trusting Self

Parents exhibiting this style of decision became very assertive and action oriented soon after their children became diagnosed with a severe to profound hearing loss. Although these families sought advice from numerous resources, they assumed "control" over their circumstances. The parents "screened" the available communication and placement options and decided on the best choice for their children and families. This action did not mean that the families never made mistakes along the way; but, when making errors, they were quick to take responsibility for their actions. The parents who started out "Trusting Self" have continued to operate within this style of parenting through their child's transition into middle school.

The Time Factor

Four of the families included in "Trusting Self" category, were driven by the belief that early intervention was a top priority. These parents

believed the sooner their children began to communicate and develop language, the better off they would be in the long run. Parent #21 described: *"I knew that language develops in the first 3 years . . . that is why I wanted the total communication. I knew she was losing out and we did not have a lot of time." (- P21)*

Parents #12 added: *"We knew he had a hearing loss [progressive loss] and we wanted to get as much education as he could while he could hear." (-P12)* Although Parent #10 did not specifically acknowledge the importance of early intervention, her actions seemed to evidence an awareness of making the initial placement and communication decisions quickly:

> *Dr. Franklin was the one who diagnosed Michael as being profoundly deaf. He was nine months old at the time . . . when Michael was 10 months we started going maybe 2 or 3 times a week for an hour session. . . . We would come home and work with him and then we would go back in a day or two then we would do it all over again. But this is how we started. (-P10)*

Parent #5 was the only parent who did not mention this push for time. This particular parent would be labeled in qualitative circles as the "discrepant" case. She remained assertive and action oriented from the beginning; yet when compared with the other 5 families, her story always seemed to "stand out" from the rest.

After reading and rereading the interviews within the "Trusting Self" category, I noted one significant difference between Parent's #5 and the other families. Their child, at birth, had other medical complications and remained in critical condition for an extended period of time. The parents had to deal with a "life and death" situation, not merely deafness. In fact, deafness seemed to take a "back seat" until the child's other medical problems stabilized. Early intervention did not begin until the child's health had improved. Even then, the parents remained cautious when selecting an educational program that matched their child's developmental abilities. The proceeding statement helped to clarify the reasons why traditional early intervention strategies were not initiated sooner:

> *I know she was eligible for services at the age of three but when Lisa was three years old she wasn't even walking. . . . She was just learning to walk because she had so many physical problems when she was born . . .. I did go to Allen County and checked out their communication class and I saw kids that were running and jumping and normal type children who were just deaf and I though there's no way. Lisa does not belong in this program. I did not want to put her in a program where I felt like she was going to be the lowest or the slowest. (-P5 Pretest)*

The Control Factor

Early Experiences with Resources. Interestingly, four of the families included under "Trusting Self" experienced some type of disagreement with resources persons at the time of diagnosis. These encounters seemed to fuel their action oriented approach when choosing placement and communication options for their child. Consequently, these parents adopted, early on, an attitude of "We're in charge" of our children's future:

> *So I asked questions about the total communication class. I was thinking it was oral and sign. They said she is really young. She is just 2 lets give it another year lets wait till she is three. I said, "No," and that was the last visit we had. I left and was so frustrated I felt I was wasting my time, my money. I had a family. We were so concentrated on her so much, but we needed to be a family and that wasn't happening. (-P21)*

> *Well we went to Lincoln County first to see what they had, and I sit in and observed a classroom where [sic] they had. They wanted to put him in a classroom with the mentally retarded kids, and I told them "No." (-P14)*

> *The first doctor we saw, that told us he was hearing impaired, wanted us to go to the state school for the deaf. . . . He said, "Oh, that would be the best place for him." We told him "There is no*

way." We have one of the best hearing impaired systems in the United States right in our back door. So that is why we did not even check into anywhere else. (-P13)

Role in the M-Team. Each of the parents involved in the study expressed an understanding about the purpose of the Multidisciplinary Team and talked knowledgeably about the process. Four of the parents included in Group #1, however, maintained a more assertive and/or aggressive role in the planning of their child's IEP:

I, as a parent, am very strong to say, "This is what I want to see happen." I want to listen to everybody's view. I am not like, "I, OK, I know what is right, and I am going this way," but I also think that I know my child a little better than they do. Yes, they may be the professionals but, "No, they don't live with her." I know what she truly can do. (-P21)

We pretty much keep on top . . .. I know what he is doing, what his homework is, where he is at. So we know where he is at, and they tell us what they think he should have, and we tell what we think he should have. We don't always agree [parent laughs]. (-P10)

They always want to go on what John's goals and objectives will be for next year. Every IEP. It is so funny. And every IEP you would think that they would know by now the [sic] I am not going to want to talk about that first. I am like "Wait a minute, I want to look

over last year's IEP. Let's document that everyone is in agreement about what objectives have been met and see where we need to go from there." (-P12)

I am going to the state and I am going to talk to a lawyer because they are not meeting his needs. They are not meeting his IEP. She [next year's teacher] can't even facilitate; she can't communicate what he has to have. She can't do it. (-P14)

I suspect the other two families (Parent #5 and Parent #13) would have adopted the same role if they found themselves in similar situations. The children who are deaf in both of these families have moved through each respective school system from preschool to middle school. The parents did not mention any major problems, obstacles, or dissatisfactions with the county administration or school personnel. Overall, they were pleased and contented with their child's education and the decisions of the Multi-disciplinary Team.

Group #2- Trusting Others/Trusting of Self

The parents included in this style of parenting initially relied on the advice of other individuals (i.e., medical professionals, friends/family, and educational professionals) when making educational decisions for their children. These parents appeared to lack confidence in themselves; hence,

they generally followed the lead of others when making communication and school placement decisions.

The particular parent group shares one distinguishing feature, at some point, they experienced a "shift" in their parenting style. For some parents this shift came unexpectedly, while for others it came after a period of crisis. Parents moved from a more passive role to a more active role and began to trust themselves when making educational decisions. All of the parents who "made the switch" have continued to maintain a strong, assertive role in their child's education. Parent #8 made the "shift" soon after the diagnoses of her son:

> *So one morning in July, I woke up and went "What am I doing?" . . . I have been letting these people tell me what to do with my child. I have been letting these people do with my kid whatever they want to do and have been going along with it. But, I don't know what we are doing; I don't know why. (-P8 Pretest)*

Parent #1 and Parent #4 made the change when they decided against sending their children to the state school for the deaf:

> *They wanted me to take her to the state school, which is in Alexandria. . . . Dr. Smith was pushing us for that direction. . . . I had just had her little brother, and I said I was not sending her away; you know . . . me and her father had her and we wanted her and we loved her and we wanted her to have a home and feel like she is*

wanted. . . . We done brought this new baby in and she saw him and she's gonna think Momma and Daddy just sent me away. You know, I did something bad, they don't love me anymore. And I said no, not at two-and a half, she is not going to a deaf school. (-P4 Pretest)

So they suggested the school for the deaf which I was really against . . .. I did not feel that academically he would be challenged there, and he did no want to go down there. He did not want to leave, neither did we. So actually the M-Team we had at the end of 5th grade was very heated [italics added] cause they were pushing. (-P1 Pretest)

Parent #6 described her struggle when deciding to send her son to the state school for the deaf:

The interpreters there [local county program] were not good. All the children complained about the interpreters and we looked at the program here. . . . Actually, it was probably the hardest decisions I ever had to make to send my twelve-year old to live somewhere else through the week and come home on the weekend. (-P6 Pretest)

When Parent #11 faced opposition from the regular education teachers, she decided to challenge the system and fight against educators who were not accepting of the deaf:

I have not had any problems with teachers since. But it was a devastating effect on the kids. . . . Susan [another parent] and I decided then and there . . . that we would never, ever allow that to happen again. If the teacher did not want them, that they were not putting our children in that class. (-P11)

As a direct result of one parent's shift to "Trusting Self," a support group for families with children who are deaf was formed:

