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DEAFNESS IN ROCHESTER:
A PROPOSAL TO IMPROVE UNDERSTANDING
THROUGH THE DEVELOPMENT OF A
COMPREHENSIVE WEBSITE

Master's Project

Submitted to the Faculty of:
The Master of Science Program in Secondary Education
of Students who are Deaf or Hard of Hearing

National Technical Institute for the Deaf
ROCHESTER INSTITUTE OF TECHNOLOGY

By

Allison Masteller

In Partial Fulfillment of the Requirements
for the Degree of Master of Science

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ABSTRACT

The purpose of this proposal is to inform people about issues related to deafness through a comprehensive website with up to date information that is easily accessible and navigable by all people. Creating a professional website will benefit professionals and parents with a variety of information from many different sources. Both parents and professionals need to be aware of the many important decisions that come with raising a deaf child.

Many parents are unaware of the vast decisions that come with raising a deaf child. The decisions that parents make are not only very important, but these decisions must also be made at a very young age. This can become an overwhelming situation given the lack of information they may have and lack of time to make decisions. Some may typically see deafness as "just another disability" to cope with, however, this view is not shared by all. Many disabilities are not as complicated as deafness in that they have a more clear-cut path to making decisions. Deafness is also not always seen as a disability. Many people prefer deafness to be seen as a community and culture, rather than a physical problem that needs to be fixed.

These beliefs usually come at a later age when the individual has identified themselves through life experiences and maturation. However, the infant who is deaf that is born to hearing parents, are dependent upon the parents to make decisions for them early in life. Parents are often dependent on professionals who provide parents with vital information in making decisions for their child. Public Law 105-17 or IDEA, under section 631 clearly states the need for early intervention and identification of conditions, which include deafness. While this provides recognition for identification and assessment of the deaf

infant, parents and professionals are only become aware of the condition itself. They must also become aware of the numerous issues related to deafness and the decisions that will soon come to follow. What happens to decisions that parents make if they are unaware of all the issues at stake? How will this affect the child who is deaf if parents are unaware of other related issues?

When addressing the concerns of an infant who is deaf these decisions for the parents include choosing a communication mode, selecting an appropriate educational environment, enrolling into an early childhood intervention program, and deciding on what technology if any should be used to aid the infant's hearing loss. As one can see by the above list of issues, deafness is more complicated than one would think. The problem with making these decisions as a parent is clear. Ninety percent of deaf children are born to hearing parents. The vast majority of these hearing parents are uneducated about the array of decisions and the impact that these decisions will play in their infant's life. Research has shown that parents are very unlikely to seek a secondary source of information. It is therefore imperative that professionals (teachers of the deaf, pediatricians, ear nose and throat specialists, speech pathologists, and counselors) are educated and resourceful with information to educate parents who have just given birth to an infant who is deaf.

INTRODUCTION/STATEMENT OF THE PROBLEM

The purpose for developing this website is to provide professionals and parents with current information regarding the complexities of deafness. The website will contain six components. The first four components will address issues such as; School setting (mainstream vs. residential), Communication mode (ASL, Oral, Cued Speech, MCE's, etc.), Early intervention services (age of enrollment, program philosophy), and Technology (hearing aids, cochlear implants, etc.). The last two components of the web page will provide the browser with additional resources; Research (current topics, magazines to subscribe to, contacts) and, Resources (organizations, groups, websites, and literature)

There is a great deal of importance in creating a website such as this. Currently to the best of my knowledge, there is no website that has information addressing all of these issues from a variety of perspectives. Many websites that currently exist address audiences who are already familiar with deaf issues. This website however will be designed targeting people who know very little about deaf related issues and who have little to no experience navigating on the World Wide Web.

By presenting the material as a website, it allows the parents to absorb the information at their own pace and in privacy. Instead of relying on the professional who may or may not have an understanding of a certain related issue about deafness, this website will become for parents, a one stop resource information site. The benefit of a website is that information that is outdated can always be easily updated by the Webmaster. With a growing ability for people to publicly access the World Wide Web, access to this website is easily obtained.