That is when I realized that parents were not educated. We don't know our rights. We don't know what else is out there, so we started a support group. I became very outspoken. (-P9 Pretest)

The Time Factor

Originally, time was not a driving force in the decision making process for these families. Basically, they followed the advice of other professionals. After making the shift from "Trusting Others" to "Trusting Self," some parents mentioned the importance of time, in hindsight. Parent #9 recounted how she came to understand the importance of time after watching a friend's child regress academically: "*The child lost almost a full year of learning. For any deaf child you can not lose. . . . I mean time is very important." (-P9 Pretest)* Parent #9 also described her reactions when learning her son was considered illiterate:

> *At 5th grade that was when I was told that Sam was illiterate. He was going to be going to a 6th grade program with a 1st or 2nd grade reader. . . . it was at that time I called the other parents and we pulled all our children out together. (-P9 Pretest)*

One parent told of her frustration when realizing her son was "losing" the limited reading skills he had acquired while in school:

> *They refused to give any kind of support for the language and he was going down hill. . . . He had learned to read on a second grade level but he had learned to read. He was losing that fast, something had to be done. We did not have a lot of time here. (-P8 Pretest)*

The Control Factor

Parents in Group #2 did not initially assert a lot of force with making decisions about their child who is deaf. Prior to their "shift" in parenting styles, the families relied heavily on the advice of professionals. This dependence on professionals was especially evident during the early intervention years.

Early Contact With Resources. Researcher: *So, tell me how you decided on a preschool program*? Parent: *I didn't. They [county special education administration] just told me what I had to do and I just did it. (-P11)* Parent #9 recounted how she felt helpless against the demands of the local country program:

They came to kindergarten and they sat at meeting with my IEP meeting. . . . The county people were sitting there and they wanted my child. They wanted that number . . .. I did not have a choice really. If I had not had that woman he would have become Scott County's. (-P9 Pretest)

Role on the M-Team. As the parents made the switch to "Trusting Self," they developed more self-assurance and demonstrated a more active voice on the Multidisciplinary Team:

I pretty much speak my mind . . .. I have Greg on the educational track right now. He gets bored with that vocational teaching about factories, assemble line work and he gets bored and gets in trouble . . . and so I told them I did not want him in that. I told them I want him on the educational track. (-P6 Pretest)

I think basically we know when we come in what we have in mind . . . I think that when we come to a meeting we already have goals and we know what we want for Sam. We see how well he has done through the year. (-P9 Pretest)

Parent #8 reflected on the M-Team Meeting when her family informed the county of their decision to transfer out of the program:

We decided that we would bite the bullet and go to court and get a lawyer if that is what had to be done because it was not only behavior

problems, wasn't just communication problems. He was not being educated. (-P8 Pretest)

Group #3- Trusting Others

Parents within this group chose a more passive role when making educational decisions for their child. Many of the families expressed admiration for professionals and valued their opinions. Because the majority of parents equated educational training with competency, they felt professionals were better equipped to make educational decisions for their children. Although the parents adopted an overall acquiescent role in their children's education, in certain situations they stepped out of their conventional role and asked tough questions.

One interesting characteristic of this group, not evidenced in prior groups, was a sense of lingering grief over their child's deafness. Unlike the parents in Group #1 and Group #2, some of the families continued to evidence signs of loss and discouragement when discussing deafness. Parent #24 relates her thoughts:

I realized [when child entered middle school] that Janey was not going to talk and that was like hitting another brick wall. Through the elementary years you still have the hope. You still are learning. . . . Well at about that time you realize, "Well, this is it. It's not going to change." They start growing up and becoming independent. (-P24)

Parent #25 described the struggle she experienced when her son began to use sign language. Although presently she is more accepting of this mode of communication, she continues to search for alternate methods:

> *To come here and go back to sign language it was upsetting. If sign language was the future that was not what we had in mind. . . . Although it was not my first choice but later I realized that this is the way he is comfortable, and this is the only way I can communicate with him. It was a good and bad feeling . . . I would like to explore cued speech . . .with the cued speech you can better refine the use of the implant. (-P25)*

The Time Factor

Parents in this group were not influenced by a strong sense of time during the stages of early identification and entrance into elementary school. As middle school approached, however, the families began to have concerns about the children's academic performance. Parent #25 speaks of her son's new school placement: *"He did much more than I expected in the first year here . . .; he just carried on with what he had learned the first year to the second year. He did learn a little bit more but not a whole lot." (P-25)*

Even though some of the parents mentioned these concerns to professionals, they chose not to "push the issue." Once the professionals made a recommendation, they generally conceded. Parent #16 and #23

revealed their apprehensions when the school suggested changing to a certificate track:

> *She [the teacher] said instead of going diploma we should think about certificate. So we thought about it . . .. They said this way there would not be so much push and pressure. They [sic] would be at her own pace and she could learn, so we decided to do that . . ..*
>
> *But I don't see how in the world could someone move up and she is still in 1st or 2nd grade reading level. And she is going into 6th grade? (-P16)*
>
> *I want to be concerned over reading, but they assured me over the years that is with most deaf kids. But me, I say, I have always been an excellent reader and my children have been straight A but than they say, "Ma'am you don't understand." But starting this year it sunk in that most deaf kids don't read well. (-P23)*

The Control Factor

Parents in this group chose to limit their control when making communication and placement decisions for their child. They treated the opinions of professionals very seriously and generally followed their lead. This does not mean the families never spoke out against problems. As mentioned early, they had genuine concerns with regard to their children's education. Nonetheless, many chose not to act on these concerns.

The reason parents chose not to "take action" when dealing with professionals varied among the families. Several of the parents lacked the self-confidence necessary to challenge and confront professionals. Parent #24, when asked to give advise to other families, stated: *"I still don't know everything that I should know . . .. I don't think a parent ever knows. So, you know, I hate to give advice." (-P24)* Others decided to suppress their frustrations in order to maintain "peace" with the school system. Parent #25 related her thoughts about living in a rural area:

> *If you don't have a choice of a teacher being in a small place. And that is the only choice you have, as long as you are in the school district you do not want to displease her. That is another reason you want to listen to her and be nice to her so that the next year it may be better than the last one. (-P25)*

Another parent expressed happiness when locating a school equipped to meet the individual needs of her son:

> *I guess what encourages me most is just knowing that there is a school that he can attend and get some education . . .. Like I told you earlier, there is no schools out in here that will work with them. They don't have the teachers and the stuff they need to communicate with the child. So to me, we are lucky to have the state school for the deaf. (-P3)*

Early Contacts With Resources. Families in Group #3 maintained an accommodating role in the decision making process spanning from early intervention to middle school. As they moved through the grief process, the families usually accepted the advice offered by professionals and trusted their guidance. Although accepting some of the advice proved difficult, the parents felt that following through with the recommendations of the professionals was in the best interest of the children. One parent described her dilemma when meeting the speech therapist for the first time:

> *It kind of bothered me. It was the first time I ever met this lady. . . . She said, "You know Nancy, I know you don't know me but . . . an hour a week for this child [age two] will not help her, will not be enough." . . . She said, "I have never done this before, but I would like to take her home during the week and you can have her on the weekends." . . . And I said, "Well ah, I don't know about this." . . . I came home; me and Sammy [the father] talked about it, and I said, "You don't just let your kid go." So anyway, we decided we are going to go . . .. We did that all summer until Stacy [the child] was two and one-half. (-P16)*

Parent #23 shared her struggle as different professionals gave conflicting advice:

> *Parent: The people from school would call and say "Oh, you are Joey's mother." I would meet them at the store and they would say,*

"Oh, it is a shame what they do to your boy. . . . They lock him up in a utility room cause he would blow his top and he was hard to manage. . . ." The same teacher, Ms Jones, the one he had when he was 2 ½ years, she came here crying . . .; she said, "Betty, you got to take Sammy away from there." I said, "I know." . . . I went to the school and set a meeting [with the principal]. "Oh no, don't take him out; why would you want to take him out? We are going to have a teacher just for them. . . ."

Researcher: So did they get a teacher?

Parent: So they got the teacher. That is, the teacher come one day a week. And then some days I found out . . . she would only come some days. . . . If I had known that, I would not have listened to her. (-P23)

Role of the M-Team

When discussing the M-Team meetings, most of the parents felt the freedom to contribute their opinions and concerns. Parent #3 stated: "*We just basically sit down and talk about his needs, what he has accomplished. How far behind he may be for his particular age. What he needs more work in and just all kinds of things like that." (-P3)* Nevertheless, when describing the actual meetings, the professionals appeared to dominate the discussion of the children's goals and objectives:

Back in Florida, I did not know what IEP means, so it was helpful to sit there and hear what the teacher has to say about the child, and what the child needs to do . . .; so now, I do have some knowledge, not a lot, but most of the time the teacher just wants to have coffee. It is not easy to tell them I want this and them agree to it. (-P25)

They just kinda go through the papers and kinda read them to me, you, you know. Ask if you have any questions, kinda explain what she will be taught. (-P24)

They are very nice and they tells me about their goals and what they are going to be working on the remainder of the school year. (-P23)

Summary

Several common themes emerged throughout the data analysis phase of the research project. The majority of families participating in the study experienced a period of grief and confusion when discovering their children's deafness. When faced with making important communication and educational placement decisions for their children, the families utilized the following resources: the parents (themselves), family and friends, the medical profession, and the educational profession.

As the children transitioned into elementary school, families tended to shift their focus to issues centered around "managing" their children's

current educational goals and placement. Parents expressed both positive and negative experiences with regards to their participation on the multidisciplinary team as well as socio-political issues which impacted the quality of education for their children. During the transition period into middle school, families felt that the greatest differences between elementary school and middle school centered around: 1) facilities, 2) scheduling, and 3) student responsibility. The majority of parents expressed satisfaction with the dedication of the middle school teachers and the opportunity for their children's participation in organized sports. Although most families viewed the teachers as caring and dedicated, many parents expressed a desire to raise academic standards for their children.

Three styles of parenting emerged from the data analysis: 1) Trusting Self, 2) Trusting Others/Trusting Self, and 3) Trusting Others. Parents included in the first style of parenting were assertive and action oriented soon after the diagnosis of their children's deafness. Parents included in the second style of parenting initially relied on the advice of other professionals then switched to a more assertive decision making role after they experienced a period of crisis. Parents in the third style of parenting maintained a more passive role when making educational decisions for their children and felt professionals were more knowledgeable and better equipped to make these types of decisions.

CHAPTER 5

SUMMARY

"The best thing you can give parents is information and hope."

(-P9 Pretest)

Introduction

What does it mean to "parent?" Some of the concepts commonly associated with parenting include: nurturing, rearing, caring for, and sustaining. These words carry a tremendous amount of responsibility for individuals known as "parents." The rearing of any child, no doubt, involves an enormous task. Nevertheless, when parents learn their child has a disability, the family often experiences depression, shock, and a sense of helplessness. Once the documentation of the child's deafness, many parents encounter a period of grief and anxiety due to unmet expectations and the fear of the unknown. These periods of anxiety may reoccur during critical periods such as the child's entrance into formal schooling and transitions into elementary, middle school, and postsecondary education or work.

Brantlinger's study (1991) provides a literature review of research addressing the effects on families who have children with disabilities.

Brantlinger (1991) states: *"The stressor event for families is learning about the disability and dealing with the implications of the disability through the years"* (p.251). Brantlinger continues by discussing potential problems which can affect the quality of support services offered to families with children who are disabled and guidelines for implementing effective home-school partnerships. Interestingly, several of Brantlinger's suggestions for improving support services to families reinforced the outcomes and conclusions drawn from my research study. For this reason, I chose to incorporate some of Brantlinger's ideas when discussing my findings and recommendations for future research.

Findings

Seventeen families with middle school age children who are deaf volunteered to participate in this study. The families, residing in remote areas of Georgia, Kentucky, Louisiana, and Tennessee, had chosen a wide range of communication and placement options for their children who are deaf. Through the process of collecting and analyzing the research data, three styles of parenting emerged. These unique styles of parenting serve as the theory basis for this research study and are as follows: 1) Trusting Self, 2) Trusting Others/Trusting Self, and 3) Trusting Others. Parents included in the first style of parenting adopted a more assertive parenting role soon after discovering their children's deafness. Parents within the second style

of parenting were more passive during the early stages of identifying their children's hearing loss. After a period of crisis these families shifted to a more action oriented role when making educational decisions for their children. Parents included in the third style of parenting viewed professionals as the experts and relied heavily on the advice of others when making important educational decisions for their children.

After making comparisons and noting relationships among the families within each style of parenting, several common themes emerged. The majority of families related experiences of grief and fear when discovering their children had a severe to profound hearing loss. As the parents began to cope with the implications of their children's disability, they were also faced with making decisions centering around communication and educational placement choices for their children. The resources which families employed when gathering information about deafness and related issues included: 1) the parents (themselves), 2) family and friends, 3) medical professionals, and 4) educational professionals. Parents related that a number of these resources proved valuable while others were ineffective.

Of the four resources listed above, the two primary support systems utilized by families when exploring educational options for their children focused on individuals in the medical and education professions. The common themes noted by the families across all three parenting styles and

my recommendation for individuals working within these professions follow. Recommendations specific to each parenting style will be discussed within the section addressing educational professionals.

Medical Professionals

When searching for information about their children's hearing loss, parents frequently turned to their family physicians or their children's pediatricians. In this particular study, a few of the physicians responded quickly to the parents' concerns and handled the crises with sensitivity and competency. The majority of physicians, however, did not act on the concerns of the families. Frequently, the physicians considered parents "over anxious or over protective." For this reason, many children remained undiagnosed, until a later date, or misdiagnosed. Often these families experienced feelings of confusion, uncertainty, and developed an attitude of "professionals don't know best." When physicians failed to address the concerns of parents, a delay in early intervention services occurred.

Recommendations. I feel medical professionals can take positive steps to encourage an awareness of the early signs of hearing loss among infants and young children. First, medical professionals can work towards the development of standard screening procedures for infants and young children. Typically, parents first suspect a hearing loss during the first three years of their children's lives. Informal methods of "testing" for a hearing

loss, such as stomping the feet or banging an object, are generally inconclusive. The children may feel the vibrations from such tests through the floor, or a sudden motion within the room may alert them. If the establishment of standard procedures for screening children at an early age existed, the diagnosis of a hearing loss could occur quickly. An early diagnosis would allow families to begin the process of coping with their feelings regarding deafness and allow them to explore early intervention strategies during their children's formative years of language development.

Until such screening standards become a reality, physicians can implement the following steps to assist in identifying children with a possible hearing loss:

1. They can acknowledge the concerns of the parent and take immediate steps to either verify or rule out the suspected hearing loss:

Researcher: Tell me about when you first discovered your child had a profound loss.

Parent: He was 2. It took a long time to get anyone to believe me that he could not hear. I tried from the time he was probably about 6 to 7 months old telling them I did not think he could hear me. But, nobody would believe me. (-P6 Pretest)

2. They can inquire if other family members, care givers, or friends noted concerns about the child's behavior: *"The babysitter noticed one day.*

Her husband was using a drill and all the kids just shirked, but he did not." (-P1 Pretest)

3. They can inquire into the past medical history of the child and parent/s. Has the mother been vaccinated for rubella? Has the child been treated for meningitis? Was the child born prematurely? Do the parents have a family history of deafness?:

Parent: We brought her to Nashville . . .. They said she was profound deaf.

Researcher: Do they know what caused her deafness? Was she ill?

Parent: No.

Researcher: No history of deafness in your family?

Parent: Oh yea, see my grandmother, my mother's mother was deaf and she had a brother and a sister that was deaf.