In promoting my website and project, there are three simple goals:

- 1) Increase professionals understanding of the complicated issues of deafness

- 2) Educate and empower parents with information and resources
- 3) To learn (for myself) more about personal perspectives of parents and professionals and the diagnosing process itself here in Rochester, New York.

LITERATURE REVIEW

THE HEARING PARENTS AND THEIR INFANT WHO IS DEAF

The purpose of this literature review was to seek information about hearing parents and their deaf children in the early stages of the child's life. In this timeframe of life, many critical issues have surface regarding the child's development, parental adjustment and the diagnosis of deafness itself. The studies reviewed will give insight to understanding how these issues relate to one another. The overall implications are significant for future teachers of the deaf and other related professionals who may come in contact with hearing parents who have children that are deaf or hard of hearing.

FINDINGS FROM LITERATURE

Parenting a child who is deaf comes with heavy responsibilities and decisions to make for the child at a very early age. What becomes overwhelming to the parent is two-fold; the actual diagnosis of the deafness and the many important decisions that they need to make for their child. This kind of pressure can inflate hearing parents' stress levels. As found in 5 of the 10 articles, parental stress is affected by many things such as the amount of support given to parents, quality of intervention services, communication level with their deaf child and amount of other life stressors (Boison, 1987; Calderon & Greenburg, 1999; Eleweke & Rodda, 2000; Hadadian & Rose, 1991; Meadow-Orlans, 1995).

Once a parent has formally received deafness as the diagnosis for their child, a parent can go through a variety of feelings. These feelings can include anger, guilt, frustration and aggression (Boison, 1987). While parents roller coast through these feelings, they also

have the additional responsibility of making timely important decisions for their child; communication mode, amplification devices, educational placement, intervention services, and contacting professionals for support. What most parents do not know is how valuable time is for a young child who is deaf or hard of hearing in terms of receiving appropriate services.

AGE OF DIAGNOSIS

Several of the studies examined explored the age at which the child was formally diagnosed with deafness. Willams & Darbshire (1982) found this median age to be at 48 months. Meadow-Orlans, Mertens, Sass-Lehrer & Scott-Olson (1997) found the median to be 22 months of age. And finally, Harrison and Roush (1996) found the median age for formal diagnosis to be 22 months of age. It should be mentioned however that in Meadow-Orlans et al. (1997) study, the demographics of the families in the survey were not revealed. Parents who had deafness in the family or who had other deaf children would effect this median age for formal diagnosis. In Harrison and Roush's study the median ages are based on families with no known risk factors. The average of these median ages is 30 months of age or 2 years and 6 months of age. It is after this age that the child will start receiving formal support services. After formal diagnosis, parents must scramble to put together bits of information to make educated choices for their child.

SUPPORT SERVICE SATISFACTION

Parents reported various levels of satisfaction with professionals and the quality of information provided. In a case study, Eleweke & Rodda (2000), examined parents using a sign language approach (SLAPS) and the parents who used an aural/oral approach

(AOPS) and their level of satisfaction with professionals and the quality of information given to them. The SLAPS stated that they had lost faith in the professionals thereby leaving them to follow their own instincts. The SLAPS received information through teachers of the deaf but only from one approach; amplification without sign language. Later they came into contact with a deaf social worker who proposed using sign language. The SLAPS felt frustrated with professionals who diagnosed their daughter's deafness late in age. They also claim that the information given to them was dictated by, "departmental policy and the philosophy" of the department. The SLAPS felt it would have been more beneficial to have received information about the variety of options.

You have to have choices and be involved in the discussions, and someone from the audiology department should tell you something about communication options. But in our case, the authority and professionals where we live believe only in oral communication, not sign language. . . We think the thing in our area is that they want the hearing impaired children to be as 'normal' as possible without taking into consideration the child's particular needs. That is why we are so angry with our local authority (Eleweke & Rodda, 2000).

The AOPS believed they had been given misleading information about amplification devices and other assistive learning technology. The information that was given to them left them with high expectations for their child to hear like that of a "normal" child. These expectations would later be proven to be false. In addition to this, the AOPS were not satisfied with the amount of information that teachers of the deaf had given them.