4. They can handle "informal tests" with caution and if in doubt order a more formal hearing test such as the auditory brain stem (ABR) or testing in a sound treated audiometric booth (depending on the age of child):

He [the doctor] did the general test just clapping behind her and that kind of thing. . . . She didn't respond. So he made an appointment to go to Kentucky. I think it was the University of Kentucky. . . . I had her tested there and actually she was asleep at the time. . . . So they tested her and said she could not hear up to so many decibels. (-P24)

Parent #8 described:

I was taking Jimmy in for a well baby check . . .. I told them what we were observing and they took out a little tuning fork and put thing right here [pointing to the side of the head]. And so he had great peripheral vision . . .. He responded and [the doctor] said, "Oh yeah, yeah, no problem." (-P8 Pretest)

5. They can inquire about the child's language development and make comparisons with the accepted norms for other children the same age.

John had quite a few other ear infections and minor problems so when [sic] were in to see the pediatrician every three weeks. The pediatrician got to know him quite well. She said his speech is not developing the way she thought it should . . .. So she ordered an audiogram. (-P12)

6. If they make a diagnosis, physicians can assist the families in finding appropriate early intervention sources who offer a wide range of educational and communication options for children who are deaf.

Researcher: So after you found out, "Yes, he definitely has a hearing loss," how did you learn more about what to do for children who are deaf?

Parent: That was the problem. The doctor that we went to did not tell us anything. . . . "He will never have hearing, there is nothing you can do about it." That is, that is all he told us. . . . He was not

helping us in anyway. Why is Frank hearing impaired? What can we do? We were not getting any answers. (-P13)

Some of the steps mentioned previously may seem like "common sense" approaches that medical professionals would automatically take. Unfortunately, a number of the physicians serving the parents in this study did not follow through with the concerns of the families. Although the children included in this study were diagnosed with a hearing loss approximately 10 to 12 years ago, the possibility of physicians overlooking a child's hearing loss still exists today.

Parents can also benefit from knowing the types of questions to ask if they suspect their child has a hearing problem. By possessing an understanding of issues surrounding a hearing loss, parents can become more knowledgeable and confident in their interactions with those in the medical field.

Educational Professionals

After the documentation of the children's hearing loss, the majority of families participating in the study, sought the advice of educational professionals when choosing a method of communication and school placement for their children. Some educational professionals provided valuable, objective guidance while others in the educational field biased the parents toward their philosophical viewpoint. I feel that educators can learn

from the experiences of the parents participating in my study and work to improve the quality of support services to families with children who are deaf by implementing the following practices: 1) They can present all possible communication and educational placement options to families, 2) They can raise the standard of academic achievement for children who are deaf, 3) They can expect students who are deaf to function similar to their hearing peers while at the same time respect the unique characteristics associated with deafness, and 4) They can acknowledge the differences in parenting styles and work to build better parent-teacher relationships.

Recommendations

Presenting All the Options. In order for educators to become effective, they must believe what they practice has value and significance. For example, if a teacher in an oral program for the deaf does not possess the educational background or belief that the oral approach has merit, the educator's ability to succeed becomes hampered. Even so, I believe that the possibility exists for an educator skilled in one educational method to possess an appreciation for and knowledge about alternative approaches to education.

As parent #8 commented:

> *I think in a way that is what you want. You want people to think that what they are doing is the right thing . . . because why would they be*

doing it if they didn't think that? But, I guess that is my wish. . . .

That everyone would be more open-minded. (-P8 Pretest)

Families have a right to explore various approaches to communication such as: oral methods (speech, speech reading, and the use of residual hearing) and manually coded systems (i.e., American Sign Language, Signed Exact English, and Cued Speech). Educators should accept the responsibility for presenting these communication options to parents so the families can make informed choices for their children. Brantlinger (1991) explains: *"There is a need to be truly open to parental preferences and to build symmetrical home-school relationships." (p 247)*

Raising the Educational Standard. Ponce de Leon (1520-1584), a Benedictine monk, holds the honor of being recognized as the first teacher of the deaf (Moores, 1996). Although his techniques for teaching remain a mystery, some accounts of Ponce De Leon's work exist. In the 1851, Peet (as cited in Moores, 1996) quotes Don Francisco Velasco, one of Ponce de Leon's students:

While I was a boy and ignorant, ut lapis [as a stone] I began to work by copying what my teacher had written; and I wrote all the words of the Castilian tongue in a book prepared to that purpose. Hereupon I began . . . to spell, and to utter some syllables and words with all my might . . .. Then I began to read history, and in ten years read the history of the whole world. Afterwards, I learned Latin. All this was

through the great grace of God, without which no mute can exist. (p.149)

Do present day educators of the deaf share similar expectations and standards for their students as Ponce de Leon? The answer to the question becomes apparent as one reviews the average reading performance of children who are deaf living in America. Countless students who are deaf exit high school annually reading on a third or fourth grade level. In fact, the low reading achievement of students who are deaf has been well documented over the last several decades (Allen, 1986; Holt, 1993; Trybus and Karchmer, 1977; & DiFrancesca, 1972).

Parents participating in the study frequently cited concerns over the low academic standards for their children. Several of the families specifically mentioned their apprehensions in regard to the poor reading skills of their children. Families frequently commented on the low expectations of teachers and the need for educators to challenge and expect more from their children who are deaf. After carefully reviewing the data obtained from the parent interviews, I noted that the parents appeared to want educators of the deaf to "raise the standard." As parents discussed expectations for their children, the common theme of "treat them as normal" appeared time after.

Treat Them as Normal. The majority of the families involved in the study expected their children who are deaf to perform on a similar level as children with normal hearing. Although the parents respected the

individuality of the child, they did not cater to their deafness. Parent #21 reasoned:

> *Expect from a deaf child what you expect from a hearing child. You may have to take a different avenue to get there. I have four daughters and I have the same expectations. All four are different. I don't look at my daughter as the "deaf daughter." Yes, she is deaf but . . . I don't try to compare. They each have their own goals and personalities. (-P21)*

Parent #23 and Parent #14 shared similar thoughts:

> *You gotta love them but you can't treat them no different. They have a handicap but if you want them to succeed, you have to treat them like you do your normal child. You have no restrictions. (-P23)*

> *Encourage them . . . anything they want to do, let them try it. Don't never stop them because they can do anything any other child can do. . . . Don't never put them down. (-P14)*

Have teachers of the deaf grown accustomed to focusing on educational barriers associated with deafness instead of capitalizing on the untapped resources within the students? In light of Ponce de Leon's achievements, the current teaching practices for the deaf and expectations for students who are deaf demands attention. Lowering a high standard on a student by student basis will accomplish more than never raising the standard at all. The field of deaf education must never loose sight of the vast

potential each child has to offer society. Educators of children who are deaf must encourage students to reach their fullest potential. This goal remains our greatest ambition.

Acknowledge the Different Parenting Styles. Three styles of parenting which emerged from the data analysis of this study are as follows: 1) Trusting Self, 2) Trusting Others/Trusting Self, and 3) Trusting Others. Parents in the first group adopted an assertive, action-oriented role soon after their children's initial diagnosis and maintained this role as their children progressed through elementary and middle school. Parents in the second group followed the advice of others during the early stages of their children's diagnosis. After a period of crisis, however, these families made a "shift" to a more assertive parenting style. Parents in the third group generally trusted the guidance of professionals when making educational decisions for their children. In certain situations, these families did express disagreement with professionals, yet, the parents seldom pushed the issue. Overall, families in this group felt unqualified to make educational decisions alone.

Although the three styles of parenting which emerged in my study cannot be generalized to other populations, I feel that educators can gain insight and a better understanding of the possible parenting styles which may surface in their classrooms. Because all families are unique and share different life experiences, parenting styles will vary accordingly. For this reason, educators must take caution not to favor one type of parenting style

over another. Each style of parenting will have its own distinct strengths and weaknesses. For instance, parents resembling the "Trusting Self" group may take the initiative to explore all possible resources before making educational decisions for their children. Nevertheless, these same families might become assertive to the point where they totally ignore the advice of others. Regardless of the parenting style, educators should make every effort to enhance the strengths of each family and work to minimize the weaknesses.

Educators should also realize that parents with different parenting styles may adopt different roles when participating on the Mulitdisciplinary team for their children's education. In keeping with the previous example from my study, parents in the "Trusting Self" category were more likely to ask numerous questions and at times challenge the opinions of others in the group. In similar situations, members on the Multidisciplinary team should be prepared to respond to the questions of the parents and not take offense at their assertiveness. A natural characteristic of this type of parenting style is to problem solve through debate and compromise. Parents included in the "Trusting Others/Trusting Self style of parenting were more passive during the initial Multidisciplinary team meetings. At a later date, however, these parents shifted to an action oriented role on the team. Educators encountering a comparable situation should be patient with families as they assume a more assertive role in the decision making process. Many times

the parents have been through some type of crisis and as a result feel that "professionals don't know best." Educators can work at building trust and respect by carefully explaining their views and goals for the children and by listening to the needs and concerns of the parents.

Parents in the "Trusting Others" style of parenting usually adopted a more passive role on the Mulitidisciplinary team. These families often felt that professionals are more knowledgeable and better equipped to make important educational decisions. If parents comparable to this type of parenting style surface in the educational setting, educators must be cautious not to falsely label them as disinterested or unconcerned about their children's education. Although these families had questions and concerns about their children's education, they often lacked the self-confidence needed to ask tough questions and to challenge the opinions of professionals. In similar instances, educators can reinforce the importance of the parent role on the Multidisciplinary team by asking specific questions to elicit helpful information or discussion. Examples of possible questions to ask include:

1) How does _____ communicate with his/her siblings?

2) Do you feel comfortable communicating with _____?

3) What does _____ like to do in his/her free time?

4) Is _____ able to complete his/her homework independently?

5) Is there anything that you are worried or concerned about?

All families possess a wealth of information and insight which can enhance the educational decision making process. Some of the parenting styles which emerged in my study may appear in other educational settings, and some may not. Additional parenting styles or variations of the three groups in this study may also emerge. In any instance, educators must recognize and be willing to work with the various parenting styles which families bring to the educational setting in order to build better parent-teacher relationships. According to Brantlinger (1991):

> *Although parent involvement is alluded to in survey and method texts and teacher-preparation programs, most professional preparation of teachers deals with classroom management and academic instruction. If teachers are to become more active in family support, preservice programs must be modified and in-service instruction provided so that they become more knowledgeable about family dynamics, communication techniques, conferencing skills, legal issues, the nature of handicapping conditions, and services provided by agencies other tan school (pp.256).*

Recommendations to Other Parents

In the field of deafness, "Who is the expert?" This question has plagued me since the onset of the study. I began this research project believing that "professionals are the experts." Perhaps my idea of the

"professional knows best" stems from my experiences working with other colleagues knowledgeable in deafness and open to various educational options. In the past, however, I have encountered some individuals working within the field of deaf education who possessed unyielding and dogmatic philosophies. Nonetheless, I placed the uncompromising educators under the category of "extreme cases." I thought, "Surely they must be the exception to the rule."

Considering the same question, "Who is the expert?," at the end of the study, I would respond differently. I believe any individual who possesses the following characteristics holds expertise in the field of deafness: 1) Knowledge and objectivity about the various communication and educational placement options for children who are deaf, 2) A realistic view of the overall potential of children who are deaf, 3) The ability to advocate for children who are deaf, and 4) The attributes of patience and encouragement. These four categories emerged from the 17 parent interviews as parents responded to the following question: What advice would you give to other families with young children who are deaf as they make educational decisions for their children? Based on the insight and practical suggestions offered by the families, I feel they have become "experts" within the field of deafness. I have chosen to use the advice offered by the parents participating in the study as the basis for my recommendation to other families with children who are deaf.

Research and Explore All the Options

The parents overwhelmingly expressed the need for families to research and explore all the available communication and educational options for children who are deaf. Once parents become aware of their options, they must decide the method of communication and school placement which can most effectively meet the needs of their children and families. Parent #10 suggested that families living in remote areas explore the Internet to learn about available resources and educational options:

> *Well, the first thing is you have to search for yourself to see what is out there, what is offered. . . . You have the Internet now. You have places everywhere to find out what is best for my child.*
>
> *. . . . We had to go outside our community to find these things. (-P10)*

Parent #21 and Parent #24 shared their insight into the various modes of communication and school programs for the deaf:

> *Several years ago I would have said sign language communication. Now I think I would have to determine what is the best mode for your child whether it be oral or ASL or Signed Exact English . . . . Whether it be a mainstream or residential. It is hard for me. I know what I have done. Of course, I have experienced all of it. (-P21)*
>
> *Educate themselves, learn, try to learn about everything not just, lipreading, Signed English or ASL, learn about it all. Try to you*

know, make yourself aware of what all is available because every child is different. (-P24)

Several of the parents spoke about maintaining "flexibility" when making educational choices for children who are deaf:

I would look at all them [program options] and decide which one it was that I liked best, but if it doesn't work out change it. Nothing is engraved in stone. Nothing says since we chose this it has to stay. If it does not work, change it [italics added]. (-P6 Pretest)

Always be looking at it. If this doesn't work, let's start finding something else. Don't make the kids suffer because you are too proud to change your mind. (-P8 Pretest)

Talk to a lot of people, teachers, parents, find out all the information they can and need for their child, you know. Just go and visit different schools and find out what programs that they have. (-P16)

Everybody is different; every family is different. One family ASL that is the right thing and they should be at the deaf school, another one an oral program, a mainstream, that is the right thing. There is no right and wrong. (-P12)

When you find out, it is better to know what all the options are. If you are comfortable with that this is all I want for my child, that is

fine. But later in life 10 years down the line you should not regret what you decided. (-P25)

Being Realistic

Another area of advice the parents offered to other families with young children who are deaf focused on maintaining realistic expectations: Parent #5 suggested: *"Be realistic, take what we have now and go from here and don't worry about it. Have a little faith that it is all going to work out." (-P5 Pretest)* Another parent added: "*I think you must be realistic and you cannot waste any time and play around here and there." (-P9 Pretest)* Parent #12 said, *"Be realistic. What is good for one person does not mean that it is good for everybody." (-P12)*

Becoming A Parent Advocate

The majority of parents interviewed advised other families to become active participants in the planning of their children's education. Often parents adopted an assertive role in the educational decision making process. Parent #6 and #8 explained: "*Be hard headed. Be stubborn. Tell them what you want because only you are the only one looking out for your child." (-P6 Pretest)*

[Mother speaking} Know your child and stick to your guns no matter what. . . . Always, always know your child.

[Father speaking] Nobody else is going to stand up for that child, your child like you. Nobody. (-P8 Pretest)

Parent #11 stated:

I'm a parent; I am Melissa's parent period, and I don't know anything about the educational system and don't want to get into it. But I want to make sure Melissa gets what she wants. (-P11)

Parent # 4 expressed her sentiments on advocating for school choice: *"Take her to school and fight for her." (-P4 Pretest)* Another parent reflected back on her family's early experiences with making placement decisions for their son who is deaf:

We backed off when we should not have. So I would tell anyone to be like . . . a she tiger. I think that is what you have to be and we are now. (-P1 Pretest)

Practicing Patience

The families included in the study talked readily about the daily struggles involved with parenting a child who is deaf. The ability to practice patience seemed to help parents endure difficult times. Parent #23 simply stated "*[Have] a lot of patience and a lot of love." (-P23)* When asked about giving overall advice on parenting children who are deaf, Parent #13 concluded: "*Patience. Patience and have a wonderful support group." (-P13)* Parent # 20 remarked:

Be patient. You have got to find your patience . . .. I m talking about 12 years, it is a daily struggle. I feel, I mean sometimes you just feel like I can't do this another day . . .. I have just had it. But you do. You keep on. (-P20)

Conclusion

The stories of the families who participated in this study have served to increase the awareness of the decision making process of parents with children who are deaf. I believe this work can be used as a foundation for other researchers who wish to expand the study by increasing the number of participants, by targeting larger geographical areas, and by examining in more depth the overall themes and styles of parenting which emerged from the data.