The information given wasn't enough at that time because we had to keep asking and asking because they seemed very reluctant to give information. They just tell you, "Your child is deaf." We wanted to know everything. We wanted to know if there was any remedy. We wanted to know if she could have one of our cochleas . . . They (the professionals) just don't care. To them it is just a job. Because of this we learned that from experience with the audiology department where we live. They gave us the wrong and broken ear molds, hearing aids, etc. They sent the ear mold to a company which didn't know the right tubing and so they sent it back broken to

the department which in turn just sent everything like that back to us (Eleweke & Rodda, 2000).

The AOPS and the SLAPS interviews made it very clear that parents need accurate, unbiased and relevant information (Eleweke & Rodda, 2000).

In William & Darbshire's study (1982), 88% of the subjects interviewed, "expressed a need for factual information about hearing loss, its implications, and their child's future prospects." As a result, parents' frustration in their search for information and help may lead to anger and disappointment with the professionals themselves.

In Meadow-Orlans' et al. survey (1997), hearing mothers rated professional service much higher than mothers who were deaf or hard of hearing. Results from this survey concluded a mean score of 14.1 satisfaction with professional services on a 16-point scale. Teachers were documented as being the most helpful and supportive from two-thirds of the parents involved in this survey. Medical doctors were documented as helpful by only 20% of the participants (Meadow-Orlans et al., 1997).

While parents may live in an area that has plenty of opportunities to contact various professionals for their child who is deaf, others who live in rural areas may not have this luxury. Parents may not be fully aware of the various choices they have in terms of amplification devices and communication modes. In an interview (Kluwin & Stewart, 2000) with parents who had children who recently had been given a cochlear implant, 27 of the 35 parents felt they had enough information to make the decision to implant their child. However, 15 of the 35 parents interviewed used other parents as their primary source of information. Medical staff such as pediatricians, audiologists and members from the actual

implant team were the primary information source for only 13 of the 35 parents. Out of the 13 parents who used medical staff as their primary source of information, only 3 of them used a secondary source of information. The most motivating factor for these parents to implant their child was their desire to have a child who could function as a hearing person. This motivation was partly caused by their frustration with not being able to adequately communicate with their child. (Kluwin & Stewart, 2000).

PARENTAL ADJUSTMENT

With all the emotions of deafness as a diagnosis and the chaos of seeking appropriate information for their child, it would seem that hearing parents of deaf children would struggle more than the average hearing parent with hearing children. However, Hadadian (1995) examined the correlation between attitudes toward deafness from hearing mothers and fathers and found no differences in their security attachment scores. When compared with hearing families, the results seem consistent. In other words, "the parental attitudes toward deafness were significantly correlated with the attachment security scores (Hadadian, 1995)." In an earlier study done in 1991, it was noted that, "Fathers of D/HH infants are marginally less attached to them, compared [to] their wives (Hadadian & Rose (1991))." This raises an important issue to make serious efforts to include fathers during early interventions services. Does this information imply that parental stress relates to parental adjustment in raising a child who is deaf or hard of hearing?

Meadow-Orlans (1995) found that hearing mothers who have a deaf or hard of hearing child score higher on the Parenting Stress Index when compared to hearing mothers of hearing children. The hearing mothers who have deaf children scored higher in stress level for the categories of; depression, attachment to child, restriction of role, competence,

relations to spouse, and health (Meadow-Orlans, 1995). After analyzing the Stress of Life Events, mothers with deaf infants scored higher in stress (when compared with mothers who have hearing children) in the areas of; relationship, care of newborn, health and work (Meadow-Orlans, 1995). Using over a dozen formal assessment tests, Calderon & Greenburg (1991), discovered that, "mothers reporting more negative life stress and who have a child with more severe hearing loss are more poorly adjusted to their child (Calderon & Greenburg, 1991)." Secondly that, "mothers who reported high satisfaction with their social support were rated as better adjusted to their deaf or hard of hearing child despite degree of maternal negative life stress or severity of the child's hearing loss (Calderon & Greenburg, 1991)."