The experiences shared by the families have increased my understanding of the challenges parents face when making educational and placement decisions for their children who are deaf and the strengths families bring to the educational setting. In order to development true partnerships, educators and families must build relationships upon trust and respect. As Brantlinger (1991) remarks: *"There is a need to avoid the patronizing image of the professional expert benevolently guiding the ignorant parent." (p. 257)*

As a parent I feel fortunate other families allowed me the opportunity to share their joys and sorrows when discussing how deafness impacted

their lives and the lives of their children. While conducting the interviews, I experienced a wide range of emotions ranging from fear to a sense of hope. I believe individuals in the field of deafness must focus on "hope" instead of "fear." For this reason, I have chosen to conclude this study by presenting several statements[3] made by parents when discovering their children's deafness with statements from the middle school years.

Parent #10

9 months:

It is like, I don't know. When you find our that your perfect baby is not perfect. That is like somebody hits you in the gut. I don't know it is hard to describe . . . . It is like your whole world is falling apart and you don't know what to do. (-P10)

11 years:

What he had last year [regular education with resource], it worked because he came out one of three in the fifth grade that stayed on the principals list. I'm proud. (-P10)

Parent #8

8 ½ months:

---

[3]Additional quotes are included in the Appendix E.

I was sitting there watching the movie . . .. It was like I was up above watching myself watching the movie thinking "I have a child who will not enjoy this. I have a child who will not go to movie theaters and who will not understand what is going on and what do I do?" (-P8 Pretest)

14 years:

[Mother speaking] I am encouraged by the fact that I think Bobby is going to be just fine. Bobby's self esteem is high. . . . His reading and writing ability has improved. . . . it is good enough for him to communicate on a basic level. . . . [Father speaking] We now know that he can survive. (-P8 Pretest)

Parent #11

22 months:

[Mother speaking] I felt like I wanted to die. I felt like I had fallen into a pit, like I was in hell. [Father speaking] You always told me, like you had been cheated. [Mother speaking] Like I had been cheated. If felt like somebody came in the middle of the night and took my child and replaced her with somebody that looked exactly like Susy but just was not. . . . All your hopes and dreams for your child are gone.

11 years:

It just amazes me that she can understand, she can comprehend all this stuff without having speech, you know, to back it up. I mean, she understands protons, neutrons, and electrons and all that kind of stuff. . . . It just blows my mind when she understands all this. . . . We tell her, "what do you want to be when you grow up?" And she says, " I want to be a judge" and I say "Good, you can be anything you want to be." (-P11)

It is my intent that other parents, educators, and service providers may take comfort in knowing that young children who are deaf develop into strong, independent individuals. The experiences shared by parents in this study offer insight and advice to others, who by choice or circumstance, find themselves thrust into the world of deafness. As the quotations so vividly illustrated, a great deal can be learned by reflecting on the successes, as well as the failures, of the parents as they transitioned through the various developmental stages of their children's lives. Some of the resources utilized by the families proved effective, while others did not. By examining the practices and interactions between parents of children who are deaf and resources available at the local and state level, others may gain insight into avenues for improving the communication and educational placement options for families of children who are deaf.

The research inquiry provided information by documenting the similarities and differences among the families when making educational decisions. As professionals begin to develop a better understanding of the various types of parenting styles, I hope this study can assist other service providers as they develop strategies to best meet the individual needs of each family. Perhaps other parents with children who are deaf can benefit from the experiences and advice offered by families as they reflect on their children's educational history. A sense of "reality" intermingled with "hope and encouragement" may render support and reassurance to families struggling with difficult communication and educational placement decisions for their children who are deaf.

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APPENDICES

APPENDIX A

DEMOGRAPHIC INFORMATION SECTION AND A LIKERT SCALE

Table 1. Frequency and Percent of Selected Demographic Characteristics of the Research Participants Children Who are Deaf (N = 17).

CHARACTERISTICS	N	%
Sex		
Female	6	35.3%
Male	11	64.7%
Degree of Hearing Loss		
Severe (70 to 89 dB)	4	23.5%
Profound (90 dB and above)	13	76.5%
Age Hearing Loss Diagnosed		
birth to 1 year	5	29.4%
1 to 2 years	5	29.4%
2 to 3 years	5	29.4%
3 to 4 years	2	11.8%
4 +	0	0%
Person Responsible for the Diagnosis		
Audiologist	11	64.7%
ENT	4	23.5%
Pediatrician	1	5.9%
Unknown	1	5.9
Primary Mode of Communication		
Oral only	3	17.6%
Oral and Sign Language	2	11.8%
Sign Language	12	70.6%
Cued Speech	0	0%

Table 1 (continued)

CHARACTERISTICS	N	%
Age Special Ed. Services Began		
birth to 1 year	2	11.8%
1 to 2 years	3	17.6%
2 to 3 years	7	41.2%
3 to 4 years	3	17.6%
4 years or older	2	11.8%
Type of School Currently Attending		
Residential	8	47.1%
Public	9	52.9%
Type of Public School Programs for the Hearing Impaired (N = 9)		
Self-contained	1	11.1%
Self-contained w/Mainstream	3	33.3%
Regular Ed. w/Resource	4	44.4%
Regular Ed./Inclusion	1	11.1%
Distance in Miles from Home to School		
1-15	5	29.4%
16-25	2	11.8%
26-40	3	17.6%
41-100	4	23.5%
101-150	2	11.8%
151+	1	5.9%

Table 2. Percent of Rating Scale Responses Per Research Participants (N = 17).

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1. I am aware of the different types of educational programs for children who are deaf	41.2%	41.2%	5.9%	11.8%	0%
2. I know about the laws which protect my rights as a parent and the rights of my child who is deaf	29.4%	47.2%	11.8%	11.8%	0%
3. I understand what the Multidisciplinary Team does at my child's school	29.4%	35.3%	17.6%	11.8%	5.9%
4. Currently, I have a lot of people and places to go if I need help in making educational decisions for my child who is deaf	17.6%	47.1%	0%	23.5%	1.8%
5. I am satisfied with my child's current educational placement/ program	29.4%	47.1%	11.8%	5.9%	5.9%
6. The professional's at my child's school/ program think my opinions, as a parent, are important	29.4%	41.2%	23.5%	0%	5.9%

APPENDIX B

RESEARCH PACKET GIVEN TO PARTICIPANTS

STUDY INFORMATION SHEET

Dear Parent **Date**_____.

You are invited to participate in a research study which will be conducted, during the **Spring and Fall of 1998**, by Ms. Vicki L. Wolfe from The University of Tennessee, Knoxville. She is a doctoral student and has received funding from Gallaudet University in Washington, DC, to interview parents of middle school aged children who are deaf. **Ms. Wolfe is also a parent of an elementary school age child who is profoundly deaf.**

The purpose of the study is to increase understanding among families, educators, and other professional service providers about the information needs and concerns of parents and families in making decisions about the educational placement options for their children who are deaf. **Your personal experiences as a parent, with a child who is deaf, are very important. This study will give you the opportunity to share these experiences with others in the field of deafness.**

Ms. Wolfe will conduct the interview within your home at a time which is convenient for you. If you do not wish to meet in your personal residence, a designated room at your child's school will be available. Ms. Wolfe, the parent/s, and an interpreter (if necessary) will be the only individuals allowed to be present during the interview session. **Only one interview will be scheduled for each family. The interview should be completed in one hour or less.** If the parents wish to continue the interview after one hour, they may do so. However, the maximum time allowed for any one interview will be two hours. All interviews will be audio taped and later transcribed by a University of Tennessee employee. Interviews in which an interpreter for the deaf is requested will be videotaped and transcribed by a University of Tennessee employee. Prior to the interview you will receive a brief questionnaire which must be completed by the interview date. A total of 30 interviews with parents who have middle school age children who are deaf (70db or greater) will be conducted within predetermined areas of Georgia, Kentucky, Louisiana, North Carolina, South Carolina and Tennessee.

The names of parents, children, or school systems will not be included in any oral or written reports resulting from the research. This gives you the opportunity to openly express your personal experiences and concerns as a parent of a child who is deaf without being identified or linked to the study. Your experiences will add to the limited amount of resources available to

educators, other service providers and families about the information needs and concerns of parents when making educational placement decisions for their children who are deaf.

The information which is obtained from the questionnaire and interviews will be kept **confidential and stored in a locked cabinet.** The data will be made available only to persons conducting the study. The transcriptionists, interpreters, and the research auditor will be required to sign a letter of confidentiality. No reference will be made in oral or written reports which could link you to the study. There are no monetary compensations offered for your participation in this study or in future publication of this study.

Your participation in this study is **voluntary**, you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty. If you withdraw from the study before data collection is completed your data will be destroyed.

****If you are interested in participating in the study or would like to learn more about the study, please return the YELLOW postcard to Ms. Vicki L. Wolfe at The University of Tennessee, Knoxville. She will contact you as soon as the postcard is returned.** If you have any questions about the study or the procedures, you may contact **Ms. Wolfe** at the following address:

Ms. Vicki L. Wolfe
The University of Tennessee, Knoxville
2229 Dunford Hall
Knoxville, TN 37996
(423) 974-1195 (V/TDD)
Fax (423) 974-3522
E-Mail: vwolfe@utk.edu

If you have questions about your rights as a participant, contact the UT Compliance Section of the Office of Research at (423) 974-3466.

Thank you,

Vicki L. Wolfe

PARTICIPANT CONSENT FORM

You are invited to participate in a research study which will be conducted, during the **Spring and Fall of 1998**, by Ms. Vicki L. Wolfe from The University of Tennessee, Knoxville. She is a doctoral student and has received funding from Gallaudet University in Washington, DC, to interview parents of middle school aged children who are deaf. **Ms. Wolfe is also a parent of an elementary school aged child who is profoundly deaf.**

The purpose of the study is to increase understanding among families, educators, and other professional service providers about the information needs and concerns of parents and families in making decisions about the educational placement options for their children who are deaf. **Your personal experiences as a parent, with a child who is deaf, are very important. This study will give you the opportunity to share these experiences with others in the field of deafness.**

Ms. Wolfe will conduct the interview within your home at a time which is convenient for you. If you do not wish to meet in your personal residence, a designated room at your child's school will be available. Ms. Wolfe, the parent/s, and an interpreter (if necessary) will be the only individuals allowed to be present during the interview session. **Only one interview will be scheduled for each family. The interview should be completed in one hour or less.** If the parents wish to continue the interview after one hour, they may do so. However, the maximum time allowed for any one interview will be two hours. All interviews will be audio taped and later transcribed by a University of Tennessee employee. Interviews in which an interpreter for the deaf is requested will be videotaped and transcribed by a University of Tennessee employee. Prior to the interview you will receive a brief questionnaire which must be completed by the interview date. A total of 30 interviews with parents who have middle school age children who are deaf (70db or greater) will be conducted within predetermined areas of Georgia, Kentucky, Louisiana, North Carolina, South Carolina and Tennessee.

The names of parents, children, or school systems will not be included in any oral or written reports resulting from the research. This gives you the opportunity to openly express your personal experiences and concerns as a parent of a child who is deaf without being identified or linked to the study. Your experiences will add to the limited amount of resources available to educators, other service providers and families about the information needs and concerns of parents when making educational placement decisions for their children who are deaf.

_____ **Participant's Initials**

The information which is obtained from the questionnaire and interviews will be kept **confidential and stored in a locked cabinet.** The data will be made available only to persons conducting the research. The transcriptionists, interpreters, and the research auditor will be required to sign a letter of confidentiality. No reference will be made in oral or written reports which could link you to the study. There are no monetary compensations offered for your participation in this study or in future publications of this study.

This consent form is required by the University of Tennessee to protect you and allows Ms. Vicki L. Wolfe (UTK; 2229 Dunford Hall; Knox, TN 37996; 423.974.1195 V/TDD) to use the information you will supply to fulfill the requirements of a Gallaudet University Grant (Partners in Progress), her dissertation work, and any future presentations/publications. This signed copy will be kept in a locked cabinet on the University of Tennessee, Knoxville campus for at least three years from the date of signature. If you have any questions about your rights as a participant, contact the Compliance Section of the Office of Research at 423.974.3466.

In signing this consent form you agree to participate in this study of your own free will at a time and place of mutual agreement. You have the option at any time to refuse further participation or withdraw from the study without any penalty. If you withdraw from the study before data collection is completed your data will be destroyed.

Participant Consent:

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature_____
Date_____

Investigator's signature_____
Date_____

APPENDIX C

PARTICIPANT QUESTIONNAIRE AND INTERVIEW GUIDE

Participant Questionnaire

Date:_____

Name:_____ **Address:**_____

Employment:_____ **(Father)** **Level of Education (circle one): HS/College**

_____**(Mother)** **Level of Education (circle one): HS/College**

Please answer the following questions:
(check the appropriate response)

1. What is your relationship to the child who is deaf?

_____Father _____Mother _____Grandparent
_____Legal Guardian _____Other (list)

2. What is the sex of the child who is deaf?

_____Male _____Female

3. What is the degree of hearing loss (unaided pure tone average, better ear, from school records) of the child who is deaf?

_____Severe (70 to 89 dB) _____Profound (90 dB and beyond)

4. Who diagnosed your child's hearing loss?

_____Audiologist _____Pediatrician
_____ENT Physician _____Other (list)

5. At what age did the child who is deaf start receiving special education services?

_____birth to 1 year _____1 to 2 years
_____2 to 3 years _____3 to 4 years
_____4 years or older

6. What type of educational program is your child currently attending?

_____Residential _____Public school

If your child is attending a public school, please indicate the type of program.

_____Self-contained _____Self-contained with mainstreaming
_____Regular ed. classes _____Resource room
_____Itinerant _____Other (list)

7. At what age did the child who is deaf enter his/her current school program?

_____eleven years _____twelve years
_____thirteen years or older

8. What is the driving distance from your family's home to the child's school?

Distance in miles

_____1 - 15 _____16 - 25 _____26 - 40
_____41 - 100 _____101 -150 _____151 +

Please give your opinion on the following items by circling your response.

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
9. I am aware of the different types of educational programs for children who are deaf.	**SA**	**A**	**U**	**D**	**SD**
10. I know about the laws which protect my rights as a parent and the rights of my child who is deaf.	**SA**	**A**	**U**	**D**	**SD**
11. I understand what the Multi Disciplinary Team does at my child's school.	**SA**	**A**	**U**	**D**	**SD**
12. Currently, I have a lot of people and places to go if I need help in making educational decisions for my child who is deaf.	**SA**	**A**	**U**	**D**	**SD**
13. I am satisfied with my child's current educational placement/program.	**SA**	**A**	**U**	**D**	**SD**
14. The professionals at my child's school/program think my opinions, as a parent, are important.	**SA**	**A**	**U**	**D**	**SD**

Interview Guide

1. Tell me about when you first discovered your child had a severe to profound hearing loss?

2. What did you do to try and learn more (deal with) about your child's hearing loss?

3. What do you do then?

4. How did you find out about the different school programs available for children who are deaf?

5. Tell me about the Multi Disciplinary Team (IEP Meeting/Team) at you child's school?
   What do you do at these meetings?
   Who attends these meetings?
   What do you do at these meetings?