CONCLUSIONS

Given the literature reviewed, some valuable implications can be drawn regarding the early years of deaf children and their hearing parents. Professionals must be aware that parents may not be likely to contact a secondary source of information. This may be due to the fact that parents are unaware of the numerous options available to their child in terms of school setting, communication mode, and aided technologies. Because of this, professionals must be educated to give parents access to information regarding all of these important decisions they will soon be making for their deaf infant. The research has implied that professionals have expertise and knowledge but only from one perspective. This can be very detrimental to the parent who is naive to alternatives for their child.

Professionals who should be educated in providing parents with appropriate resources extends beyond the medical profession. Teachers of the deaf, counselors, speech

therapists, and most importantly parents need to be empowered with knowledge to make educated decisions for the infant who is deaf.

Teachers of the deaf in particular should be prepared to supply hearing parents with non-biased information and contact information to other parents and professionals, schools, and specialized organizations and groups. While teachers of the deaf should not be expected to give medical advice, they should be ready to supply parents with literature about deafness.

When planning early intervention services, professionals need to make sincere efforts to include the father as much as possible in all aspects of raising a child who is deaf or hard of hearing. Parents working as a team can be a strong influence or "the agents of change" in successfully meeting the needs of their child (Williams and Darbshire, 1982). Furthermore, teachers and related professionals should take note of hearing parents stress factors. This will help professionals in understanding and meeting the needs of the parents and their child who is deaf or hard of hearing. Introducing information to the parents slowly and clearly will help to ensure that they will not become overwhelmed and confused. Providing parents with appropriate and adequate support will empower parents to make decisions for their child.

Additional research is needed to be sure that professionals are meeting the needs of their clients. Professionals need to continually be conscious of new research regarding servicing deaf children and their families. More research should be done to find out what kind of information is given to parents who have a child who is deaf or hard of hearing. By using parent's feedback and analyzing the weaknesses of information currently being distributed, professionals can work together to strengthen and develop appropriate

supports for parents. This in turn can help reduce parents' frustrations and increase trust in professionals and teachers. By providing parents with strong support from an array of professionals, we will directly improve the development of children who are deaf and hard of hearing at a young age.

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ACTIVITIES

To aid in the creation of the format for the website itself, I will be informally questioning friends and family members who are deaf or who have a family member that is deaf or hard of hearing. In my conversations I hope to find out what kind of information they wish they had access to when they first found out about deafness. The people that I will be questioning will range in age and population. I will be asking parents who have a deaf child, deaf and hard of hearing college colleagues, professors and teachers. By sampling from such a broad population, it will give me many ideas as to what needs to be addressed and how it can be presented without overwhelming the browser who may not be accustomed to navigating the World Wide Web.

After documenting comments and sketching an initial framework for the website, I will then make contact with initial leads to start collecting information. This will be from staff at Strong Hospital, professionals at the University of Rochester, Pediatricians, Ear Nose and Throat Specialists, and Audiologists. By contacting these professionals, I hope to get a sense of what a hearing parent goes through when first finding out that their infant is deaf. By collecting information from these professionals, I hope to better understand what kind of information is passed onto the parents and also how deafness is diagnosed and managed in Rochester.

It is my intent to approach this project with an open-mind. The aim of this project is to establish a website that is targeted towards people who do not know very much about deaf related issues and who may be unskilled at navigating the World Wide Web. It is not a website intended to condemn or support any one aspect of the many issues being

addressed. Instead, it will offer facts and resources to empower people to make their own decisions by educating them. I hope in the end that professionals will be supportive of my efforts and promote my website to their clients and maybe even use it to learn more about deaf related issues for their own benefit.

Before the website has been formally published, I intend to have numerous people test browse the site. This population will include parents and adults who are familiar and unfamiliar with the World Wide Web. Using their feedback, I will make needed adjustments for easier navigation through the website.

After the website has formally been published, I intend to send a letter (postal or e-mail) out to those professionals who I had been in contact with during this project. By word of mouth, I hope that the website I produce will eventually be published on brochures and pamphlets. This will in turn promote the site as more and more parents and professionals visit the website.