6. When you think about your child's your _____(child's school program), what things are you most satisfied with.....most dissatisfied?

7. How is Elementary School similar/different to middle school?

8. Your child is in the _____grade, When you think about his/her educational goals (academic, social, emotional), what encourages you..... what are your concerns?

9. What advise would you give parents of young children who are deaf who are faced with choosing an educational program for their child?

10. Summarize the responses and report back to the parents.

11. Is there anything else you would like to add?

Extra curricular activities:

APPENDIX D

PLEDGES OF CONFIDENTIALITY (TRANSCRIBERS, INTERPRETER'S AND RESEARCH AUDITOR)

TRANSCRIBER'S PLEDGE OF CONFIDENTIALITY

As the transcribing typist of this research project, I understand that I will be hearing and/or viewing tapes of confidential interviews. The information on these tapes has been revealed by research participants who participated in this project on good faith that their interviews would remain strictly confidential. I understand that I have a responsibility to honor this confidentiality agreement. I hereby agree not to share any information on these tapes with anyone except the primary researcher of this project.

Any violation of this agreement would constitute a serious breach of ethical standards, and I pledge not to do so.

_____ _____

Transcribing Typist Date

INTERPRETER'S PLEDGE OF CONFIDENTIALITY

As an interpreter for this research project, I understand that I will be facilitating communication between persons who are hearing, deaf, or hard of hearing through the use of the deaf or hard of hearing person's primary mode of communication. The information during the interview session has been revealed by research participants who participated in this project on good faith that their interviews would remain strictly confidential. I understand that I have a responsibility to honor this confidentiality agreement. I hereby agree not to share any information from the interview session with any other persons.

I am aware of the Registry of Interpreters for the Deaf code of ethics (see attached). Any violation of this agreement would constitute a serious breach of ethical standards, and I pledge not to do so.

_____ _____

Interpreter Date

AUDITOR'S PLEDGE OF CONFIDENTIALITY

As an auditor for this research project, I understand that I will be reviewing data obtained from the participant questionnaires and interviews. All information collected during the study has been revealed by individuals who participated in this project on good faith that their responses would remain strictly confidential. I understand that I have a responsibility to honor this confidentiality agreement. I hereby agree not to share any information from the research data with anyone except the primary researcher of this project.

Any violation of this agreement would constitute a serious breach of ethical standards, and I pledge not to do so.

_____ _____

Auditor Date

APPENDIX E

ADDITIONAL QUOTES MADE BY PARENTS

ADDITIONAL QUOTES MADE BY PARENTS

Parent# 9

14 months:

I was stunned. I kind of knew but I did not. I got maybe a block from the audiologist's office and I had to pull over and cry (-P9 Pretest).

15 years:

Sam's goal is to go to NTID [the National Technical Institute for the Deaf]. The teachers all have that goal for him . . . . They will look at you and honestly say this is what we have in store for Bill. This is his strengths. This is where he has potential. He can be somebody. (-P9 Pretest)

Parent #5

4 months:

When you have a child who can't eat and can't breath, you do not worry about much else . . . . I thought, that is just one more thing and we will worry about that later. (-P5)

13 years:

Lisa has the personality that carries her really far in life and she is going to be successful (-P5 Pretest)

Parent #13

3 ½ years:

Researcher: How did you feel when he [the ENT] told you that? Parent: Devastated . . . . My best friend is just wonderful. Like she said, "God does not give anything that you can't handle." So after that it took a lot of adjusting. (-P13)

13 years:

He is a good student. He tries his best and that is all I ask of him. He far surpassed what we were told to expect with him. We were told to expect maybe an average or below average child in school. 90% he is on the honor roll. So he really tries hard. (-P13)

Parent #12

3 years:

At that time it created a panic in my family, because my husband was in the Army and we were two weeks away from being transferred. . . . They revoked our permission to travel with my husband because of my son's hearing loss. (-P14)

12 years:

John is a straight A student. . . . I a surprised with all he has been through that he doesn't have more of a chip on his shoulder. I think he is pretty good. I think he is very stable. (-P12).

Parent #4

2 ½ years:

It was shocking. We didn't want her to be deaf and then we decided we got to. What do we do about it? Where do we go from here? (-P4)

14 years:

She has no problem at all in subjects . . . . Susy says she wants to be a veterinarian (-P4).

Parent #6

2 ½ years:

I didn't think he could hear me, but nobody would believe me (-P6 Pretest).

15 years:

I guess what encourages me is he seems to have so much enthusiasm. He likes school (-P6 Pretest).

Parent # 1:

3 ½ years:

We all went out to eat lunch and celebrate because we knew what it was . . . . I was in special education. I had autistic children . . . .

I don't think I can do this all day. So we went out to celebrate. (-P1 Pretest)

13 years old:

His writing skills are pretty good compared to other deaf children with a severe to profound loss. He, socially is outgoing. His temperament is very good.

Parent #25

2 ½ years:

Oh, it was the world came to an end for both of us.

12 years:

*Math is a strength, spelling is a strength. It is rewarding to see that he is interested in it. He works on those subjects all by himself. I do not have to tell him and so far he has gotten all A's in Math and Spelling. And it does make us feel good that there is something in which he has interests. (-P25)*Parent #24

Parent #24

9 months:

I was devastated. (-P24)

14 years old:

She is not that strong academically, but she has a good head on her shoulders . . . she surprises me sometimes with how strong she can be. (-P24)

Parent #21

11 months:

I was very saddened and it is a process . . .; it is a grieving process that I went through. At first I was angry, denial, guilt, but I was very angry. Then I was very unsure as to what do or how to go about doing it. (-P21)

13 years:

She is a capable learner. She is an avid reader. . . . I can't see where she should have any problems academically if she continues to pursue her dream of being a doctor and going to medical school. (-P20)

Parent #23

13 months:

I just would not accept. No. He is going to hear you know. . . . I used to cry . . . I would sit in church and the Junior choir would sing first and third Sunday. And I would sit in the audience and the water would flow. (-P23)

13 years:

Joey will take my little niece and nephews over there and he will watch them and take care of them. Even at school, in the elementary, he was in the work program. He done well. . . . He likes to work, he is getting paid. (-P23)

Parent #16

12 months:

We went there had our tests done and he [the ENT] said, " Ms. Johnson, she is profound deaf." . . . I was by myself and there was ice on that bridge and they, a couple [was] standing in that road. I was in a daze and thank God what they did . . . . See they were standing in the middle of the road and they were flagging be down to try to tell me and I finally saw them and slowed down. . . . They were like angels that day cause I was in another world. (-P16)

12 years:

Stacy plays basketball, she plays soccer, she plays baseball, she is in Girl Scouts. She has been in Girl Scouts every since she was old enough to be in scouts and she just she cannot wait till school starts back.

Parent #14

24 months:

Devastated. Horrible, cried. Why? (-P14).

11 Years:

When he picks up a book and reads it . . .. He can look at a newspaper article and read it and tell me what is going on or closed caption T.V., you know. I don't have to sign to him. . . . He can read it himself. (-P14)

VITA

Vicki L. Wolfe was born in Oberlin, Louisiana. She attended the public schools of Allen Parish where she graduated with honors from Oberlin High School in 1983. The following fall, she entered Southeastern Bible College located in Birmingham, Alabama and graduated in 1988 with a Bachelor of Arts degree in Elementary Education. During the fall of 1988, she enrolled at Southern University and Agricultural and Mechanical College at Baton Rouge, Louisiana. She graduated with a master's degree in Elementary Deaf Education in 1989. After teaching three years in a self-contained classroom for children who are deaf in Alexandria, Louisiana, she and her husband relocated to Knoxville, Tennessee. In 1994, Vicki enrolled as a doctoral student at The University of Tennessee, Knoxville and worked as a graduate research assistant for the Postsecondary Education Consortium for the duration of her studies. In May 1999 she received her doctoral degree in Leadership Studies/Higher Education.